

Thursday, 10 October 2019

(10.04 am)

SIR BRIAN LANGSTAFF: Today is one of those days in which all the witnesses are anonymous. Let me say something largely for the benefit of those who may at the moment be watching online and it's this, that in the hearing room you will see and hear the witnesses. There will not be any live stream visually of our first witness. He will be known as Paul.

Then after the break AH, as he wishes to be known, will be known, will give evidence from outside the room. You will not see him but you will hear his voice. Those who are remote from this hearing room will have neither. There will be no live streaming.

There will be no live streaming either of our third witness, who will give evidence in front of you, but whose voice will not be simultaneously transmitted around the country.

It doesn't mean that their evidence will simply disappear and not be recorded for the benefit of the public so that they can follow this Inquiry.

A transcript of the evidence that each gives will be provided later.

So slightly different arrangements for each of the three but we start, if we may, with Paul and in

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course of this Inquiry.

I need not remind you but anyone else who may be listening, breaking that order has serious consequences. Please don't go there.

So Paul.

PAUL, sworn

Questioned by MS RICHARDS

Q. Paul, you have severe haemophilia A.

A. Yes.

Q. During your childhood you received cryoprecipitate but you developed inhibitors. Can you just tell us a little about that.

A. Yes. I was diagnosed with haemophilia after about a year/18 months. I've got no haemophilia in the family. I'm a genetic mutation so I was the only one. I started cryo I think about '66 when I was two or three years old. It was evident quite early on that I had inhibitors or resistance to it so basically my body was rejecting the clotting factor my body was missing in the first place.

Treatment was given though only for essential bleeds and their thinking was because of the inhibitors they would only give me cryo when I really needed it because every time they gave it me my inhibitor levels would raise, so it was treatment only

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his case let me read out the restriction order and bear in mind what I said at the start of this set of hearings.

It is so easy to think you have heard it all before and not to take notice but it is important to each of the individuals concerned as it is to all who have asked for and been granted anonymity and it is important that they should feel as comfortable as they can be in giving evidence which is, as those of you who have done it will know, those of you who have yet to do it will anticipate, is not at all easy.

So the order in his case reads as follows:

I order that the name and address of Paul, the name of any other member of Paul's family and any other identifying information such as Paul's image or a description of his appearance cannot be disclosed or published in any form unless express permission is given by me or by the solicitor to the Inquiry acting on my behalf.

Witness W1003 -- numbers become quite important today because each has a number -- witness W1003 must be referred to only as Paul. This order remains in force for the duration of the Inquiry and at all times thereafter unless otherwise ordered and I may vary or revoke the order by making a further order during the

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when it was really necessary.

Q. For that reason, you were generally treated with bed rest, ice packs, splints analgesia and gentle physiotherapy for a large part of your childhood.

A. That was most of how my bleeds were treated, yes.

Q. One of the points that is important to you, as I understand it, to make is when you needed treatment it was not for life-threatening reasons and this was not life-threatening, the life-saving treatment that you were receiving?

A. No, my whole life I've never had a life-threatening incident. I've never had -- I'm very lucky in that respect. I've never had appendicitis or a car accident or anything like that. All my bleeds have been in my joints, my knees, ankles, elbows. So all the factor I was given was just to stop the bleeding, to just basically stop joint damage. But I did have a lot of joint damage as a kid.

Q. From 1974 to 1976, and the significance of 1976 will become apparent in a moment, you didn't receive any cryoprecipitate at all. You were just treated in this rather more gentle and restful way that you have described?

A. Yes, that's right. I went a whole two years without any treatments. It was just ice packs, cold water

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1 bandages, splints, yes, for that time period. In
 2 fact, on one of my notes in my medical records it says
 3 only dare to treat Paul in the event of
 4 a life-threatening bleed. So I didn't have any
 5 treatment at all for a few years.

6 Q. You've produced a letter written by your father in
 7 March of 1975 and we're just going to look at that
 8 letter and what prompted it.

9 Paul, it's 1003017, please.

10 It should come up on the screen in front of you.

11 You will see it's addressed to Dr French who was your
 12 haematologist. It is dated 2 March 1975. It says:

13 "Dear sir, I am the father of Paul. Having
 14 observed the public interest lately in the blood
 15 extract Factor VIII, I find the article published in
 16 the Sunday Times page 3, February 16th, 1975, most
 17 disturbing. I've raised monies by charity organising
 18 in the past years for haemophilia research in the hope
 19 that one day haemophiliacs could be helped, if not
 20 100 per cent, even 50 per cent. I'm writing to you
 21 after having thought deeply about this article to ask
 22 your [and then there's some words unclear] opinion
 23 regarding any personal help if possible for Paul.
 24 I would be willing to spend monies I have available to
 25 ensure a less painful way of life for him."

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1 Britain's haemophiliacs for several months but then
 2 refers to there being a snag in terms of the funding
 3 of that.

4 Then if we pick it up, please, Paul, third
 5 column, again towards the bottom of the column:

6 "Last year, the two drug firms stuck with
 7 a large stock of Factor VIII with a limited shelf life
 8 started to re-export and protested strongly to the
 9 Department of Health. It responded last October by
 10 buying 500,000 units of Factor VIII from the companies
 11 and then offering it to the regional health
 12 authorities at the normal commercial price. What this
 13 was intending to achieve is uncertain, nor is it known
 14 whether all the material was brought up. A senior
 15 official at the Department of Health said it was
 16 certainly not purchased for the exclusive benefit of
 17 haemophiliacs. It may have been to promote good will
 18 towards the drug firms."

19 Then it refers to the department having since
 20 licensed two other firms.

21 Then there are two quotes from a Dr Letsky at
 22 Great Ormond Street which, Paul, you have drawn the
 23 Inquiry's particular attention to. The first is this:
 24 even the famous Great Ormond Street Hospital in London
 25 is so short of Factor VIII that it cannot give John's

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1 That's a letter your Dad wrote.

2 A. Yes.

3 Q. It was prompted by an article he read in the Sunday
 4 Times and we've got that article.

5 Paul, could we have the Sunday Times article up
 6 please. Thank you.

7 So we can see it's dated 16 February 1975. It
 8 talks about a particular child, not you, with
 9 haemophilia and it then goes on to discuss the
 10 question of Factor VIII products.

11 If we pick it up in the left-hand column, Paul,
 12 please, towards the bottom of the page it says this:

13 "Little Factor VIII has been made in Britain
 14 partly because the Department of Health was unwilling
 15 to put up money for processing facilities and partly
 16 because blood is scarce and a large quantity is needed
 17 to make a little extract. Other countries however
 18 have been making Factor VIII. It is available under
 19 the health schemes of many European countries. In
 20 1973 the directors of British haemophilia centres,
 21 annoyed that many British patients were not benefiting
 22 from Factor VIII began to put pressure on the
 23 Department of Health", and then it refers to two drug
 24 firms being licensed to import 10 million units of the
 25 extract from America and Austria, enough to treat all

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1 [that's the child referred to in the article] mother
 2 a few days supply for use at home. John will
 3 undoubtedly be permanently crippled unless he gets
 4 home treatment with Factor VIII soon says Dr Elizabeth
 5 Letsky who treats him. If we had sufficient Factor
 6 VIII a bright boy like John could become a valuable
 7 member of society, but if he has to continue this way,
 8 coming in five or so times a week after an hour's
 9 journey he is in danger over spending his life in
 10 a wheelchair and becoming a burden."

11 Then there's reference to Lord Owen and a pledge
 12 of £500,000 to improve the blood transfusion services
 13 and then in the right-hand column we see this:

14 "At present, most National Health haemophiliac
 15 patients are treated with a crude blood product called
 16 cryoprecipitate."

17 Then it says this:

18 "This contains many impurities which makes it
 19 dangerous especially for children, Dr Letsky says.
 20 'Each time I inject a child who is allergic to cryo
 21 I have a sinking feeling. I never know whether he
 22 will develop a serious reaction. There are no such
 23 problems with Factor VIII.'"

24 That's the Article that unsurprisingly prompted
 25 your Dad to write to your doctor to say, "Is there

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1 something that can be done for my son"?

2 A. I mean, I've only, as you know, I've only seen this

3 article this week as the Inquiry team was trying to

4 locate it. Yes, it says "cure". It says "cure" at

5 the top in the headlines. Any parent of anyone with

6 haemophilia, it's going to attract their attention.

7 If they've got a senior doctor saying there are no

8 such problems with Factor VIII it's going to obviously

9 attract interest in using the product.

10 I think as well one of the most important things

11 of this article that I mean, it's obviously '75 so

12 looking back, the whole article is about if you don't

13 have Factor VIII, it's crippling, wheelchair,

14 unfortunately being a burden on society. There's only

15 a little comments from Dr Rizza that mentions

16 life-saving and, as I say, for most people with

17 haemophilia, most bleeds, about crippling, are about

18 joint damage, about muscle wasting. Without

19 Factor VIII we would have undoubtedly all of us ended

20 up in a wheel chair and probably been a burden, but

21 how many people actually have life-saving treatment

22 with Factor VIII is probably quite minimal.

23 Q. Just for the sake of completeness we will look briefly

24 at Dr French's reply to your Dad. Paul, it is

25 10031003, please.

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1 Obviously having been told in the past I wasn't

2 able to have these treatments to have a senior doctor

3 then say that they are now finding that there's

4 benefit obviously my Mum and Dad -- I mean, I was 11

5 at the time -- they were obviously don't like to see

6 me in pain, which I was obviously in a lot of pain at

7 the time with bleeds that were being untreated, this

8 was an option to move we thought at the time.

9 Dr French made a referral to Oxford and I do

10 actually remember going down with my Mum and Dad to

11 see Dr Rizza who basically put forward a programme for

12 me to start using Factor VIII as home treatment.

13 I think it was recorded that I was one of four

14 patients in the country at the time with inhibitors on

15 home treatment. So, yes, it was what we thought was

16 cutting edge I suppose at the time. I remember

17 feeling very happy to be having something that was,

18 yes, helping my joint bleeds and not having so much

19 time on the sofa or in hospital.

20 Q. So your treatment switched to Factor VIII products.

21 As far as you're aware, were your parents ever told of

22 any risk of infection associated with the use of

23 factor products?

24 A. Not at all.

25 Q. We'll just have look at some of the correspondence.

11

1 It says -- it is dated 6 March '75:

2 "Thank you for your letter about the question of

3 Factor VIII concentrate. As you say, this is causing

4 a good deal of public concern, which as a doctor who

5 has to treat haemophiliacs I welcome. The question is

6 one of money which as always is in limited supply and

7 of how best to use the money that is available. Very

8 strong representations have been made in the medical

9 press and elsewhere by doctors seeking to make

10 Factor VIII concentrate more readily available for

11 their patients."

12 Then he goes on to talk about, in your case, the

13 issue in relation to the inhibitors and only daring to

14 use Factor VIII to treat you in the event of a severe

15 possibly dangerous haemorrhage.

16 A. Yes.

17 Q. So that was the position in 1975 but the treatment you

18 received changed in 1976. We'll look at some letters

19 in a moment but can you tell us what was the change in

20 1976? How did you come to receive factor products?

21 A. There was two instances really. One of them was my

22 parents attended the World Haemophilia Congress that

23 took place in that year and Dr Charles Rizza was

24 giving a talk on the use of Factor VIII, promoting the

25 use of Factor VIII for patients with inhibitors.

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1 Paul, could have up on screen, please, 1003007. This

2 is a letter of 17 June 1976. We have actually only

3 got the first page here but it is from Dr Rizza to

4 Dr French. Dr Rizza has seen you in his clinic. If

5 we pick it up in the third paragraph, please, it says:

6 "I see from your letter that Paul has not had

7 a dose Factor VIII since 1 January 1974."

8 Then the next paragraph says this:

9 "I've had a long talk with [that's your parents]

10 about the prospects of home therapy. They are both

11 very keen for Paul to have it. Paul himself likes the

12 idea."

13 Then it says this:

14 "I think it would be wise to try as far as

15 possible to treat him with the NHS concentrates and

16 I would suggest that you get in touch with Dr Maycock,

17 Lister Institute, to see if he can supply you.

18 Failing that, get in touch with me again and I will

19 see what we can do from this end. As a last resort,

20 I think it might be justified to put him on to one of

21 the commercial Factor VIII concentrates and I would

22 suggest Kryobulin, the material made by Immuno of

23 Vienna."

24 There's a number of references in your records

25 around this time in the correspondence to the fact

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that you should be treated with the NHS product and with a commercial product only being used as a last resort.

Do you know why that was being said?

- A. It doesn't say, does it? It doesn't say. No, I mean, I'm looking back, I mean, there was nothing to say that because one was safer than the other. I just probably presumed it was about cost, yes, because like the Article in the Sunday Times was all about cost and money. I think I do remember the doctors talking a lot about the cost of the treatment. That was always mentioned on the wards and in the clinics as a reason for not having -- and to use your Factor VIII responsibly because of the cost. It was always the cost not the safety. So, yes, I can see why now looking back but at the time that wasn't obvious.
- Q. We can just look at the letter that was then sent from your consultants to Dr Maycock with the request following on from Dr Rizza's suggestion.
- 1003006 please, Paul, 21 June 1976. We can see it is Dr Blecher writing to Dr Maycock at BPL in Elstree saying this:
- "The above lad is a haemophilia patient of ours who has developed a Factor VIII inhibitor. In discussing his case with Dr Rizza recently, Dr Rizza

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Paul, again it refers to you having been seen by Dr Rizza and then it says:

"The Factor VIII preparation preferred is NHS concentrate from the Lister Institute or that prepared at Oxford. Failing this, the commercial Factor VIII concentrate might be used."

Then we can see, please, Paul, at 1003004, this is a letter September 1976 again from Dr French and we can see from the last paragraph that by this time, September '76, your parents had been trained to give the doses of factor to you so that you received treatment at home.

- A. Yes.
- Q. One of the observations -- or you have, I think, an observation to make about the use of home treatment as an idea, as a concept.
- A. Yes, I spent a lot of time off school and all the rest with bleeds that weren't treated so actually having the treatment was better for obviously I wasn't spending as much time in pain. I was having more of a fruitful life suppose. But the thing is with home treatment everything was talked about the cost. When the doctors were giving home treatment, the treatment was taking place in your own house, in the kitchen, whatever.

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mentioned that at Oxford nowadays they are treating such patients who have inhibitors with frequent and regular Factor VIII therapy and obtaining good results. He recommended that I place Paul on weekly prophylactic Factor VIII therapy."

So there were two changes to your treatment regime at this time, first that you were moving to use the Factor VIII products but, secondly, it was going to be given to you prophylactically.

- A. Yes, it was but I think actually looking back at my records there wasn't enough factor consumed for it to be once a week and I think it probably was more on demand but, yes, it was suggested I go on it prophylactically.
- Q. The letter continues:
- "It would be obviously be preferable to use the NHS concentrate."
- Again, as you say, it doesn't explain why that is seen as obviously preferable?
- A. Yes, obvious to who? Not to the patients or the parents, I think.
- Q. Then lastly in terms of the correspondence in June can we have up 1003005, please, and again we see this is a letter from Dr French. It's to whom it may concern and if we look at the body of the letter, please,

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If the doctors knew, you know, obviously, use NHS not commercial, if they are saying things like that, if the doctors did know there was a risk I think it was almost like they didn't have to see the risk. That risk was out of their vision. It was being done in my house. I don't know whether they would have felt differently if they were injecting it into my veins, if they knew it was risky.

It was almost like, well, we're not seeing it so we don't have to deal with it and then the patients at home, myself, we weren't aware of any risks. I actually remember thinking it was great that I'd actually got things -- well, later on I ended up on commercial products. We'll probably talk about that later, but yes. It was great for us but I don't think the doctor -- I think there was, yes, a discord between the risk factors and what we knew at home and because the doctors weren't seeing it they didn't have that responsibility. That's only my thoughts.

- Q. You said in your statement you were treated prophylactically as far as you know from your records from the summer of 1976 to April of 1977 but after that you were treated on demand --
- A. More or less, yes.
- Q. -- when you had a bleed.

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1 By the end of 1976, despite what had been said
 2 in the letters that we've seen and for whatever
 3 reason, you had started to receive the commercial
 4 Factor VIII products rather than the NHS products.
 5 A. Yes, and I don't know why that was, whether that was
 6 a financial thing, but we go from letters in June and
 7 doctors' notes in June saying, you know, NHS Elstree
 8 products, you know, and the last result commercial
 9 products. That was documented in September '76, but
 10 by December '76 I was on American commercial products.
 11 It was only a three month difference, so we had gone
 12 from, yes, one extreme to the other really.
 13 Q. We've got a list of the products that you had from
 14 1980 onwards in your witness statement and we'll just
 15 call up that list, please.
 16 Paul, could we have Paul's witness statement up,
 17 please and we'll go to the second page.
 18 We can just see here this list. It gives us
 19 a sense of it, from 1980 onwards you've got Koate,
 20 Kryobulin, Huminate, there's then in '81 the NHS
 21 product being given, then Factorate, Koate again,
 22 Kryobulin, Factorate. In 1982 you are recorded as
 23 having Hemofil and so on. We can see from that the
 24 majority of products you received during that period
 25 were the commercial products with you only

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1 different, this was. It sort of changed things
 2 a little bit for me inside and I think the family as
 3 well because they treated it like it was something
 4 serious, the whole family, my Mum and Dad, my brother
 5 and sister, they were all blood tested to see if
 6 they'd got it. I remember having to have separate
 7 towels, face washing cloths, mugs, knives and forks.
 8 Everything was -- I was treated separately for a point
 9 of hygiene really and I was aware that something was
 10 dangerous with the blood.
 11 I had the hepatitis B in the acute form, not the
 12 chronic, so I actually displayed all the symptoms very
 13 readily and I was ill for a couple of months and sort
 14 of, yes, I was young. I was 13 at the time.
 15 I bounced back from it. I thought I'd been unlucky.
 16 I was told I was unlucky and that was my experience of
 17 hepatitis, yes. You go yellow, you don't eat your
 18 food. I lost weight. Couldn't eat anything fried for
 19 a long time. I think one of my doctor's notes says,
 20 "Keep Paul on a bland diet", and that was more or less
 21 it really.
 22 Q. In terms of risk, you were, as you say simply told,
 23 your family was told you had just been unlucky.
 24 A. Yes. Well, if it was anything more serious I suppose
 25 that was negated by the fact that they continued

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1 occasionally receiving the NHS product?
 2 A. Yes.
 3 Q. Was there ever, as far as you know, any discussion
 4 with your parents about that change or any reasons for
 5 it?
 6 A. No, only financial. I think it was probably some
 7 products were cheaper for the hospital to buy in.
 8 Yes, there was -- I mean, something significant
 9 changed in 1977 for this but -- no, it was anything
 10 and everything. I remember having porcine factors at
 11 one point but my factor records were a bit sketchy
 12 really what I've received from the UKHCDO on my files.
 13 Q. It was in April of 1977 you developed acute hepatitis
 14 B. What can you recall about that?
 15 A. Having had my first commercial Factor VIII in December
 16 which I think the Cutter product was mentioned in my
 17 notes. Yes, by April '77 I had Hep B, I had nose
 18 bleeds, I was losing weight, I was jaundiced in colour
 19 and, yes, they diagnosed me as having hepatitis B.
 20 I was told I was very unlucky. Yes, within four
 21 months of having my first commercial factors I'd got a
 22 strain of hepatitis.
 23 I remember it being a very strange time because
 24 I was aware of my haemophilia at that age, it was all
 25 I'd known from growing up, but this was something

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1 putting me on the same factor products that I was
 2 using before having Hep B, so they didn't like stop my
 3 treatment. I still continued to use commercial
 4 products after that because I had just been unlucky
 5 that time.
 6 Q. We can see from your records, I won't call them up on
 7 screen but you referred to them in your witness
 8 statement and we have them, that not only was your
 9 family test and you were given advice about having
 10 separate utensils and so on, but that also action was
 11 taken by your doctors to write to the manufacturers of
 12 the products that you had been receiving to report
 13 a possible problematic batch.
 14 A. Yes.
 15 Q. You have contrasted your experience in relation to
 16 what happened when you had acute hepatitis B with what
 17 happened eight years later when you learnt of
 18 a further infection.
 19 A. Yes.
 20 Q. We will come on to that. You recovered, in any event,
 21 after a few months from the acute hepatitis B.
 22 A. Yes.
 23 Q. Then you have recalled in your witness statement in
 24 around 1983/1984 becoming aware or your family
 25 becoming aware of the issue of AIDS and you refer to

20

1 a World in Action programme.
 2 A. Yes.
 3 Q. What do you recall?
 4 A. I think the first time we were alerted. I mean,
 5 because I had had the Hep B I was aware and my family
 6 was aware there was a risk of something. But, as
 7 I say, that risk of the hepatitis was me being ill for
 8 a couple of months and if that's the most dangerous
 9 thing, then if the Factor VIII is actually reducing my
 10 pain, helping mobility, helping me have more of
 11 a normal childhood then I think you sort of weigh
 12 those risks up, don't you.

13 When the World in Action came out, obviously it
 14 alerted us. My Mum and Dad were members of the local
 15 haemophilia group. I think they had had a phone call
 16 to say something's on the telly and we watched it.
 17 I remember watching that. I think my next appointment
 18 at the doctors I think they played it down.
 19 I remember them playing it down. I remember them
 20 saying it was sensationalised and all that, "Oh,
 21 that's not going to be happening in England, in
 22 Britain, it was a sensationalised television
 23 programme". The doctors seemed quite happy to keep
 24 prescribing me the Factor VIII so, you know ...

25 We did have, like a lot of people who have sat

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1 syndrome, AIDS, in haemophilic patients has strongly
 2 suggested transmission of this disorder by blood
 3 products and epidemiological studies have suggested it
 4 may be related to a transmissible agent."

5 Some further information given about work being
 6 undertaken in America and in Paris. It says:

7 "These reports should be received with optimism.
 8 Obvious benefits from such findings would be the
 9 provision of a blood test for both affected persons
 10 and donated blood and in the long-term the development
 11 of a vaccine. In Great Britain the number of
 12 haemophiliacs who have been reported with AIDS remain
 13 at two, thus the incidence is less than 1 in 1,000
 14 patients at risk."

15 Then there are a number of other observations
 16 and if we just go over the page, please, we can see
 17 the author of this, it would seem, is CA Lee senior
 18 registrar at the Royal Free, Dr Christine Lee.

19 That is the first leaflet you have referred to
 20 in your statement. We will just look at the second
 21 and then come back to your evidence about it.

22 Paul, could we have up on screen, please,
 23 1003019.

24 This is the subsequent release, release
 25 number 4, Haemofact AIDS, 24 September 1984, and then

23

1 in this chair, trust in doctors. I mean, because of
 2 the nature of haemophilia you were a patient your
 3 whole life. It wasn't a one-off so you had
 4 a relationship with your doctors. You saw more of
 5 them than you did members of your own family, so there
 6 was trust there. So when the doctors said, "This
 7 television programme's sensationalised. Don't worry
 8 about it. Carry on taking the factor", yes, we did.
 9 Q. You have said that the other source of information for
 10 your parents as well as the doctors who responded in
 11 the way you have described was the Haemophilia Society
 12 and you've referred in your statement to some specific
 13 leaflets that were disseminated by the Haemophilia
 14 Society at the time?

15 A. Yes, the Haemofacts.

16 Q. You have quoted from a couple of them. We have the
 17 actual leaflets, so we will just have those on screen.

18 Paul, could we have 1003018.

19 We can see here the date of it. This is
 20 Haemofact AIDS release number 3. It is dated
 21 11 May 1984 and if we go over the page, just in the
 22 first and second paragraphs it refers to -- so it's
 23 described as:

24 "Acquired immuno deficiency syndrome, an update.

25 "The occurrence of acquired immuno deficiency

22

1 over the page we can see this is authored by Dr or
 2 Professor Kernoff, again from the Royal Free:

3 "The possibility that the acquired immuno
 4 deficiency syndrome, AIDS, may be caused by an unusual
 5 virus has always been a strong one."

6 Then again it refers to the work being
 7 undertaken in France and the USA to isolate the
 8 viruses. That is described in the next paragraph as
 9 a major step forward, suggests that tests may take
 10 some while to be developed. Then towards the bottom
 11 of the page, last five lines, it says this:

12 "The presence of antibodies implies past
 13 exposure to LAV/HTLV-III but this in itself isn't too
 14 surprising. Most haemophiliacs have antibodies to
 15 a variety of different viruses in their blood,
 16 probably as a result of repeated exposure to small
 17 amounts of these viruses in transfused blood products.
 18 The presence of antibodies [top of the next page,
 19 thanks, Paul] is usually taken as evidence of immunity
 20 to infection and perhaps one reason why the risk of
 21 AIDS in haemophilia is so low, around 1 in 1,000, is
 22 that many patients are immune to it."

23 Then it goes on to say there are probably other
 24 reasons too and then there's a reference in the next
 25 paragraph to AIDS being:

24

1 "... a relatively new problem for haemophiliacs
2 but infection with hepatitis B virus being an old one
3 which is fast on its way to being solved."

4 Then we've got, for the sake of completeness as
5 part of the documentation from you, the follow-up
6 leaflet but I don't think we need go to that for
7 present purposes.

8 What you have said in your statement about these
9 leaflets is that they provided a further degree of
10 reassurance to your family because they essentially
11 gave the impression that the risk was a very low one.
12 Is that correct?

13 A. Yes. I mean, it's in black and white there. My Mum
14 and Dad got a lot of information from the Haemophilia
15 Society. They were active members within the
16 Haemophilia Society. These are the information
17 leaflets. I didn't actually see these until some
18 years ago. My Mum had actually kept them. I think
19 she kept them because after they realised I had been
20 infected with HIV that it was something tangible to
21 hang on to, to sort of say, "Well, we weren't making
22 a mistake. We were trusting the doctors".

23 Not only were they trusting the doctors we saw
24 in person that were still administering the
25 Factor VIII and sending it to my house for us to use

25

1 us ended up with the whole ...

2 Q. What you have said in your statement with this
3 information from doctors and from the patient
4 organisation and, of course, the Haemophilia Society
5 leaflets that we've just looked at, what they are
6 based upon is advice from, it would seem, the doctors
7 there named. It says:

8 "No-one was saying anything different. We
9 accepted the risk was minimal."

10 Then you say this:

11 "My doctors were still advising continued use of
12 factor concentrates, even advising me to take factor
13 more regularly on the same day that I was unknowingly
14 tested for HTLV-III."

15 Can you just expand on that last point, please,
16 Paul.

17 A. Yes, this is something when I got my medical records
18 back that I really did look through with, yes, more of
19 an inquisitive eye, I suppose, really. I had a
20 group -- I know it was 19 April, I remember from
21 reading my notes, 1985, that my notes in the doctor's
22 records from the actual appointment of a normal clinic
23 check up appointment, I was still having lots of
24 internal bleeds in my left knee, is asking me
25 basically to take Factor VIII on a more prophylactic

27

1 at home, but the information that was coming from the
2 Haemophilia Society which was and has been the only
3 really information source and support for people with
4 haemophilia, in two separate articles they are saying
5 the risk is 1 in 1,000, saying the incidence is low.
6 They are saying that we might have antibodies that
7 will actually protect us. It's quite -- well, it's
8 bad enough if 1 in 1,000 get infected with HIV but it
9 was almost like if that's the only risk we've got is 1
10 in 1,000 people probably took that risk because they
11 didn't really know the implications of HIV at the time
12 and nobody was -- nobody was saying don't use it.
13 They were saying continue.

14 I mean, this other article that we've not
15 discussed that was -- at the same time there was
16 the -- Peter Jones had got the booklets AIDS in the
17 blood and there was a question in that was about
18 "Should stop my factor treatment", and he says no.
19 I think it says something along the lines of there
20 would be more damage done from not treating bleeds
21 than there ever would be from any possible risk of HIV
22 transmission.

23 We went from I guess, I say guess, whether they
24 worked that out I don't know, but from 1 in 1,000 it
25 actually turned out to be 33 per cent, a good third of

26

1 basis and to undertake some gentle physio or, if I am
2 going to do anything physical, to take the Factor VIII
3 prior to doing any physical exercise, so they are
4 actually telling me to use more Factor VIII.

5 It's been said time and time again during this
6 Inquiry from people with haemophilia that when you go
7 for your clinic appointment they take bloods. It's
8 just part of the routine, and with me they always
9 checked bloods for my inhibitor levels and they'd
10 check platelets and full blood counts.

11 What I didn't know that day was they were also
12 testing me for HTLV-III. There's no mention of it in
13 my notes. It wasn't discussed with me. I didn't know
14 they were testing for that. There was no mention of
15 it.

16 Q. If we can have up on screen please 1003 --

17 SIR BRIAN LANGSTAFF: Just before we go there, can I just
18 take you back to the Haemofacts 3 and Haemofacts 4, 18
19 and 19, first of all, 18.

20 Did it ever occur to you that Dr Lee in the
21 first might be using the word "risk" in a different
22 sense from the way that Dr Kernoff appears to have
23 been using it in the second?

24 Look at the first. It's number 3. It's the
25 page before. Just pause there:

28

1 "In Great Britain the number of haemophiliacs
2 who have been reported with AIDS remain at two,
3 thus ... [I am not quite sure it follows but] ... thus
4 the incidence is less than 1 in 1,000 patients at
5 risk."
6 So she is talking there about incidence.
7 If we look at the Kernoff letter which is number
8 4, thank you, can we look at the --
9 **MS RICHARDS:** Second page.
10 **SIR BRIAN LANGSTAFF:** Second page, thank you. It is the
11 bottom of one page and the top of the other, the
12 bottom of the screen:
13 "The presence of antibodies taken as evidence of
14 immunity of infection perhaps one of the reasons why
15 the risk of AIDS in haemophilia is so low ..."
16 So that's talking about the risk in haemophilia
17 whereas the first one is talking about the incidence
18 and incidence and risk might be thought of as two
19 separate things. So when Dr Lee is talking about
20 incidence it's incidence of those who are at risk, in
21 other words, every 1,000 people at risk 2 get
22 full-blown AIDS. This is talking about the risk of --
23 in a population and it may be two different things.
24 **MS RICHARDS:** Yes, of course, you, Paul, were a teenager
25 at the time.

29

1 your statement you were not told that bloods were
2 being taken that day for the purpose of testing for
3 HTLV-III.
4 **A.** No. There was nothing in the records. I would --
5 it's the sort of thing that I think you'd stick with
6 you. No, I had no idea that's what they were doing.
7 **Q.** We'll just put up on screen the test result. It's
8 very faint but it's 1003014.
9 The date taken, it's not very clear on this but
10 actually it is possible to see it on the underlying
11 documents and we've looked at them, is 19 April 1985
12 as you have said and the test result says this:
13 "Antibody to HTLV-III present."
14 Now, I want to talk next with you about how you
15 learnt of this test result. That was 19 April that
16 the bloods were taken. You then received a letter in
17 June. We'll just look at the text of that, 1003015,
18 24 June 1985 from Dr Blecher. It says this:
19 "Dear Paul, I've now received the results on all
20 the tests we carried out on your recent blood samples,
21 including one result I have only just received from
22 a specialist laboratory in London. I should like to
23 briefly discuss one or two of these results with you
24 personally. Could you therefore please come to see me
25 for a short time one day next week. Please telephone

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1 **SIR BRIAN LANGSTAFF:** You wouldn't have looked at it that
2 way I suspect, you just saw the two figure, but you
3 took it that you had a very low risk.
4 **A.** Yes, I think anybody else that was probably reading
5 those information leaflets would have read it the
6 same.
7 **SIR BRIAN LANGSTAFF:** I think we can explore this later.
8 **MS RICHARDS:** Absolutely, sir. Certainly I think we have
9 the potential to do so with at least one of the
10 authors.
11 **SIR BRIAN LANGSTAFF:** Yes.
12 **A.** No, I never looked at it like that.
13 **MS RICHARDS:** Just picking up upon the reassurance that
14 your family may have placed upon this, you found
15 I think these leaflets in your Mum's bedside drawer.
16 She kept at least one of them you have said in her
17 bedside drawer until the time of her death.
18 **A.** Yes, my Dad gave them after my Mum had passed away.
19 She kept them all that time. I hadn't seen them
20 until -- you know, it was 20 years ago now.
21 **Q.** Returning to 19 April 1985, you went along for
22 a clinic appointment. You were encouraged, as you
23 say, and we don't have the record in the documents
24 here but the record absolutely says this, to use
25 Factor VIII and bloods were taken. As I understand

30

1 my secretary to arrange a time convenient to you and
2 during my working hours."
3 You make some observations about that letter in
4 your statement. Perhaps you could tell us what those
5 are.
6 **A.** There's only one paragraph and yet it says an awful
7 lot to me now. I mean, the specialist laboratory in
8 London. I don't know where that was, and that's quite
9 an interesting thing in itself now looking back. But
10 he wanted to briefly discuss the results with me and
11 the appointment was only -- make an appointment for
12 a short time. There didn't seem any urgency to it.
13 "Phone my secretary to make an appointment."
14 The fact that he briefly wants to discuss something
15 with me and he only wants to see me for a short time,
16 to me, at the time, that said to me that wasn't very
17 important. It was going to be something that was --
18 it was a brief chat. Why would you have a brief chat
19 to tell somebody they've got a terminal illness? It
20 wasn't for my benefit and just -- yes, I just think
21 that was very, very poorly thought out.
22 I was working at the time. I was 21 years old.
23 I just basically asked my boss if I could have a short
24 time off work. I'm going to go to the hospital. I've
25 got an appointment. I'll only be a hour or two.

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I may well even work through my lunch hour or something to cover it or something that day. I can't remember, but I remember the day, the afternoon, very well when I went for that meeting, which was, yes, I think early July when I found out.

So they took the bloods in April. They wrote to me the end of June. I went for the appointment in July. I didn't actually see Dr Blecher who wrote that, I saw the other of those two doctors.

Q. Dr French you saw.

A. Dr French, he saw me. He didn't make eye contact with me, just looked up and down. It was all very strange because I was very used to going to the hospital, like all the other people with haemophilia, very used to going to the clinics. I went to the normal clinic and I was told it wasn't there today. It was somewhere else, and I was then told to sit outside.

I was on the ground floor in a corridor, which was a main thoroughfare. There was just a seat, one seat outside. It was a room I had never been in. It was like a storage cupboard. I think the alarm bells started to ring a little bit at that time but even then I didn't expect anything like that that day. He wants to see me for a brief time to discuss something that's only going to take a short moment.

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would -- the HTLV-III virus would probably manifest to full-blown AIDS in I think he said two to four years, don't have sex. If you do only wear a condom.

It all seemed very strange because that was it. I was asked, any questions. I didn't have any questions, go. I remember even standing in the corridor thinking did that really happen. I went back to my car, sat in the car park. I just sat in my car for a while thinking did that really happen, running through, trying to run through what he said, trying to make sense of it all, expecting something, follow-up and there was no follow-up.

When I look back to when I was infected with hepatitis B in '77, which was eight years earlier, I was told, I was given -- well, the family were given advice then, you know, about the transmission possibilities. We were told about face cloths and towels and cutlery and all the rest and I was given no advice with this at all. I wasn't given any advice -- I'm sorry, it wasn't just, "Don't have sex, wear a condom". It was, "Don't have sex, wear a condom, and don't tell anybody". That was reiterated very strongly, "Don't tell anybody".

I went back to work that afternoon because I thought I would be in trouble with the boss if

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I walked in the room. It was a windowless room. I just remember there being some filing cabinets, one desk with a chair one side where the doctor was sat and me on the other side. I remember him telling me they had taken some tests for the HTLV-III. I had antibodies to the HTLV-III. I asked what the HTLV-III was. He said it was the virus that causes AIDS. I actually, do remember in my naiveté at the time saying, "I've got antibodies to it. Does that mean I'm protected against it?" And he said that the antibodies in this case meant that I'd actually got the virus present in my body.

I remember him asking me if I'd got any questions. I hadn't got any questions because it was just -- I was just like I think a rabbit in the spotlights then. If I'd been told in April that I was having this test done I would have had time to actually think about it. If when the letter came it had given me a bit of indication. If it said, you know, take the afternoon off, bring somebody with you or whatever, I might have thought it a bit more serious.

It seemed a very surreal moment that I was being told. I remember him saying to me the only advice -- I didn't have any questions. He told me I probably

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I took any more time off because I said I'd only be gone an hour or so, so I just pretended that everything was normal.

Q. You have said in your statement you remember thinking it was odd that they didn't ask for your girlfriend at the time or your parents or siblings who you were living with to be tested, again contrasting that with what happened when you had the acute hepatitis B eight years previously.

A. Yes. Okay, this is where my head -- my mindsets at the time. When I had Hep B which I was ill with for two months, all the family were tested to see if I had passed it to them. When I was given the HIV diagnosis, nobody was called in. So, in a way, that gave me a false sense of security that maybe -- or maybe it's not so bad. If it was really bad, well, maybe it's not as bad as the hepatitis B was. It was very confusing.

Q. You have described it in your statement as the briefest, most unprepared and most uninformed appointment?

A. Yes. I had no preparation for it. They knew what they were going to tell me. Because they knew what they were going to tell me, I mean, looking back at it they should have prepared a lot -- they should have

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1 known that telling someone -- yes, telling someone,
 2 those doctors had treated since I was a toddler.
 3 They'd known me. They know my family. They knew what
 4 I was like and everything. They just saw me for a few
 5 moments, gave me the most devastating news I'd ever
 6 had. Told me that I've only got a few years to live,
 7 telling me to keep it a secret. Everything went out
 8 the window that day. Everything changed that day.
 9 Q. You were, as you say, 21 years old. You've said in
 10 your statement you "had the world at my feet"?
 11 A. I thought I did.
 12 Q. You had a good job, a girlfriend, an active social
 13 life, but on that day your life changed forever.
 14 A. Yes.
 15 Q. You still thought you were one of the unlucky ones,
 16 you were the 1 in 1,000.
 17 A. Oh, yes, that was the other thing. I didn't realise
 18 how deep this was because they called me in and I had
 19 been given this and I was told not to tell anybody. I
 20 was unlucky to have the Hep B. I thought I was
 21 unlucky to have the HIV. I just -- because of all the
 22 literature was saying 1 at 1,000 in risk I just
 23 thought I'd been really unlucky, that was all. I just
 24 thought, well, you know, life is life and some people
 25 are luckier than others and I just thought, yes, I was

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1 time to talk about things, but I just basically
 2 bottled that up for two years.
 3 I saw a councillor there as well but at that
 4 clinic everything was different because it was the
 5 first clinic I had been to that -- I think I was the
 6 only guy with haemophilia there. It was fairly
 7 obvious, to me at the time anyway, that most of the
 8 people there were gay guys and all the guys with
 9 haemophilia were all tested, children, adults, we were
 10 all tested in '85, around '85, without our consent.
 11 They didn't test all the gay guys in the country
 12 without their consent. People were getting ill, so in
 13 many ways I think a lot of the gay guys were getting
 14 iller probably before -- those that were knowingly had
 15 HIV were actually exhibiting illnesses and then got
 16 tested and then came to the clinics. So I was seeing
 17 people for the very first time that were actually ill
 18 and that was -- yes, that was definitely a changing
 19 moment for the psyche in me that, yes, this is real.
 20 This is what I've got. I'm going to end up looking
 21 like some of these people in this waiting room. Yes.
 22 It was a big dawning for me that was.
 23 Q. Can you --
 24 A. They --
 25 Q. Carry on.

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1 just drawing the short straw every time and that's
 2 what I, probably quite selfishly I thought I was just,
 3 yeah, one of the unlucky ones. If there had to be
 4 1 in 1,000, I was the one.
 5 Q. Did you receive, following that appointment, which you
 6 have described in the way you have, did you receive
 7 any follow-up care, any follow-up appointments at the
 8 hospital in relation to the HIV diagnosis?
 9 A. Not initially, no. I still went for the normal
 10 haemophilia clinics which I think at the time were
 11 every six months, which was probably quite normal.
 12 No, I didn't have anything -- there's nothing in my
 13 notes and there's nothing in my memory that say I had
 14 anything up until about '87, which was about two years
 15 later.
 16 I was referred then to I suppose it was one of
 17 the very early HIV clinics. It was in the same
 18 hospital and it consisted of seeing two doctors, one
 19 was a chest expert because most of the people with HIV
 20 who were developing AIDS at the time had a lot of
 21 pneumonia, a lot of chest complaints, was probably the
 22 most common, and a doctor from the sexual health
 23 clinic, the GUM doctor, and I saw them.
 24 It was good. They talked to me differently.
 25 They treated me differently. They gave me a bit more

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1 A. They had a councillor there that was part of the team.
 2 I remember seeing her. She was a lovely woman but
 3 just remember her telling me how brave I was.
 4 I didn't come away with anything constructive to use
 5 or they didn't allay any of my fears. Yes, but I did
 6 feel like somebody was taking that part of my illness
 7 a little bit more seriously.
 8 I'd lost my faith in the haematologists at this
 9 point as well because the haematologists were putting
 10 in the print risks of 1 in 1,000. My haematologists
 11 at the hospital were continuing to prescribe me
 12 Factor VIII. Risks weren't really being given and
 13 then I ended up with the HIV virus.
 14 So I didn't really trust them. I started to
 15 mistrust my doctors at that time.
 16 Q. The impression that your statement gives is that a lot
 17 of the information and practical advice and guidance
 18 that you've obtained since that time has been not from
 19 the medical profession but from the gay guys and the
 20 drug users and the organisations that were set up to
 21 support them rather than from the NHS bodies. Is that
 22 right?
 23 A. Yes. The Haemophilia Society had been my mine and my
 24 family's source of information about haemophilia.
 25 This was different. Where did you go for information

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about HIV? Well, yes, the organisations that mainly supported gay people gave the information about HIV. So, yes, I think one of my first phone calls was either to the Terrence Higgins Trust or Body Positive.

They didn't have a lot of people with haemophilia phoning them, as was obvious from the switchboard people that answered. There were different questions and I felt that there was some support there and I then started going to HIV clinics in which I had -- yes, I'd befriend people with HIV that were gay guys, not haemophiliacs. So, yes, my sort of support avenues changed quite a bit.

With drug users as well, that probably came a little bit later when -- I'm stepping ahead but I know you will come back to this with my hep C diagnosis, because at the time it was the gay guys with the HIV and the drug users with the hepatitis and people with haemophilia we had both, and you'd phone one organisation or get support for your HIV but they didn't really know a lot about hep C at the time and you go to the hep C organisations, people like Mainliners, the British Liver Trust. They weren't all that geared up for HIV because their specialism was hepatitis C. So yes, it was a bit of a run around.

So meeting other patients with HIV and

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someone, "How's your Paul?"

"Oh, our Paul's okay. He was a lucky one." People would ask me, "Have you had this AIDS test thing then?"

"Yes, yes, I'm fine, I'm lucky." I used just to brush it off if people asked. I stopped telling people I'd got haemophilia in case they asked. Yeah, things changed a lot. I became -- I was very, very aware of my mortality, yes. I didn't sleep very well after then. Everything changed. My job went downhill, my performance at work, I wasn't sleeping at night. I'd keep it together all day long, trying to keep a lid of things, trying to keep my emotions, petrified that people would find out. I do -- my -- yeah.

Q. You put it this way in your statement, Paul:

"The thought of dying never left me. I closed my bedroom door at night and my world collapsed. I was very fragile inside by now and would breakdown. I cried a lot at first, always alone and always when I knew it was safe to do so. I had been given this virus and I hadn't been given any tools to know how to deal with it. I kept it to myself and it stewed and rotted me away from inside."

A. Yeah, that's about right and I think that's, yes, the

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hepatitis C was great for me because, yes, peer support, that peer support, whether they had haemophilia or not, if they had HIV and hepatitis C we had something in common.

Q. I just want to ask you a little about how the diagnosis of the HIV infection affected you in those first years, both mentally and physically.

Start with the mental impact. You talk in your statement about believing you were going to die and being very, very scared?

A. Oh, yes. Yes, it was -- the stigma was intense from all avenues. I think the best advice my doctor ever gave me was don't tell anybody. Yes, you couldn't tell people. People's attitudes to HIV were vile. This inquiry's seen a lot of people's experiences. I'm glad to say I didn't really have any horrible experiences and the only reason I didn't was because I kept it so secret. My family kept it secret; I kept it secret. That day, from that moment onwards, I got very good at lying.

Q. You told people you were one of the lucky ones, that you didn't have it?

A. Yes. Our families, we knew people with haemophilia, you know, my Mum and Dad knew other people and other parents and, you know, you'd probably bump into

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doctors knew I'd got this. I hadn't been given any mechanisms to actually work it out, apart from me. I had to work it out myself. I just felt so lonely with it all.

Q. You talk in your statement about it being about five years later you were introduced to a psychologist who you felt comfortable with and you started talking about your fears and she set up a self-help group for infected people with haemophilia in your area.

What can you tell us about that?

A. Yes, yes, this was a very illuminating time and a very, very sad time too. I mean, I had had four or five years, five years with the diagnosis at that point, the HIV diagnosis. At that time I didn't find out I'd got hep C until later but the doctors changed at the hospital. The two doctors that had been treating me that have been mentioned so far had both left. We had a new consultant in, a haemophilia consultant. He called a clinic, a new clinic, it was like a review clinic which I thought was great, a new doctor, new start.

That clinic, what was very different about that first clinic was the people in the waiting room.

There were people I hadn't seen for years. There were -- because having haemophilia as a kid when there

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1 wasn't the treatments around and when I got my
2 inhibitors I would always end up in hospital and my
3 Mum and Dad were members of the local group I knew
4 quite a lot of people with haemophilia in my area and
5 I hadn't seen a lot of them for a long time.

6 I never really questioned it really but I saw
7 a lot that day, at least four or five of them that I'd
8 known from childhood, from hospital stays in my
9 childhood and it was a bit like a little reunion. It
10 was sort of penny drops, that lot of them didn't look
11 very well and I think the consultant had called
12 a meeting for all the people with haemophilia on his
13 books that were HIV positive.

14 That was the moment I'd actually realised that,
15 hang on, I wasn't 1 in 1,000. I didn't actually
16 realise so many people had been infected. I didn't
17 realise how many people I actually knew had been
18 infected. It was a bit of a door opening, a light
19 shining that day.

20 But the consultant, he's still around today, he
21 also invited -- sorry, he was aware that we hadn't,
22 none of us on our records had seen anybody
23 professionally to talk about anything and he had set
24 up a psychologist and at that appointment, as
25 I remember it, there was an opportunity to see

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1 tools of survival by their problems. A number of them
2 had started AZT. It was all the guys that were on AZT
3 that looked the illest. Whether it was they became
4 ill first and then had AZT but we used to sit in those
5 meetings, it was the guys that were on treatment that
6 were the ones that didn't stop scratching at sores and
7 the ones that were being -- yeah, just showing
8 symptoms of being poorly. We all talked about our
9 illnesses.

10 There's bits about secrecy. There were guys
11 there that were older than me that had kids. Some of
12 them had told their work employees and their bosses.
13 Everything changed that day, they said. They said
14 they wished they had never told their boss. People
15 stopped talking to them. One guy said that we used to
16 have a canteen in the workplace and it was just mugs.
17 The day after he told his boss he went to work his
18 desk had been moved and all the mugs had gone and
19 paper cups had been brought in, so he said everybody
20 in the office had known.

21 Kids -- friend's of his children were no longer
22 allowed to come round play. His kids were no longer
23 invited to birthday parties. I realised really how
24 important it was to keep this secret. I might have
25 been at that point, having five years I've lived with

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1 a psychologist. So I saw the doctor, first time I'd
2 seen him, had a review, all the normal stuff, how far
3 can you bend your knee, how far can you bend your
4 elbow, and feeling around my lymph glands and things,
5 and, yeah, I had had a few issues at that time as
6 well, HIV-related with lymph node problems and coughs
7 and colds that wouldn't go away, but, yes, I saw this
8 psychologist. She was great.

9 It was the best help I had had from anybody at
10 that point. It was the first time I had actually had
11 to talk about it. She was aware that none of us had
12 actually spoke to anybody else about it so she set
13 this little support group up. It was probably 10 or
14 11 of us, probably all the adult people with
15 haemophilia in the area that were HIV positive. Four
16 or five of them I had known from childhood. It was
17 great at first. It was like we all had an opportunity
18 to talk. We met once a month. It was a basement room
19 at the hospital, again no windows, shut door, no sign
20 on the door. We felt safe in there.

21 Yes, everybody talked about their problems,
22 everybody talked about their issues. It was
23 incredibly sad, people's stories. However, I don't
24 think I'd be here today if it wasn't for those people
25 because probably in a selfish way I developed those

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1 it, at the cusp of wanting to tell people but no, that
2 reinforced the need for secrecy, it reinforced the
3 need to be aware of the medications that were being
4 offered, because at the time the doctors were trying
5 to get me on AZT every time I went for an appointment.

6 But it was mainly the haematologists, you know.
7 I might have been to this -- I only started going to
8 the GU clinic, which was a sexual health clinic for my
9 HIV, quite sporadically at that time. It wasn't a
10 regular -- the haemophilia doctor was still taking
11 most of my control over my virus. It never really sat
12 well with me but he was, yes -- his specialism was
13 haemophilia not HIV. Just because his haemophilia
14 patients had developed HIV he suddenly hadn't
15 developed a specialism in HIV himself.

16 So I wasn't a great patient as far as the
17 doctors were concerned because I questioned
18 everything. I was very awkward as a patient but that
19 awkwardness is probably why I'm here today. Probably
20 one of the reasons.

21 Q. That group that you describe of patients, you talked
22 about people being more ill every month, people
23 getting thinner every month and then the group getting
24 smaller and smaller because people were dying.

25 A. Yes.

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1 Q. You would be going to funerals.
 2 A. Yes. I knew, some people said I won't be coming
 3 again, you know. This one guy in particular, he'd
 4 got -- the HIV had crossed the blood brain barrier.
 5 He'd started to -- well, he was only in this 20s and
 6 he was showing signs of a pensioner with Alzheimer's.
 7 He couldn't form his words. He couldn't speak
 8 properly. He was very frustrated, very confused.
 9 Yes, it was very, very frightening seeing these
 10 illnesses and things and, yeah, the group got smaller.
 11 When the group got down to two or three of us
 12 there was no real point in having a group, and that
 13 was over a three-year period. Weirdly, it was the
 14 people that were on AZT that went the first. I think
 15 there was one, one or two people alive after that
 16 early '90s period as well as myself.
 17 Q. You describe in your statement from those meetings and
 18 from watching people getting iller and dying, anger
 19 started to grow in you and you started, amongst other
 20 things, and we will come to a couple of examples later
 21 on in your evidence, but you started, amongst other
 22 things, writing to politicians?
 23 A. Yes, that was around the time, round about 1990 when
 24 I started going to this group, when I realised so many
 25 people had been infected, when I realised, you know,

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1 herself. It was from whoever replies, her secretary
 2 or some civil servant, suggesting that this wasn't --
 3 I haven't got a copy of the reply. There's a lot of
 4 letters that I had in the early days that I lost but
 5 she suggested that I write to my local MP to bring
 6 this up with my local MP.
 7 Well, it just so happened at the time that my
 8 Mum and Dad lived in the constituency of Ken Clarke
 9 and he was their local MP, so as Ken Clarke had been
 10 the Health Secretary and the Minister of State for
 11 Health, I thought he would be an ideal person to write
 12 to. So after writing to Margaret Thatcher and I felt
 13 fobbed off I wrote to Ken Clarke and I actually got
 14 quite positive about that. I thought he's the Health
 15 Minister. He knows what he's talking about. He's
 16 also the local MP. I'll get a response. I did get
 17 a response.
 18 Q. We might as well look at that.
 19 A. Let's have a look at that.
 20 Q. It's 021, please. 22 January 1990:
 21 "Thank you very much for your recent letter.
 22 I am sorry you are so disappointed by the level of
 23 payment we are making to every person infected by HIV
 24 as a result of treatment for haemophilia. I do not
 25 accept that the infection was the result of any

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1 it was a lot of us that had got HIV and those people
 2 that knew, that did make me -- weirdly, I was more
 3 probably angry for the people that I knew had been
 4 infected than I was myself in a way at the time. It
 5 was a very confusing time. My head was full of
 6 contradictions. I thought I was going to die.
 7 I really did. But on the other hand I thought, no,
 8 I'm going to beat this, you know. It's like a Jekyll
 9 and Hyde on different shoulders and, you know --
 10 sorry, Jenni, what was the question?
 11 Q. No, you have answered the question. You have
 12 absolutely answered the question. The --
 13 A. The anger?
 14 Q. Yes.
 15 A. Yes, I did. I got very angry about it and it did lead
 16 to me asking questions, yes, and fall-outs with my
 17 doctors and then, yes, somebody must be responsible.
 18 I must get more answers.
 19 I wrote to Margaret Thatcher. I mean, I wasn't
 20 really that interested in politics as a younger man.
 21 I was interested in music and normal things that
 22 teenagers and young men are interested in and
 23 I certainly got interested in politics after that.
 24 I wrote to Margaret Thatcher quite naively
 25 thinking she might be helpful. She didn't reply

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1 negligence on the part of anybody in the National
 2 Health Service let alone the Government as you claim.
 3 This tragic occurrence was the direct result of the
 4 emergence of HIV infection in the western world and
 5 haemophiliacs needed the best treatment that could be
 6 provided in the then state of medical science and
 7 knowledge and that was what they received. If any of
 8 those affected are able to produce evidence to the
 9 contrary, obviously the courts will provide much
 10 larger sums by way of compensation. The Government
 11 made available the money that we have quite regardless
 12 of any question of legal liability. We did so as some
 13 expression of our sympathy for those who have been so
 14 terribly afflicted by these events."
 15 That was the letter you received in 1990?
 16 A. Yes.
 17 Q. You have, in fact, or someone has written on your
 18 behalf more recently to Kenneth Clarke MP and we've
 19 got the response to a more recent letter, if we can
 20 have the next document, please. We can see it is
 21 dated 19 May 2017 and it says this:
 22 "Thank you for your recent email on the subject
 23 of haemophilia and the contaminated blood products.
 24 I do, of course, recall very clearly the tragedy of
 25 the infection of haemophiliacs that occurred in the

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early 1980s. The lives of many people were destroyed or seriously damaged and every sensible person sympathises with them and their appalling position. I was one of five ministers at the DHSS at the time but I was not the minister responsible for blood products and I did not take any direct part in any of the decisions."

He refers to a Mail on Sunday article and says this:

"I think they are taking an answer that I gave to a written Parliamentary question in the House of Commons. I did answer such questions because the minister responsible for blood products was a member of the House of Lords and a Commons minister had to answer on his behalf in the chamber of the House of Commons. The answer that was quoted was based on the best medical and scientific evidence available to ministers at the time. I am sorry that people have come to believe that there was some sort of conspiracy and a criminal cover-up on this subject. Although not directly involved and with no expertise myself, I think that the haemophiliacs were the victims on the inadequacy of scientific and medical knowledge on the subject of AIDS in the first year or two when it first hit us as a scourge. No-one would have authorised the

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the time and no-one would have authorised contaminated Factor VIII, which as we know now there was lots of evidence at the time.

Q. Paul, can I take you back now to the early 1990s. We've talked about the mental, emotional and psychological effects of the diagnosis in those early years. You also over the years experienced a significant range of physical effects from the HIV infection.

You had coughs, colds, lethargy, night sweats, rashes and other infections. What was it like physically for you in those first years?

A. I think the first few years it was more of a mental thing. I think it was just that fear. Well, obviously a fear of dying, fear of dying and getting very poorly, seeing other people with AIDS-related symptoms. None of them are pleasant. They were horrible, horrible diseases and disorders and illnesses.

My overriding concern during all that time which used to keep me awake was the fear of infecting other people. That really I think that was the hardest for me to get my head round. I couldn't bear the thought of passing that on to somebody else and I was always extremely careful with everything. I'd always, just

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continued use of contaminated Factor VIII if scientific advice had been against it. There have already been two full inquiries into the subject which have taken and examined evidence, the most recent was a Scottish one. I think that the Government is taking the view that another public inquiry would not be able to draw on any evidence that has not previously been examined."

Then I think six weeks later the public inquiry was announced.

A. Yes. I had an inkling that the public inquiry was going to be happening. There was a lot of pressure building up, as we all know here it had been coming. I wanted to get in there with Ken before and my letter to Ken was to basically inform him what the Mail on Sunday had said about him and to ask about if he supports the public inquiry and that was his response.

So, yes, although Ken didn't feel a public inquiry was justified I'm glad you did Sir Brian. It's quite poignant that he wrote that just before the Inquiry.

I also think what's also quite poignant, we've got a 27-year gap between the 1990 letter and the 2017 letter and he's almost sticking to the same line, that it was the best scientific and medical knowledge at

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in case caught myself, I'd always have at a handkerchief in my pocket to wrap around a cut or I'd always have a pack of plasters on me in my pocket or my wallet or things like that. I was always very careful about my hygiene.

I couldn't tell anybody I was dangerous. I used to actually tell people when I had my hep C diagnosis it actually became easier. I don't want to downplay people who have only had hep C because that's been absolutely traumatic for them and has been a horrible, horrible disease in itself, but I actually felt more comfortable telling people I had hepatitis and so I had to be careful with my blood so they didn't find out I got HIV.

That's where my head was at with that.

Q. You learnt of the hepatitis C diagnosis in 1992. How did that come about?

A. Again, a routine clinic appointment and, yes -- I mean, I was reading things about this by then. I was aware from previous conversations with doctors that there was -- in that I'm talking about in the late '80s -- that there was an issue about me having non-A non-B hepatitis. So, you know, I can't say that I was completely oblivious to the fact they had come up with the next letter, C. If they were going to

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1 give a name for something that was non-A non-B it was
2 going to be C. I thought that was, you know, wasn't
3 rocket science.

4 Having had Hep B in the past in its acute form
5 and been ill for a few months with it and bouncing
6 back, I didn't really have that much importance put on
7 hepatitis. So when I was told I'd got hep C and I did
8 ask the doctor at the time what that meant, I was
9 told, "Don't worry about the hepatitis C. The HIV
10 will kill you a long time before the hepatitis C will
11 cause you any problems".

12 I was even told to have a drink if I wanted to
13 because wasn't sleeping well with the HIV diagnosis
14 and I often, yeah, would have a drink to get myself
15 off to sleep. I didn't drink heavily but, you know,
16 you need crutches and that was one of my crutches,
17 I suppose.

18 Q. Then you received at some later stage a letter in
19 relation to a possible risk of vCJD, possible exposure
20 to vCJD.

21 A. Yes.

22 Q. What can you recall about that and how that affected
23 you?

24 A. I just, at this point I almost give up at that point,
25 you know, I'd had Hep B, had HIV, had hepatitis C.

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1 So I was put on the CJD register in Edinburgh.
2 I've never been told I've been taken off that
3 register, so I'm presuming my name is still on there
4 as some kind of risk factor category.

5 Q. In terms of treatment, first of all, for HIV for the
6 reasons you have already explained having spoken to
7 and observed people on AZT you did not want to have
8 AZT.

9 A. No.

10 Q. You resisted treatment for a number of years.

11 A. And all the following drugs that came up. I mean,
12 when I said I was in the self-help group that was set
13 up that was great. It was proper peer support because
14 that was people with haemophilia with HIV. We had the
15 same issues going on.

16 Because a lot of them had passed away by the
17 early '90s and then I had my hep C diagnosis by then,
18 I'd also met and was familiar with a number of the gay
19 guys that used to go to the GU clinics. The
20 transition then was to go to one of the local HIV --
21 well, one of, it was the one, HIV drop in centre.

22 There was a social worker there. I went because
23 they had a complementary therapist. I used to have
24 a back massage once a month.

25 It was, yes, I met a lot of people there from

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1 I was very, very lucky to still be alive with them all
2 and I have a letter telling me I was -- possible got
3 a risk of CJD. It had all been on the news about the
4 mad cow disease and you were seeing how that was
5 affecting people.

6 I mean, I was angry at every point but it was
7 anger and despair thrown into one at that point, it
8 was. The letter was basically asking me, like it was
9 to an awful lot of other people with haemophilia here,
10 "Do you want to know if you have had a batch that has
11 been directly implicated with the death of a donor
12 that's been infected with" -- yes, has your blood
13 product come from somebody that has died of CJD? Of
14 course wanted to know.

15 One of the most important things that I took
16 from the 1980s, the Government's campaign of "don't
17 die of ignorance", I changed that a little bit in my
18 own psyche to "don't die in ignorance" and that's when
19 I sort of set on a mission to know everything. Of
20 course I wanted to know if I had had a batch of CJD
21 blood. I hadn't. It was a relief. My doctors said
22 that I hadn't had any implicated batches but the
23 letter also said it didn't preclude that other people
24 are going to also drop dead in the future of mad cow,
25 CJD, and it did turn out they were on blood donors.

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1 either the drug use past or people, gay people, that
2 had had HIV. They became my support. I think there
3 was only one other guy with haemophilia went there.
4 But, yes, I had a lot of support from them.

5 That was the opportunity on the coffee table,
6 that's where all the magazines were, all the
7 information about drugs and things. I had
8 opportunities to talk to other people about what drugs
9 they were on, what drugs were coming out. People were
10 very open.

11 That's when I used to see -- I saw the side
12 effects of the drugs, not those that were getting
13 better, and the earlier drugs in the early '90s were
14 very crude. A lot of them gave lipodystrophy,
15 lipoatrophy, which was like body fat changes.
16 People's appearances were changing. It wasn't just
17 what was going on inside, it was physical on the
18 outside as well. It wasn't just people getting
19 thinner and losing body fat. It was a lot more
20 insidious than that.

21 It was, you know, but it gave me the tools to
22 talk to doctors in an informed way. I became involved
23 in the '90s in a lot of other organisations both --
24 well, all really, I suppose got involved with
25 organisations likely Mainliners, who supported people

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with IV drug issues and probably a lot of the -- involved with things like National AIDS Manual, Community Advisory Board. They were organisations that were putting out information to the HIV community.

It was an empowering time for me because I felt I was taking -- I felt like a bit more of control. But I'd completely lost my trust in a lot of my doctors and I'd lost, obviously lost, complete faith in the pharmaceutical industry. So to go on drugs that they have said been trialled and they are great, well, we've seen in 1975 "the cure" with, you know -- there was no cure. I wasn't going to believe that something had dramatically changed in the way they marketed their products.

Q. In more recent years for HIV you have been in receipt of combination therapy although you have developed -- they have to be changed over the years not least because of interaction with hepatitis C?

A. Yes, yes. I did start on -- oh, I have been very lucky to have lasted until my health got very bad at a time when the drugs got very good and I'm talking about the late '90s, '97, '98 was when I had a CD4 count of about five. The recommended treatment limit was 250. I think the normal ordinary person is around

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how to do things -- I just had lots of regular monitoring. I had liver biopsies, ultrasound scans and later in the day fibroscans to monitor my liver.

I cut alcohol out as much as I could. I had a healthy diet. I tried to maintain my liver as strong as possible. I didn't want the interferon because I knew so many people that had tried it and it was horrible for them and it wasn't working as well.

All the data that was coming out regarding co-infection, having hep C and HIV, it was working even less well for people who were HIV positive. So it was -- to go through a year's long treatment that would make me very, very poorly for something that had less than a 20 per cent chance of eradicating it when I wasn't actually ill with it, and this comes back to the point, you know, I have been very fortunate, no, I didn't want it.

When the pegylated interferon came out that was a bit better and I actually thought, well, it sounds a better chance with this and I volunteered to go on a trial for that and I got very excited about starting the treatment because by then I'd realised having co-infection had a co-morbidity effect. People with HIV and hepatitis C were dying a lot faster because the two viruses together were, in the body, weren't

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between 800 and 1,000. I dropped down to 5. My viral load was just going through the roof, up to a million at the time. I couldn't stay awake for more than an hour or two. As soon as I shut my eyes, I just went straight to sleep. I used to sweat profuse within seconds. I had no energy. As I say, sores. All sorts of different complaints I had, and I was still at this point trying to keep a lid on it, keep a smile on my face and pretend to the world that nothing was wrong, yes.

I thought my trying to deceive the public and my friends about my illness was getting a bit thin at that point. It was the time I started telling friends.

Q. In terms of treatment for hepatitis C, that's been a less straightforward path in recent years for you. You didn't want to have interferon because you'd seen, as with AZT, you had seen the effects of interferon on people that you knew and were talking to.

A. Yes. I saw -- I had a very, very good relationship with my hepatologist. We spoke very, frankly. He knew the drugs weren't great but it was all he'd got to offer. We decided between us, which was a great way of dealing with it -- I always felt it was a partnership working rather than a doctor telling me

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a great mix.

Taking HIV medication at that point I was aware that all that HIV medication was being processed by my liver. My liver wasn't functioning as well because of the hep C. In my mind, my longevity with HIV was to make sure my liver was working as well as it could. So there was a lot of things in the mix at the time.

Q. So what happened with the trial?

A. I got to the week before I started to try it and I was told I was refused to go on it because I had HIV. So I was refused that, to go on that, because they said the HIV would have been a contraindication to the trial status studies, which brings me back to the trust in pharmaceuticals that whenever they have a trial of any type they choose the best cohort of patients for that trial. It's not -- and then when the trial data comes out, the trial data's -- the trial data is set with the best possible group of patients and then it's used on everybody. So even if they are getting 60 per cent success rates with the trial data, it's sort of obvious it's going to be 40 per cent or less with everybody that they excluded from the trial.

Again, I was seeing people who had started the pegylated interferon and ribavirin and they were still

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1 having side effects, it weren't really any less and
2 the bounce back, people had been cleared and then the
3 virus bouncing back. That psychologically affected
4 people and by this time, I know it probably seems
5 quite fragmented my story, but by this time, when
6 I started going on HIV meds, I thought it was really
7 important that I started touching base with the
8 haemophilia HIV community again. I got very involved
9 with the Birchgrove Group which was the self-help
10 support group set up to support people with
11 haemophilia. It was run by people like me.

12 It was very powerful part of my life at that
13 point because I did meet a lot of people that -- I did
14 do over the years that were very, very good friends,
15 people had a lot of respect for and, again, a lot of
16 those people aren't here anymore. But it was
17 a fantastic tool for me to educate myself and to be
18 able to educate others too.

19 Q. When in more recent years new types of treatment
20 became available for hepatitis C, you wanted to
21 receive that treatment but what happened?

22 A. Yes, I mean, I started hearing they were coming out,
23 I heard they were in trial. I remember going to see
24 my hepatologist and, yes, the first time I've seen him
25 really with a beaming smile on his face. "Right,

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1 friends out there who had also done their own bit of
2 investigating I found there was a guy on Facebook in
3 Australia that was selling it over the internet and
4 the clinic in India that was giving the hep C
5 treatment, it was the same agreement they had got
6 here, probably the generic drugs. I went back to my
7 hepatologist and the care team in the gastroenterology
8 department and all I wanted to know from them was if
9 NICE won't finance my drugs, if go to the clinic in
10 India and have it done, which I was prepared to do
11 that at my own expense because, again, with my fears
12 of infecting with HIV, my fears with infecting anybody
13 with hepatitis C were probably greater because
14 hepatitis C is so much more infectious than HIV.
15 I just wanted to get rid of that. I wanted to give
16 myself a clean break with it and I didn't want to be
17 infectious anymore.

18 All I wanted to know was would the nurses in the
19 hospital in my home town do the monitoring, do the
20 blood tests. I'll buy the drugs off over the internet
21 or I'll go and have three months in a clinic in India
22 but when I come back or when I get them off the
23 internet would they do the blood tests. They couldn't
24 do that because, they said, all the blood tests and
25 all the support were all costed into a course of the

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1 Paul, we've got these -- these new drugs are coming on
2 the market. We're going to be getting them soon.
3 Would you like to go on them?"

4 "Yeah, yeah, great, I'd love to", and then NICE
5 guidelines precluded me from going on them. Because
6 of the cost of the drugs they were only offering them
7 to people who had very bad de-compensated livers.
8 They were offering them to people that were on the
9 liver transplant list. They weren't offering the
10 drugs to people that were well or well-ish with
11 hepatitis C.

12 So I felt really, really angry at this point
13 because you've got the NHS there that gave me all the
14 three viruses, they gave me the hepatitis C, they
15 refused me going on trials. There was also a point
16 where the drugs were on the market, they were
17 licensed, my hepatologist is saying this is like
18 a completely new revolution in hepatitis C care and
19 treatment and the Government body NICE was saying
20 I wasn't eligible.

21 So, yes, my letter writing started again in --
22 yeah, stepped up a gear, let's say that. I spoke to
23 a lot of other guys with haemophilia, HIV, hepatitis C
24 about this as well and I wasn't making any headway
25 with the hospital. So, yes, with help from some other

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1 treatment, so they couldn't do one without the other.

2 So I basically said I would go down this line
3 but -- whether I got heavy handed or not I don't know
4 but I said I'd go to the media. I said if I'm going
5 to do this, if you are going to force me into taking
6 this other route I'm not going to do it quietly.
7 Within a week I had been offered the treatment.

8 The hep C nurse there and might hepatologists
9 were really pleased had taken that route because it
10 shook things up a bit. Within a year I think NICE had
11 changed their guidelines again and a lot more people
12 were being offered the drugs at that time.

13 Q. What was the result of the treatment, the outcome of
14 it?

15 A. I'm cleared my hep C. It was the first line of the
16 oral tablets. They work very well. They were very
17 potent, but I still got ribavirin in the mix. It
18 wasn't a pleasant three months and it wasn't
19 a pleasant time after that. It did play havoc with
20 me, I think. I didn't sleep well. I probably got at
21 best two or three hours sleep a night. I became very
22 agitated, very angry. I sort of tried to keep myself
23 out of the way of other people a lot.

24 Yes, after the treatment I was that intolerable
25 of other people I went and lived in a caravan in

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1 a field with only a cold water type and no electricity
 2 for six weeks and I felt great about it. It shows
 3 that, yes, I didn't really want -- I didn't like
 4 people. I was intolerant of people. It wasn't really
 5 like me but it cleared the hep C and that felt great.
 6 I had to wait another three months for the all clear,
 7 after the three month all clear and, yeah, it felt
 8 great.
 9 I'm still left with anxiety from it and a few
 10 other, yes, residual issues but not many, but it's
 11 great to get rid of the hep C. It really was. It was
 12 a massive weight off my shoulders for the basic reason
 13 I wasn't infectious any more. It was one less thing
 14 to worry about and it gave my liver a better chance of
 15 processing HIV meds which I will have to take for the
 16 rest of my life.
 17 **Q.** May I ask you about the impact of everything you have
 18 described, the infections, the psychological strain,
 19 the treatments on your private and family life and
 20 your ability to lead a normal family life. Your
 21 phrase in your statement is that you couldn't lead
 22 a normal family life.
 23 **A.** No. No, I couldn't. I think anyone put in the
 24 situation, we've all be tested on that one. Because
 25 I was so young when I was diagnosed with HIV, yes, my

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1 after my diagnosis. I did meet a woman that became my
 2 partner, later became my wife and I felt at the time
 3 very, very lucky. I didn't expect -- I just wrote off
 4 the idea of having a relationship but we practised
 5 safe sex constantly throughout our relationship. We
 6 would never have children. It wasn't really an
 7 option. It wasn't on offer.
 8 There was a lot of issues around my illness that
 9 affected our relationship. My partner, she constantly
 10 lived with that, that I might die some time. She
 11 joined a self-help group for the partners of those
 12 same guys that I was sat with, she was sat with their
 13 partners, wives, girlfriends, and as the guys I was
 14 sat with died one by one the partners became bereaved
 15 partners, so the elements of that group changed from
 16 being supportive partners to their haemophilia
 17 partners, they were bereaved. Their issues were about
 18 bereavement and my partner was the last one in that
 19 group that actually had a living partner. So you know
 20 she was basically ostracised from that group because
 21 she no longer had anything in common with them.
 22 There was a lot of very, very dark times in our
 23 relationship but were all based around my illness.
 24 When I was very ill before I started my HIV meds that
 25 was very hard time for both of us. We both had to

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1 plans were -- yes, the expression I put in my
 2 statement, I had the world at my feet. I expected I'd
 3 get married one day. I wanted to have children.
 4 I thought being a dad was like a natural progression.
 5 It was something I wanted to do.
 6 All that went out the window. I mean, I don't
 7 know, finding a partner, having children, all those
 8 sort of things, they just fall out the window when you
 9 are told you haven't got long to live.
 10 The effect on my parents was huge because they
 11 couldn't tell their friends. They couldn't tell
 12 anybody. They had to keep it secret. They had
 13 a massive range of emotions but, you know, guilt as
 14 well because in a way, because they fought for me to
 15 have the best treatment available. They read all the
 16 information, all saying, you know, about playing the
 17 risks down. They thought they were doing the best for
 18 me and then I end up with these viruses so, you know,
 19 the impact on them was huge.
 20 It's unnatural to lose your children before you
 21 and there's a lot of people have given evidence in
 22 this inquiry so far that that has been the case and it
 23 has been horrific stories to hear. Nobody wants that.
 24 I never thought I'd have a relationship again.
 25 My relationship at the time didn't last very long

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1 make a lot of decisions. It wasn't a natural
 2 relationship, a normal relationship with the normal
 3 issues and I always thought I hadn't got long to live.
 4 So she always knew that I hadn't got long to live so
 5 the emphasis you put on the normal things, arguments
 6 or whatever, we changed, you change the way you deal
 7 with things. It wasn't natural, a normal
 8 relationship.
 9 **Q.** And that relationship lasted a number of years but
 10 then came to an end.
 11 **A.** Yes, it did.
 12 **Q.** In terms of the effect of the infections, diagnosis,
 13 the treatment, on your education and your employment,
 14 your ability to work, how has that been over the
 15 years?
 16 **A.** Well, very sketchy. When I was a child the
 17 haemophilia was always going to be an issue. Again,
 18 because I said I didn't have factor for many years
 19 I just used to have ice packs and bed rest I was off
 20 school an awful lot, so the haemophilia played around
 21 with my schooling an awful lot. The social services
 22 were banging at the door when I had had time off work,
 23 truant officer, just to make sure my parents weren't
 24 lying about my absences. They tried to get me to go
 25 to Lord Mayor Treloars at one point, the special

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1 school for boys with haemophilia, as we know. We know
2 how special that was now.

3 My Mum and Dad, I'm very glad to say brought me
4 up as normal as possible. They didn't want me going
5 to a boarding school. They wanted me have a normal
6 relationship with my brother and sister, to play with
7 the kids on the street, to go to the school down the
8 road and they fought very hard for that, even though
9 there was a lot of pressure.

10 I'm going of the viruses now. This is just
11 a haemophilia story but, you know, I went to a special
12 school for fairly disabled children. I very rarely
13 had any time off school there. I was very well looked
14 after. I was picked up in a minibus. I actually
15 remember quite enjoying it there in many ways.

16 I went from my primary school at the time,
17 I wasn't allowed to do sports, I wasn't allowed to
18 play in the playground, I wasn't allowing to go on any
19 trips. Like a lot of people with haemophilia,
20 schooling was quite limited. Then when I went to
21 special school I ended up being the fittest kid in the
22 whole school so I had a complete role reversal.
23 I went, you know, if -- if you were playing football
24 and you were picking teams I was always the last one
25 on the wall to be picked. I went to this school I was

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1 So I came up with a plan, if I packed in my job I had
2 to do something else. I went back to polytechnic as
3 it was at the time -- well, went back to, it was my
4 first time I'd been to -- I did a four-year teaching
5 course. I chose that course because it was four
6 years. I didn't think I would see the end of it and
7 I thought it would give me an opportunity to have an
8 excuse to be doing something constructive but also to
9 give me two or three months off every summer to go and
10 see a bit of the world.

11 I was still alive after the course so I had
12 a sort of natural progression to go into teaching.
13 The career didn't last long. The first time I had
14 a bleed, I had a bleed in my knee that wouldn't settle
15 down. It was a bit unusual. It wasn't being
16 controlled by the Factor VIII. I ended up in
17 hospital.

18 The head came to see me in hospital, uninvited,
19 stood by my bed and asked me when I would be back at
20 work. I told her couldn't tell her, haemophilia
21 didn't work that way, could she explain this to the
22 staff and she was not mentioning haemophilia in her
23 school. She didn't want -- because if people knew
24 I had haemophilia, they'd automatically assume I'd got
25 AIDS because everybody knew that people with

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1 the captain. It was, you know, things had changed.

2 But the headmaster got quite concerned because
3 I wasn't learning anything. It was obvious, he said,
4 I'd got a certain degree of intelligence. The school
5 might have been good for my health but it wasn't good
6 for my intelligence. I was getting up to 11 then and
7 there was a lot of pressure and, again, you know, my
8 Mum and Dad put a lot of work into that. They got me
9 into the local secondary school, comprehensive, and,
10 yeah, they took me on, even though I still had a lot
11 of time off. I still wasn't allowed to go on field
12 trips, play sports.

13 Bizarrely, they wouldn't let me do woodwork or
14 metalwork but they let me do catering. For some
15 reason sharp knives weren't a problem as much the
16 other tools were. There were some strange decisions
17 taken about me that didn't -- I wasn't included in the
18 decisions but I just went along with things.

19 But with the viruses the HIV, I worked in
20 a bank, I stuck that for I think a year and a half/two
21 years after my diagnosis. It was all part of my
22 pretending everything was okay, trying to put a face
23 on things. Let's be normal. I thought if packed in
24 my job everyone's going to wonder why I packed in my
25 job and everyone's going to put two and two together.

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1 haemophilia had AIDS. She didn't want her school
2 reputation being tarnished. So she just, more or
3 less, told me to get better as quick as I could.
4 Well, I did come out of hospital and I handed my
5 notice in.

6 Q. You put it this way in your statement, Paul:

7 "This was in 1994 and those words were from
8 a school headteacher employed by the county council
9 who operated under anti-discrimination procedures.
10 I went home and handed in my notice."

11 A. Yes, I did. I think people thought I was a bit mad
12 for doing it, but the fact I had had so much time off
13 with my knee, again it's all about these lies and
14 secrets that you have all the time. You know, "Why
15 did you pack in your teaching job? That was really
16 good."

17 "Oh, because my knee's really playing me up and
18 I really couldn't -- it was too physical for me. It
19 was a bad choice", you know. So, yeah, I always had
20 an answer for things. It wasn't the truth. It was
21 just an answer. It was just -- yeah, I mostly quite
22 liked that job as well but, yeah. So I had a period
23 in and out of work and I did a few different things.
24 But, yes, the HIV had a massive impact on my career
25 opportunities.

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1 Anybody with haemophilia knows they've got some
2 limitations on their career paths. You know, when
3 I worked in the bank initially that was great for me.
4 I got a job for life. It was secure. It was sat
5 down. It was doable for my haemophilia. I just had
6 the HIV. I knew I didn't want to go and work in
7 a bank until I died. I didn't want to be putting
8 a suit on every morning and working for some
9 institution to keep them happy, you know. It changed
10 everything.

11 Being told you've not got long to live changes
12 the way you think about life.

13 Q. You have also described in your statement working for
14 a number of years at the Citizens' Advice Bureau.

15 A. Yes.

16 Q. You said this:

17 "I told most of my colleagues there about [your
18 diagnosis of HIV]. It was a supportive atmosphere in
19 many ways but it was never straightforward. The boss
20 was a gay man. He was very supportive of my health
21 issues in the political dimension. The deputy manager
22 told me attitudes have changed and if she was honest
23 she wouldn't have felt comfortable with me and HIV in
24 her office ten years ago. I had to tell her I had had
25 the virus for 20 years at that time", and then you

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1 for their set of criteria and their criteria would
2 change from year to year, what they thought was, you
3 know ... in the early '90s they were giving lots of
4 money away for, well, not giving it away, but you had
5 to apply for it for things like white goods.

6 Lots of people had like night sweats so things
7 like bedding, mattresses, washing machines they were
8 fairly common but if you wanted something that wasn't
9 in their guidelines, yeah, it was difficult. But even
10 if you wanted something in their guidelines, just
11 because they knew you were on their books as such, you
12 were registered under the Trust, they knew these were
13 the symptoms of HIV, you still had to get a letter
14 from your doctor or your specialist clinical nurse.
15 You then had to go and get quotes for bedding, quotes
16 for a mattress, quotes -- and it wasn't just one
17 quote. You had to get three quotes.

18 I mean, they are talking about somebody who is
19 ill having to run around getting loads of quotes,
20 going to the doctors. I'm sure the nurses and the
21 doctors had better things to do, you know, like treat
22 patients rather than be writing letters of support
23 saying, yes, this person does have these illnesses
24 and, yes, they are experiencing these symptoms.

25 Then when you submitted all the paperwork you

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1 have added:

2 "Her husband was a vicar."

3 So still in the 2000s you were experiencing
4 attitudes of discrimination and stigma?

5 A. There's still stigma around today. It's just not as
6 severe as it used to be. The only reason I put that
7 in as an analogy was to sort of say the passage of
8 time, people think, oh, it's okay today but I
9 wouldn't -- it was good to hear them being honest.
10 I can't think of a better organisation to work for
11 because the whole point of working for an advice
12 bureau is you are giving people advice, and people
13 that want advice mainly are very needy people.
14 Everybody who working there was very open minded and
15 very supportive. Yes, it was a good place.

16 Q. Can I ask about your experiences of the
17 Macfarlane Trust.

18 A. Okay.

19 Q. You've described a little in your statement it helped
20 a bit but it felt like a begging bowl. What do you
21 recall of the application processes?

22 A. They were ridiculous, the application processes. They
23 seem to change year on year anyway, depending you
24 would have -- let's say because of their budgets or
25 their funding but if you wanted anything it had to be

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1 then had to wait for their next board meeting for them
2 to sit round a table and decide whether they were
3 giving it me or not.

4 Most of the time you never got 100 per cent.
5 They would give you a percentage. It was hard work.
6 It was almost likely they made it as hard as possible.
7 I felt, yeah, it was a begging bowl.

8 Bank of Mum and Dad were a lot easier and I was
9 fortunate to have that from time to time when things
10 weren't good. But, no, it wasn't -- it felt like you
11 were begging, and because of that I actually felt
12 there was probably more needier people out there that
13 needed the money. That was the way they made it.
14 There always seemed to be -- they always seemed to
15 reiterate about their reserves and how little they
16 had.

17 Every December they would send you an income and
18 expenditure form you had to complete. You had to send
19 off evidence of what you paid on your council tax,
20 what you paid on your water bills. It just seemed
21 ridiculous to have to do that every year to show how
22 much money you had left at the end of each month so
23 they could assess how much money they would give you.

24 So, yeah, this was the only charitable money
25 that the Government said they were setting up as ex

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1 *gratia* support mechanisms. Yes, they were a support
2 mechanism and at times the money from the
3 Macfarlane Trust was very, very helpful, but it wasn't
4 an easy process.

5 Q. You have told us about the extent to which some form
6 of counselling, support from psychologist, was
7 something you were able to access a number of years
8 after your diagnosis.

9 What about your parents whose feelings of
10 responsibility and guilt and suffering you have
11 described very eloquently. Were they ever offered any
12 form of emotional support or counselling?

13 A. No. Nobody was. None of my family. It was like
14 going back to my Hep B days in '77. The whole family
15 went to see the doctor. The whole family were
16 counselled about it. There was nothing, nothing about
17 the HIV, nothing about the hepatitis C. There was no
18 counselling offered.

19 I suppose if I had made a case for it, it would
20 be another application I would have had to make for
21 the Trust to see if the Trust could, and they probably
22 would have only -- if you did have any counselling it
23 was only normally -- they would give you six sessions.
24 If you want any more you have to make a case to say
25 whether you want any more or not so, no, they were

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1 were wrong.

2 I always saw a common denominator with, well,
3 the press, the tabloids, started off so many stories,
4 gays, drug addicts, haemophiliacs. Any AIDS story
5 they had those three groups in. I didn't see myself
6 as any different from those other two groups. People
7 don't have a choice whether they are gay or not.
8 People don't have a choice whether they have
9 haemophilia or not. Drug users don't choose to be
10 a drug user, to have an addiction to drugs. It's
11 normally because of some trauma in their lives,
12 because of traumatic experiences that aren't picked up
13 by the health, by their GPs, by their doctors. They
14 were self-medicating.

15 The gay society, because they were seen as the
16 underdogs, it was like a separation from what is
17 normal society and abnormal society.

18 Having haemophilia, having a disability, you
19 were put into that bracket too. I felt a kinship with
20 the gay guys met and the drug users that I met.
21 That's where I got my support from in the drop-ins and
22 it worked two ways as well because a lot of the drug
23 users and a lot of the gay guys that got to know, they
24 hadn't had the experience that had, a childhood of
25 being able to converse with doctors, going to

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1 offered nothing, no help, no psychological help, no
2 support. No.

3 Q. You've touched in your evidence already on issues of
4 stigma, in particular how they affected you and the
5 life of secrecy that you felt driven to live. You
6 have I think some wider observations you wanted to
7 make about the stigmatisation of the community, of all
8 people who had HIV.

9 A. Yes, I do because it's been mentioned so many times
10 over the years and it's been mentioned an awful lot
11 during this Inquiry about -- it's very difficult to
12 think, unless people in this room were there in the
13 day and had the viruses, that the stigma was really
14 acute. It was vile. It was horrible, and it was from
15 all -- from everywhere. There was no escape from it
16 it seemed. There was nobody you could trust, your
17 best friends, there was nobody you could trust not to
18 actually tell anybody else or not to have an attitude.
19 It was like self-preservation to keep it quiet.

20 But to me the stigma was generated by the way we
21 are in society, which is moulded by the media. I know
22 the media are controlled to some degree by the
23 Government and by policies of the day, the newspapers,
24 the television programmes, they mould people's
25 attitudes and it was people's attitudes that I feel

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1 hospital, going to clinics, understanding what your
2 blood results meant. They were part and parcel of
3 having haemophilia. To a lot of the others it was the
4 first times they have actually come in front of any
5 clinicians.

6 So, yeah, I'd be helping them in like questions
7 to ask your doctors. In fact, I did a workshop with
8 a friend of mine who's been involved with this Inquiry
9 for one of the Mainliners' conferences and the
10 workshop we did was getting the most out of your
11 doctor, understanding your test results, how to speak
12 to your doctor, don't be fobbed off, be confident to
13 question them, go on with a list of questions, don't
14 leave that room until you have had all your questions
15 answered, if they are using words you don't understand
16 ask them to explain them.

17 It was that kind of thing. On that two-way
18 street, those gay guys and drug users with hep C, with
19 HIV or with both, they were giving me experiences
20 about their management of their conditions and what
21 drugs they were taking to help their conditions and
22 their experience of interferon or whatever was going.

23 I felt those two groups of people were very
24 supportive to me, their support organisations were
25 part of the help that I had. It's the media that's at

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1 fault for stigmatisation that all three of us had.
2 Maybe so many gay guys wouldn't have had HIV if
3 the education was put there and the support network
4 was put there, if they felt comfortable to go to
5 health clinics or doctors, but they weren't. They
6 were stigmatised.

7 With drug users, rather than blame the drug
8 users, maybe they should have been blaming the health
9 authorities for not recognising this earlier and
10 giving them clean needles, clean syringes, you know,
11 support networks, advice about taking drugs. It would
12 have been a lot more easier than blaming gay guys or
13 blaming drug users for the spread of this infection,
14 blaming haemophiliacs for the spread of infection
15 because people with haemophilia did spread this
16 unknowingly, and we've seen this time and time again
17 during the Inquiry where the doctors have known in
18 some cases for years before they have even told the
19 patients of the diagnosis.

20 People have infected their partners, their
21 wives. It was all unnecessary. It was unnecessary in
22 the haemophilia population, as it was in the
23 intravenous drug-taking population, and the gay
24 population.

25 One thing that cemented all of this, as an

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1 responsible.

2 Margaret Thatcher a few years later knighted
3 James Anderton. He became Sir James Anderton. So
4 then politics comes into this again. The guy that
5 said these things actually gets rewarded by the Prime
6 Minister.

7 For somebody living with HIV at the time, this
8 is someone who was just increasing this stigma and
9 it's not someone that's a man in the street, it's not
10 somebody that's ill-educated. So, yeah, those
11 establishments that are there, that we are supposed --
12 that we are brought up to look up to had -- I had lost
13 my faith in so many institutions, at the same time
14 increasing my anger towards these institutions at the
15 same time.

16 **Q.** Paul, those are the questions I have for you. Before
17 ask you if there's anything you want to add, I am
18 going to turn and ask Ms Monaghan if there's anything
19 further she would like me to ask you.

20 **A.** Thank you.

21 **MS RICHARDS:** Paul, there aren't specific questions but
22 Ms Monaghan has reminded me perhaps to remind you that
23 you, I think, in your closing observations may want to
24 say something about pharmaceutical companies. But
25 there are no further specific questions from me. If

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1 example which we talked about, in the -- I think it
2 was about '87/88 or probably might have been even
3 earlier, I don't know, when you are brought up in life
4 you see institutions that are there for you, the
5 Government, the police force, the church, whatever,
6 they are the establishments of our society.

7 James Anderton was a guy that was a public
8 figure, who was the Chief Police Inspector of Greater
9 Manchester Police. He stating in the press and in
10 a BBC religious programme -- he used the quote,
11 "people with AIDS are swirling in a cesspool of their
12 own making". That was a horrible thing to say.
13 I don't know whether he was referring to people with
14 haemophilia then but to me it didn't matter who he was
15 referring to. He was referring to people with AIDS
16 who were swirling in their own cesspool of their own
17 making.

18 We've got a senior policeman, who is also
19 a Christian, it was on a religious radio programme
20 I think or a religious TV programme this came out on.
21 To me I've got the police and the church both in
22 hands, both saying that this is a product of our own
23 making, we created this. It is like negating the
24 responsibility from the Government, from the
25 Department of Health, from the people that were

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1 there's anything further you would like to add, this
2 is your opportunity to do so.

3 **A.** Yes, I just hope this Inquiry -- I do realise most of
4 the pharmaceutical companies involved in the
5 infections are American. I can't -- because of
6 a legal case that happened in the States, I -- it's
7 very difficult, I think (my own observations), to
8 bring those to book or to account or to actually have
9 representatives of those pharmaceuticals sat in this
10 chair next year.

11 But what I would like to look at is the
12 relationship the Government, the Department of Health,
13 and the doctors had with those pharmaceutical
14 companies because if this Inquiry is going to change
15 anything in the future, we've got to be looking at the
16 relationship with the pharmaceuticals. Even going
17 back to that press clipping where we started off
18 today's talk of 1975, the Department of Health (or the
19 DSS, as it was called) had set up contracts with two
20 companies and it mentioned them as Travenol and
21 Speywood products. It then goes on to say that the
22 Department of Health was now setting up contracts with
23 two other companies. It didn't say who.

24 The questions I'd like to know was when they
25 have -- when the Department of Health or the

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Government have contracts with pharmaceuticals, what measures are taken regarding safety of products? Has actually -- because we've never had an inquiry into what happened to us, how do we know that things have actually changed? Is it profit-driven? Is it just about budget? Is it about safety? Trial data: do our governments or Department of Health scrutinise the trial data of the drug companies, the pharmaceuticals say are the reasons for their use?

I just would like some more robust -- to give confidence not just to the haemophilia population, not just to the other people that have been at this Inquiry that have been infected with hep C through blood transfusions, but to everybody, every citizen, not just of this country, probably the world. When pharmaceuticals are such multi-billion businesses now, the law firms of pharmaceuticals, the law arms, are huge themselves. There's a reason for that it's because they're constantly defending actions against which they've have gone wrong. We've seen it with all sorts of different -- thalidomide, for reasons -- all sorts of illnesses and diseases, they're all in the -- going on. There doesn't seem to be an end to it.

I just would like to see pharmaceuticals not get away with what they've got away with in the past and

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A. Okay, thank you.

SIR BRIAN LANGSTAFF: We'll take a break now and it will be a lunch break, slightly earlier lunch break than usual, and we will come back at 1.05.

(12.10 pm)

(Luncheon Adjournment)

(1.13 pm)

MS RICHARDS: We can now hear you I think in there. Can you hear me?

A. I can hear you.

MS RICHARDS: We're going to start, Mr AH, with Sir Brian making a restriction order.

SIR BRIAN LANGSTAFF: I don't know if you can see me or not but you will hear me speaking. Can you hear me?

A. I can hear you speaking, yes.

SIR BRIAN LANGSTAFF: As you can understand, I was going to say see but you can't, as you can understand this witness is not in the room. He is witness W1006. In his case, I make the following order. The name and address of witness W1006 (that's Mr AH to you and me, that's how he will be known), the name of any member of the witness's family and any other identifying information such as the witness's image or a description of their appearance or, in this case, the sound of his voice cannot be disclosed or

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I know a lot of people with long-term medical conditions wouldn't be living without those medicines, and I still wouldn't be alive today if it wasn't for the pharmaceutical companies that make such very good HIV drugs. I managed to clear my hep C. I'm not saying that they're the enemy but it's the way they do their business which is wrong -- very, very wrong.

Q. Is there anything else would like to say, Paul?

A. I'll probably think of something in half an hour or an hour, but I think I've held people's attention for enough and, yes, I think we'll -- I think I've said enough.

Q. Thank you. Sir.

A. I would like to thank you Sir Brian for bringing this Inquiry. Yes, I'd like to say that anger you talked about, that anger that brewed inside me, that went out the window the day this Inquiry was announced because I felt very seriously for once that something was being done about it. I've got full faith in this inquiry. So thank you very much.

SIR BRIAN LANGSTAFF: For my part, I think I might very much have enjoyed being a pupil in one of your classes when you were briefly a teacher. You put matters over so engaging and persuasively. Thank you very much for that.

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published in any form unless express permission given by me or by the solicitor to the Inquiry acting on my behalf.

Witness W1006 must be referred to only as Mr AH.

This order remains in force for the duration of the Inquiry and at all times thereafter unless otherwise ordered and may vary or revoke the order by making a further order during the course of the Inquiry.

MS RICHARDS: Mr AH, I think you are now going to be asked to swear the oath or affirmation.

MR AH, affirmed

(Evidence given via audio link)

Questioned by MS RICHARDS

Q. Mr AH, you have severe haemophilia A which was diagnosed when you were a baby.

A. That's correct.

Q. From the age of one in the late 1970s you were treated with Factor VIII for your bleeds.

A. That's correct, yes.

Q. During this time you were under the care of Lewisham Hospital and you would receive Factor VIII fairly frequently, perhaps, as often as every couple of weeks?

A. That's true, yes.

Q. In terms of the product that you received, we've got

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(23) Pages 89 - 92

1 a printout from the UKHCDO database and that shows
2 that in the period from 1978 through to the mid-1980s
3 you received occasionally the NHS BPL Factor VIII but
4 rather more frequently you received a variety of
5 different commercial products, pretty much all the
6 products that were available at the time you as a baby
7 and young child received?

8 A. Mm-hm.

9 Q. As far as you know, were your parents told anything,
10 given any warnings or information about any risks of
11 infection associated with the products?

12 A. No, none at all. They were never informed of any
13 risk.

14 Q. It was in 1984 or thereabouts when you were seven or
15 so years old that your parents were given some
16 information about your diagnosis. What were they
17 told?

18 A. So it would have been my mother, my mother always
19 attended appointments with me or for me and she was
20 told that I had tested positive for the HIV virus and
21 that they should enjoy me and my life as much as they
22 could and prepare for me to die within five years.

23 Q. Were they given any other information at the time
24 about the virus or any practical steps that should or
25 could be taken to manage it?

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1 I developed a severe cold and chest infection. We
2 were on our summer holidays and I just felt this was
3 strange to be this ill in the summer. Usually it's in
4 the winter we get coughs and colds, don't we. It all
5 seemed very odd to me and it was worse than any other
6 cough or cold I had ever had. I was very disoriented,
7 high temperatures and feeling terrible, so I was then
8 admitted to hospital, given antibiotics and, yes, at
9 this stage I still didn't know why I was there or what
10 was wrong with me.

11 Sorry, did you ask how became aware?

12 Q. Yes, how you learnt this news?

13 A. So I think it was probably on my second admission to
14 the hospital, because from this point onwards I was
15 frequently admitted and I was one of the older -- so
16 I was around 11 or 12 years of age and I was in
17 a child ward. There was a play specialist that was
18 there for the children and a teacher and, kind of,
19 developed a relationship with this play specialist and
20 she took a shine to me. She seemed to be very
21 sympathetic towards me more than the other children
22 there.

23 She took me out one day, she had an errand to
24 run, it was internal mail for the hospital and she
25 said, "Would you like to come along with me". I would

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1 A. I do believe they were told that it was a difficult
2 virus to catch and to treat me the same as any other
3 boy.

4 Q. You weren't told that at the time, given your young
5 age.

6 A. No.

7 Q. But you have described in your statement how even
8 before you were told, the atmosphere at home and
9 family relationships changed. What can you recall
10 about that?

11 A. Yes, it changed very much so. I remember the
12 household being happy. Mum and Dad laughing and
13 joking and listening to music a lot, dancing and then
14 after my diagnosis the household became quiet.
15 Communication was strained. My Dad became introverted
16 and there was -- I mean, there was a lot of stress.

17 As a young child and my sister being young at
18 the same time we could feel it, we could feel just the
19 stress and it's almost like we knew there was
20 something wrong, even at that early age.

21 Q. It was about five years before you learnt, when you
22 were 12 years old, that you were HIV positive. How
23 did you learn that information?

24 A. So I had been admitted to hospital with an HIV related
25 illness. At that time I don't know I was positive.

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1 take any opportunity to get off the ward so I said,
2 "Yes, of course", and we wondered around the hospital,
3 delivery ring and then I could tell from her she was
4 uneasy about something and at this time I realise she
5 was plucking up the courage to tell me I was HIV
6 positive.

7 She took me outside, we had a chat, and she said
8 to me, "you are" -- she told me I was HIV positive and
9 that -- I mean, I didn't really know what that meant
10 at the time but she said you've got to be very careful
11 when you are around girls, if you cut yourself.
12 That's basically what -- that was the reason why
13 I kept becoming ill.

14 I found this shocking because surely if anyone
15 should tell me it should be my parents or a doctor and
16 from that time onward I became very introverted. She
17 took me back to the ward and just sat on my bed and
18 I didn't know what to think. I was shocked and
19 disturbed. I was 12 years old. I couldn't process
20 that information correctly.

21 Q. You have said in your statement you saw her one more
22 time before she left. She was asked to leave the
23 hospital at a later stage when the nurses found out
24 about this.

25 A. That's right.

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- 1 Q. You asked her why she decided to tell you you were HIV
2 positive and what was her response?
- 3 A. So obviously the nurses and the doctors found out very
4 quickly what she had done and what she had said. She
5 was asked to leave. I saw her one more time and
6 I asked her, "Why did you tell me this? Why did you
7 say this to me", and she replied with -- said,
8 "I thought it was very unfair that you didn't know",
9 and I very soon found out that when I was put into the
10 ward my parents said, "We don't want him to know
11 (*unclear: interference*) young. We'd like to do that
12 ourselves, we'd like to tell him ourselves", so in
13 effect she just -- this play specialist felt that was
14 unfair. That wasn't her judgment to make. I had
15 built up a very good friendship with her so I didn't
16 blame her at the time for this, but thinking about it
17 later on, you know, she had no place to do what she
18 did.
- 19 Q. You have described in your statement that this was the
20 time when you began having psychological difficulties.
21 You had been given --
- 22 A. Exactly, yes.
- 23 Q. -- this information in this way. You felt confused
24 and lonely and it was the beginning of a very
25 confusing time?

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- 1 them as much as I could.
- 2 Q. You also learnt at a relatively young age that you had
3 been infected with hepatitis C. How did you find out
4 about that?
- 5 A. Yes, so that was around -- no, between '89 and '90
6 I was back on the ward and in hospital with an
7 HIV-related illness and I was in a bigger bay this
8 time. I wasn't in a room on my own I was in a bay
9 with other beds but there were no other children in
10 these beds.
- 11 A nurse came in to see me and she just
12 flippantly said, "You have been tested positively for
13 the hep C virus". I didn't know what that was so she
14 briefly explained it to me. She said, "This won't
15 become a problem for around (*unclear: interference*)
16 years so it's nothing much for you to worry about.
17 Kind of, for me it was indicating that, you know,
18 HIV/AIDS would kill first so it wouldn't matter and
19 then (*interference*) my parents hadn't been called in
20 to hear this is information with me. No-one was with.
21 She just gave me the information and walked away.
- 22 Q. It was I think some time after that that your parents
23 decided to take you to see a specialist at Saint
24 Mary's Hospital and in the period that followed you
25 said in your statement you found your new clinicians

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- 1 A. Yes. I definitely started to develop psychological
2 difficulties and I felt scared, lost and I couldn't --
3 as I said, I couldn't process the information. I was
4 very confused why would this happen to me? It was,
5 yes, an extremely difficult time, yes.
- 6 Q. What was the effect, after you had learnt your
7 diagnosis, what was the effect of that on life home
8 and your relationship with your parents once you knew
9 that this information had been not previously provided
10 to you and they knew that you knew?
- 11 A. Well, my parents explained why they didn't tell me
12 straight away. I felt angry because, you know, I was
13 12 years old thinking, you know, "I'm nearly
14 a teenage, why didn't you tell me these things". At
15 a later stage I completely understood why they didn't
16 tell me while I was that young.
- 17 I was angry. I became introverted. I'd stay in
18 my room. Communication between my parents and I just
19 became even more difficult and I felt that I had to
20 protect them. I felt knew they were upset by this.
21 I knew it was incredibly difficult for them, so I --
22 I literally took it all on myself, you know, that
23 I was causing people to be hurt and I wanted to
24 protect my parents. So I just -- I didn't talk about
25 it. I wouldn't talk about it and I stayed away from

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- 1 more helpful and forthcoming in terms of the
2 information that you were provided with?
- 3 A. Exactly. They took me out of Lewisham Hospital to
4 Saint Mary's in London where there was a specialist
5 HIV doctor. I was treated so much better there. They
6 had a lot more information about the virus and the
7 HIV-related illnesses. I felt -- well, I felt awful.
8 I had full-blown AIDS by this point and I felt
9 terrible.
- 10 I didn't really want to make the change of
11 hospitals because I was so happy with Lewisham. I had
12 been there all my life but (*unclear: interference*)
13 I felt this ... so much more educated on this virus
14 and what it did to me. It was at this point that
15 obviously I felt terrible, every night I went to sleep
16 to die. I wanted to die in my sleep -- it wasn't
17 until I woke up each morning as that feeling of just
18 hurting everyone around me and causing stress, it was
19 just too much to bear and I felt so terrible.
20 I really just wanted to die.
- 21 Q. Because it was in your early teens that your HIV
22 diagnosis was progressing into AIDS and you were
23 physically very unwell as well as having to deal with
24 the emotional psychological and mental impact of the
25 diagnoses.

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1 A. Exactly. It was a hell of a lot for a young boy or
2 young teenager to deal with. It was impossible.
3 I couldn't deal with it. I just did the best I could.
4 I've always said I did the business with the cards
5 that I'd been dealt with in life. I just wanted to
6 try my best and survive.

7 Q. You have described in your statement the profound
8 psychological impact of the diagnoses, the infections.
9 You became very depressed, introverted and later
10 suicidal, and you didn't have anyone you felt you
11 could talk to.

12 We've heard from other witnesses about the
13 stigma of HIV and AIDS in the 1980s and 1990s and how
14 it affected them. Can you tell us how that affected
15 you?

16 A. So I suppose it started with the media and the adverts
17 on TV, the scare mongering and as haemophilia and HIV
18 became more widely spoken of and linked there was an
19 occasion where my mother was called into school to see
20 the headmaster and he outrightly asked her, "Has
21 [redacted] got AIDS?" My mother felt forced to cover
22 up the truth. She just wanted me to be treated as
23 a normal boy and (unclear: interference) and not be
24 kicked out of school and ostracised that way.

25 So I don't think the headmaster ever believed

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1 of the stigma, in particular in relation to your own
2 family nowadays?

3 A. Mm-hm, yes. That's why I'm anonymous. I want to be
4 an anonymous witness now. I don't want my daughter to
5 suffer from stigma the way I did. My wife kind of
6 lives a double life where she doesn't speak about --
7 it's hard to speak about me and my illnesses when she
8 was at her place of work in case started people to
9 link things together again. I believe a lot has
10 changed in the way of stigma but just not enough, not
11 enough. Our main priority now to protect our daughter
12 from any kind of stigma, especially in school and in
13 fact my wife's mental health has been severely
14 affected by this and on top of all of the illnesses
15 I have had as well recently.

16 Q. In your teens you had been prescribed opiate pain
17 killers in hospital. Can you tell us about what
18 followed from that?

19 A. So there two things that follow from that. I was
20 given opiates from a young age. Being a haemophiliac
21 I was in a lot of pain but also with illnesses I was
22 also in a lot of pain, and so I began to self-medicate
23 with opiate painkillers, not really understanding what
24 I was doing but realising that when took these pills
25 they made me feel better, that I cared less about

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1 her because of the feelings I got from the teachers
2 and the supervisors, after that everyone just looked
3 out me with disgust. I just felt they were all
4 talking about me behind my back, so that was my
5 first stigma that ever affected me.

6 Also, at a later date my Mum told me when she
7 went to pick me up from school the parents wouldn't
8 talk to her. No-one would talk to her, you know. As
9 said haemophilia and HIV was linked with the news. It
10 was all over the papers and that's when the stigma
11 began for me.

12 Later on, I was in my local swimming pool and
13 one of the lifeguards -- I said I had haemophilia to
14 one of the life guards and she asked me if I was an
15 AIDS kid and I didn't understand what she was talking
16 about at all.

17 I went to my nurse at the time and I said,
18 "What's an AIDS kid", and it wasn't until many years
19 later when I was in my 20s that she said to me,
20 "I remember when you said that to me and I didn't know
21 what to say to you". Of course, she didn't answer the
22 question but it became -- I became aware that if you
23 talk about haemophilia then people begin to link AIDS
24 and HIV, hep C to that.

25 Q. Although times have changed, you still are conscious

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1 what -- my difficulties in life and I began to
2 increase the amount of painkillers I took every time
3 until I was taking handfuls of opiates and then when
4 I finally told someone, it was a nurse that was made
5 aware, you know, that I was -- it was risk-taking
6 behaviour. I was taking overdoses every time.
7 I would just take an overdose of opiates and then just
8 fall asleep on the sofa and feel better.

9 But there's a bigger implication of my opiate
10 use but the opiates I was given in hospital I was --
11 every time I was admitted I was given pethidine
12 basically and as haemophiliacs can't have
13 intramuscular injections I always had it IV, so
14 basically I became addicted to opiates every time
15 I went into hospital.

16 On one occasion there was a doctor that came to
17 me early in the morning, must have been about 3 am, I
18 complained of being in pain again, needing more pain
19 control, and he came to my room and he asked me if
20 I liked pethidine and I was young. I felt ashamed to
21 tell the truth but I said, "Yes. Yes, I do". He said
22 to me, "Do you like the feeling it gives you when it's
23 pushed into your vein", and, again, I said -- again,
24 I was very shy and kind of ashamed to answer these
25 questions but I said, tentatively said, "Yes. Yes,

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1 I do". He said, "Do you like the rush it gives you
2 through your body". Again, I said -- and at this
3 stage I really felt awkward but I said, "Yes, I do",
4 and he then proceeded to push it into my vein
5 extremely fast, when other nurses or health -- nurses
6 or doctors when they give it, they give it over a time
7 period so that -- they give it slowly and over a time
8 period so that you don't get that shot of euphoric
9 feelings. He just pushed it into my arm very, very
10 fast and I felt -- I won't lie, I felt very good but
11 just euphoria filled my body, but I realised this was
12 wrong.

13 The protocol after giving someone a shot of
14 pethidine is to sit with them just in case there are
15 any adverse effects. There is guy just left my room.
16 He just left me on my own.

17 Q. You transitioned, as you put it in your statement,
18 from using legal drugs to self-medicate to becoming
19 embroiled in illegal drugs which you would use because
20 of your addiction?

21 A. Yes, and just escape my every day life that I just
22 couldn't handle. I would have done anything. You
23 know, I even thought of suicide just to escape how
24 awful I felt. It was so difficult when I was younger.

25 Q. You put it in your statement this way: it was your way

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1 save me and that was probably one of the -- as
2 a youngster, as a young teenager the worst times for
3 me, the worst illness I had. I had a kidney biopsy so
4 they could find out what was wrong, which went wrong.
5 When they were giving the biopsy they put the needle
6 through a major artery and I bled profusely for days,
7 just complicating matters even more.

8 On top of the pneumonia and the kidney problems,
9 I had horrible constant stomach pains, headaches.
10 I was tested for brain cancer or are a tumour on my
11 brain, which came back negative.

12 These were the illnesses I had in my younger
13 years. The other, what would call minor stuff, would
14 have been incredibly itchy skin, lesions all over my
15 legs and my arms that I would just scratch off.
16 I would scratch everything off and then just bleed and
17 need to be bandaged up but the strange thing was
18 felled cleansed by this. If I scratched all these
19 lesions off I felt as though I was cleansing myself
20 from the virus or the illness. That was the way my
21 mind was working.

22 In fact, what I was doing was just causing
23 myself to bleed a hell of a lot and causing more
24 infections by doing that. My doctor spoke to me once
25 and said my CD4 count was zero for seven years. I

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1 of escaping the mental torment you were
2 experiencing --

3 A. Exactly.

4 Q. -- of every night going to sleep wanting to die and
5 being disappointed when you woke up each morning.

6 A. Very much so.

7 Q. How physically has your health continued to be over
8 the years? You have experienced lots of illnesses and
9 infections and suffered the effects of the
10 anti-retroviral medication. What can you tell us
11 about that?

12 A. Sorry, could you repeat that question, please.

13 Q. Sorry, it was a long question. I'll break it down.

14 You have experienced many infections over the
15 years as a result of your HIV. What could you tell us
16 about that?

17 A. So it all started with pneumonia, bouts of pneumonia,
18 numerous each year, and then later on as I got worse,
19 as my CD4 count literally dropped to zero, I had PCP,
20 it's a type of pneumonia. Then the PCP spread to my
21 kidneys and the doctors had told my parents they had
22 not seen this much before if ever and they didn't know
23 what to do with me. Basically, my parents were told
24 I was going to die.

25 I think they gave me every drug they could to

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1 literally had no immune system for seven years and he
2 had never seen that before in a patient.

3 Q. You were given AZT. What happened?

4 A. I was given AZT from the age of 12, so shortly after
5 my first bouts of pneumonia. As you probably heard
6 from other witnesses, at that time it was a very new
7 drug and they didn't know what kind of dosages to give
8 to children or even adults. They just didn't know.
9 So they later on I found I was taking -- they were
10 giving me more of an adult dose of AZT which had
11 terrible effects of my body, vomiting every morning,
12 diarrhoea. It would knock my red blood cell count so
13 I was anaemic many, many times and I had to go into
14 hospital for blood transfusions for that just to top
15 me up. Again, my red blood cell count would just get
16 knocked down again.

17 I literally couldn't leave the house for hours
18 and hours in the morning because I had the most
19 terrible diarrhoea. Whatever medication they used to
20 stop it just really didn't work. It was a terrible
21 drug to give. Constant headaches? Stomach pains.
22 Yes, it was -- it was meant to be helpful to slow the
23 virus down but I believe, as some other people have
24 said, it just made us worse and up to today I don't
25 think it really helped much at all.

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1 Q. In 2007 you underwent treatment for hepatitis C with
2 interferon and ribavirin for 12 months. What was that
3 treatment like and what was its effect on you?
4 A. Yes, I did 12 months of interferon and ribavirin and
5 it just changed me, overnight it changed me. I wasn't
6 the person that I was previous to taking these drugs.
7 I became incredibly angry. I had violent outbursts.
8 Again, it made me anaemic. I was very, very weak. My
9 now wife, who was my partner then, just felt like she
10 was living with a stranger. She didn't know who
11 I was. I did not know who I was. My wife had to go
12 part-time on her job to look after me.
13 Also at the time my sister-in-law was living
14 with us and I just felt like I scared her all the
15 time. I mean, I was an angry, angry person and
16 I believe I did scare her. I turned into a monster,
17 basically. I was quite psychotic to tell you the
18 truth. It was an awful, awful time.
19 I believe that was the time that I started to
20 develop PTSD type symptoms, so post traumatic stress.
21 Q. You clearly --
22 A. And even after the treatment I felt incredibly anxious
23 and it's left the after effects -- I've still got
24 things with me now that -- you know, mental health
25 difficulties due to that treatment.

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1 Again, you know, the vulnerability that that causes is
2 disturbing, very disturbing.
3 Q. Had you previously at any time been offered
4 psychological support or counselling during your teens
5 and young adulthood?
6 A. Yes, in my teens I was -- well, probably earlier than
7 that, I was sent to a child psychologist and
8 I just sat there quiet. I didn't answer this guy's
9 questions. I didn't want to be there and being
10 a trained [redacted] now, and looking back at those
11 times he didn't know what to do with me. He didn't
12 know what to say and, in fact, after that I've had
13 counselling and -- since, and a lot of the time in my
14 teenage years it's very, very clear to me now that
15 they just didn't know what to say to me so I never
16 received any helpful counselling, any helpful or
17 structured ways to get over the issues that I had.
18 Q. In 2012 you were diagnosed with chronic kidney disease
19 and that led ultimately to a kidney transplant in
20 2016. Can you tell us about that.
21 A. Yes. So my kidneys were declining and I, as we all
22 have, we have appointments with the HIV doctor and
23 blood tests would show that my kidneys were declining.
24 This was made clear to me and I was told to drink more
25 water, simply just drink more water, until it got to

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1 Q. The hepatitis C virus cleared from the treatment but,
2 amongst other things, you continue to experience what
3 you described in your statement as intrusive
4 flashbacks to that time.
5 A. Absolutely, yes. So I actually cleared the virus in
6 three months. I remember my hep C doctor bouncing up
7 and down in his chair he was so happy but I couldn't
8 care less because I felt extremely ill and possibly
9 suicidal at the time. He was very happy but I had to
10 carry on doing 12 months of this treatment and then
11 after that I started to develop these intrusive
12 images.
13 It was what these images were of myself being
14 attacked from behind. It was always that I was being
15 attacked and I could see this -- I could see it in my
16 head, I'd been walking. It used to happen when walked
17 down the road to a shop and it was almost that I could
18 visualise someone coming up behind me and stabbing me
19 in my back, my lower back to be precise, very strange,
20 so I would feel quite vulnerable. I looked over my
21 shoulder a lot. Very, very strange and -- very
22 strange.
23 I've discussed this with a psychologist and, you
24 know, I've never been attacked like that. I've never
25 been hurt like that. It's very strange, very strange.

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1 the stage where I was sent to a renal specialist, and
2 went to see a doctor at Guy's Hospital and he just
3 bluntly came out with the fact that I needed a kidney
4 transplant. There was nothing they could do and that
5 I needed a kidney transplant and I couldn't believe
6 what he was saying to me. I had to ask him to repeat
7 what he had said, you know, and it became clear.
8 I processed the information he was giving me, but
9 I couldn't -- I thought at this stage in -- I cannot
10 remember the year now when he told me but I thought
11 all the illness was -- had -- it was over, you know.
12 I'd come through being a teenager, to a young man,
13 suffered a hell of a lot, had so many illnesses and
14 problems that I thought, yeah, this is over now.
15 I can live my life. Then I find out I need a kidney
16 transplant.
17 Then before went to see the renal doctor, I was
18 given no indication by anybody else, any other
19 specialist doctor, that I could probably -- I had to
20 expect that I would need a transplant. It knocked me
21 for six. I didn't know what to do.
22 Q. You have given a lot of thought to what caused your
23 kidneys to fail and your belief and understanding is
24 that it can be traced back ultimately to the
25 hepatitis C infection?

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1 A. Yes, there is once I started to do a bit of research
2 or mostly my wife was doing the research, we managed
3 to talk to a professor, a renal professor, at Guys
4 because the not knowing what had caused the
5 deterioration in my kidneys was horrible. It was
6 again I was mentally tormented by this. I think the
7 not knowing is sometimes the worst part. So we saw
8 this professor and we said could my renal failure be
9 linked to hepatitis C in any way, even though I had
10 cleared the virus by now on treatment.

11 He said, well, yes, absolutely, completely. We
12 were shocked. We didn't expect, you know, an answer
13 that like, the fact that he would be so sure that it
14 could have been hep C, and I reminded him, I said to
15 him but I've had treatment and I never had a high
16 viral load for hepatitis C so it never became very
17 destructive for me. And he said, no, no, it wouldn't
18 have been. It can be the underlying effects of hep C
19 just like what you would call a grumbling appendix,
20 a grumbling element to hep C. It can cause kidney
21 failure. So I was shocked by that, happy that I'd
22 cleared the hep C virus years before but then
23 thinking, well, I may not have got away with it all,
24 you know. It could have damaged me like this and,
25 again, I say could have but it seemed quite clear to

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1 I was worried by it but I didn't want to admit
2 to myself that there may be something else wrong with
3 me so I went, I don't know, maybe a year doing this,
4 just living in denial and telling myself, you know,
5 there's nothing wrong with my heart until started to
6 get angina. I had angina just on simple exercise or
7 walking fast I would feel something wrong.

8 So then I -- the next thing that happened was
9 I was giving myself a shot of clotting factor late at
10 night, I was in bed, I think about 10 or 11 o'clock
11 and I injected this factor. When it finished I got --
12 I felt really, cold sweats, pains in my chest, a pain
13 along the left side of my jaw, couldn't breathe
14 properly, I felt absolutely awful and I thought --
15 I didn't really panic but I thought this is really
16 bad. There's something wrong with my heart.

17 I didn't wake up my wife. I just -- all my life
18 there had been a lot of panic around me and people
19 rushing around and I just -- I didn't want any of
20 that. So I should have called an ambulance but I just
21 fell asleep and I then found out later I was lucky
22 I woke up in the morning.

23 The next morning I did wake up. I went to my
24 local Haemophilia Centre, they took some blood tests,
25 one called a Trop-T test, which measures enzymes in

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1 this guy that that's what would have contributed to my
2 renal failure.

3 Q. Earlier this year you had to have major heart surgery.
4 Could you tell us about that.

5 A. Yes. I began to feel -- to have angina which I --
6 I was in denial. When I felt these pains in my chest
7 I was in denial. I had -- as I've had most of my life
8 difficulties with my mental health I thought I was
9 having panic attacks and that's why my chest were
10 hurting.

11 So I -- I kind of denied the fact that I could
12 have my heart issue. Actually, in effect, these
13 angina attacks only came on when I was injecting the
14 clotting factor so initially I thought I might be
15 having a reaction to the clotting factor I was given,
16 not that I'd ever had one before. I'd asked nurses
17 what it would feel like if had a reaction and I was
18 told you would definitely know about it, nothing more
19 than that.

20 So when I was on prophylactic treatment, using
21 treatment every other day, when I was infusing it
22 I would get pains in my chest and I thought this isn't
23 right, it's strange, it happened once or twice and
24 then it started to happen every time gave myself an
25 injection of factor clotting products.

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1 the blood that can be created when you have had
2 a heart event as they call it. This drop-T result
3 came back as elevated and I asked the doctor what does
4 that mean, and he says it indicates that you could
5 have had an event. I said what sort of event? What
6 you talking about? He said a heart attack.

7 So then thought, "Oh my God, you know, now I've
8 got something else to contend with". The thing was
9 ever since I had had the kidney transplant I couldn't
10 recover. I couldn't retrieve any kind of stamina
11 after the kidney op. I was very weak. I couldn't
12 really understand this but it seems that I had had my
13 arteries, my heart arteries, had been damaged.
14 I later found out they had been damaged for years.
15 This had been an ongoing thing, my arteries were
16 shrinking. They were extremely thin in some areas and
17 then they were aneurysmic, so they were very swollen
18 in other areas.

19 This was after it was all diagnosed and I was in
20 hospital being tested I found this out about my heart
21 arteries.

22 Q. You had a triple heart bypass operation.

23 A. I had a quadruple heart bypass operation. That won't
24 be in my statement because when I wrote my statement
25 they told me triple. They didn't want to open me up,

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1 obviously they thought I would have a lot of problems
2 with bleeding so they tried to control my condition
3 with medication and they were giving me very high
4 doses of medication which weren't working. I was
5 still having angina, so I went back to the cardio
6 clinic and spoke to a doctor and I said, "Look, I'm
7 not getting any better", or the symptoms aren't going
8 away. He then said to us, to me and my wife, "Do you
9 want to have a look at" -- had some scans done. He
10 said, "Do you want to look at the scans", and
11 stupidly -- I'm always interested so said yes and he
12 showed me on the screen my heart and the arteries
13 around it and they looked terrible. They looked
14 awful. I couldn't believe looking at.

15 As I say, they were what they call -- I had
16 lesions and aneurysms in the four major arteries of my
17 heart. My LAD -- and I am not sure what that
18 abbreviates to but it's also nicknamed the widow maker
19 artery. That was blocked, 98 per cent blocked, so the
20 only thing that was keeping me alive was the fact that
21 my heart, my clever heart, had done its own bypass in
22 a way. It has used other veins and smaller arteries
23 to bypass these blocked ones to give me enough to push
24 the blood around my body enough to keep me alive. But
25 still I had angina to alert me to this problem.

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1 possible the worst thing. I have strived really hard
2 to live as normal a life as I can and now, you know,
3 I've been lucky to -- I met a partner. Now I'm
4 married. We have a daughter. That's a very large
5 amount of my life I feel that I have some normality
6 but in earlier years not at all.

7 Even right back to childhood my family was
8 affected by all of my illnesses. My sister felt that
9 she was neglected because my parents just focused all
10 attention on me when I was ill, and I was ill all the
11 time. It caused all sorts of difficulties at home.
12 You know, I love my sister very much and I'm upset
13 that she felt left out. That's a common thing, you
14 know. It is a common thing. But just everything
15 about my life has been different because of these
16 viruses. I don't even know how my life could have
17 been different. I'm hoping it would have been a lot
18 better and I can imagine it would have. Again, yeah,
19 all encompassing. I don't know who I am and what
20 I am.

21 A lot of me is a product of having these two
22 viruses and everything else that has been any kind of
23 normality for me I've had to really fight for. I have
24 had to fight so hard to feel like a normal person.

25 Q. What's the impact of everything you have described

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1 Q. When you --

2 A. Go on.

3 Q. Sorry, Mr AH. You've been told by your doctors that
4 the heart problems that you have described are, in
5 large part at least, due to the immense strain on your
6 heart through the HIV infection and illnesses and the
7 treatment you have received for HIV?

8 A. Mm-hm. Yes, some of the drugs that I've taken over
9 the years haven't been good for the heart. My actual
10 heart is fine. The function of my heart is good but
11 the arteries were destroyed. I had an arterial
12 disease that has been attributed to some of the
13 medication I was taking, some of the HIV drugs.

14 Q. In your statement you say this about the impact of
15 your infections:

16 "The impact of HIV and hepatitis C infection
17 upon my life has been all encompassing since I would
18 have been infected from the age of 1 year old.
19 I didn't have the chance to experience life without
20 these viruses. What would my life have been like
21 without HIV and hepatitis C? This is a question which
22 has affected my mental health considerably over the
23 years so I came to the conclusion that I must do my
24 best with the hand that I have been dealt."

25 A. Absolutely. Like said earlier, the not knowing is

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1 been upon your parents?

2 A. The impact upon my parents, yes. As I said earlier,
3 my mother mostly looked after my health issues,
4 appointments, and also when I was being treated at
5 home for my bleeds it was mostly my Mum that was
6 giving me injections. She had a huge battle with
7 herself later on in life because she felt she'd given
8 me the infected doses of Factor VIII, and that's
9 just -- that's still with her today. You know, she
10 hasn't bounced back from that and I don't think she
11 will unless I could find out which batches of factor
12 actually infected me. My Mum had a breakdown. My
13 mother and my Dad became distant. Later on they
14 divorced.

15 You know, I felt -- not because of my mother and
16 father's break up but I just felt scared and lost for
17 most of the time. My sister felt neglected. The
18 whole household was affected by this and I'm sure you
19 know that's an ongoing theme for a lot of people but,
20 you know, somebody I feel needs to answer or there
21 need to be some answers for any kind of healing to
22 occur for myself and other people in my community.
23 I believe it would help a hell of a lot.

24 Q. Your wife, you've touched on the impact upon your wife
25 of looking after you, and all the very substantial

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1 physical health problems that you have experienced
2 over the last few years. What's the ongoing impact
3 for your wife and your daughter?

4 **A.** Okay, so we try and -- well, we try and shield our
5 daughter as much as we can. It was difficult when
6 I was in hospital for my quadruple bypass because
7 there are a lot of difficulties. I bled huge, huge
8 amounts. I was in critical care for a long time and
9 I had to be opened three times for them to clear out
10 all the blood in my body.

11 My daughter didn't know where I was. Obviously,
12 she's [redacted] now and we couldn't tell her where
13 I was, so she had to live without her Dad for these 38
14 days that I was in hospital.

15 My wife has basically -- she's my carer.
16 She's -- when I can't research some of these
17 illnesses, she's doing research for me or for us. My
18 wife has had to put her career on hold. We just live
19 off of my finances. It's -- especially the last five
20 years have been incredibly hard. I've got one kidney
21 now that that could last 15 to 20 years if I'm lucky
22 and then I'll need another one. I've had my arteries
23 replaced with a vein from my leg and hopefully they
24 will last 10 to 15 years and then they will need
25 further work.

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1 been able to earn a living from it. You describe
2 yourself in your statement as having to live on what
3 you term as handouts from the *ex gratia* support
4 schemes?

5 **A.** That's right.

6 **Q.** Why don't you tell us what your experience has been of
7 those schemes, the Macfarlane Trust, et cetera, and
8 latterly the EIBSS.

9 **A.** So if talk about the Trust or the English Infected
10 Blood Support Scheme. The other day I was talking
11 about the money we receive from them and I was
12 referring to them as payments and realised what I was
13 saying when said the word "payment". You know, I'm
14 not doing a job. This isn't a payment. I'm not being
15 paid for anything. What am being paid for? The
16 wording just felt ridiculous. It felt ridiculous
17 and -- I can't think of the right word, incompetent?
18 Incomplete?

19 With regard to using the schemes I had heard
20 about how difficult it had been, from early years
21 I had heard about how difficult it had been to apply
22 for grants and I decided I didn't want to have to feel
23 like that. So I wouldn't apply for grants and
24 I didn't -- I was tired. I didn't want to fill out
25 forms. I didn't want to answer intrusive questions.

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1 You know, it's never over. It's never going to
2 be over now and at one stage in my life I thought it
3 was going to be over. I'd make plans for myself and
4 my wife, plans that we couldn't fulfil or it would be
5 incredibly hard to fulfil.

6 You know, the impact of having two viruses is
7 just -- I want to say destroyed my life but it's not
8 destroyed me. I'm a survivor. I'm not the victim.
9 I'm a survivor and I will do my best with what I've
10 got, as I've already said. Just things keep coming up
11 and I'm basically scared. I'm scared for my future.
12 I feel like a ticking time bomb especially with the
13 kidney. In my lifetime I will need another kidney.
14 in my lifetime I will need my heart arteries worked on
15 again and that creates a hell of a lot of anxiety,
16 post traumatic stress.

17 So although things got better at one stage when
18 we got new anti-retrovirals, better haemophilia
19 treatment, it's not over for me and it never will be.
20 That's the way I feel, and more than that, not over
21 for my family, my daughter is [redacted] years old.

22 **Q.** Your education was very significantly disrupted
23 because of your illnesses but a few years ago you
24 decided you wanted to use your skills in a positive
25 way and you undertook voluntary work but you have not

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1 I didn't want to have to justify what I needed in the
2 form of answering a bunch of questions about,
3 basically, my -- I was going to say personal income
4 but income even sounds terrible to me, but the way in
5 which I used the money that they supply me with,
6 I don't want to answer those questions. It feels
7 demoralising, so ...

8 The scheme changed from the Macfarlane Trust to
9 the England Infected Blood Support Scheme, which
10 I think is a disgusting name and nothing really
11 changed. You know, not much changed. You talk to
12 them on the phone and they don't even know what you're
13 asking them.

14 They don't understand -- I believe that the
15 training they have been given is inadequate, the
16 people that answer the phones, the phone operators.
17 There are a few people you can talk to that actually
18 understand or realise what you may need. I just try
19 to stay away from them as much as I can.

20 **Q.** Those are the questions I have for you but I am just
21 going to move away from the screen and ask
22 Ms Monaghan, who represents you, if there's anything
23 further she would like me to ask you.

24 **A.** Mm-hm. Thank you.

25 **Q.** There are two points that Ms Monaghan asks me to raise

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with you. One is about the uncertainty over the potential long-term implications of the drugs that you have been receiving over the years. You are the generation that has been through these various drugs and I think you wanted to say something about that.

A. Yes. In effect, we are -- the people that are surviving today, we're the longest standing community of people that have been using these drugs and so essentially -- again, the doctors, the healthcare, they are learning a lot from us but we are suffering potentially life-threatening and life debilitating illnesses from some of the side effects of these drugs and the way that they work.

I've not looked into chemistry, I do not know how they work, but I know they have been destructive to some people. I believe there's not enough screening of potential long-term, the potential long-term implications of the drugs, although, you know, I'm looked after very well at my Haemophilia Centre, which also manages my HIV care and I always thought that. I always thought, "I'm safe here. They won't let anything happen to me", but it already has. My kidney issues, the heart artery issues and, I mean, I always said to my wife, "At least my heart's good, you know, we can count on that", but I can't. So,

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injecting it.

Also, the other issue I had when I was in hospital having my open heart surgery, there was an incident while I was an in-patient with my clotting medication. It's a medication called Factor VIIA or NovoSeven and when I have operations or -- I've got an inhibitor, so I use different clotting factors to someone without an inhibitor, and this Factor VIIA was given to me over 24 hours on a syringe pump driver similar to a drip but an incident happened with that in IOR, that's intensive overnight recovery, with very highly trained nurses, one-to-one care and it's, you know, supposed to be one of the safe this places in hospital.

The pump that was being used to infuse me with my blood clotting medication, there was an issue and when pumps or drips have an issue they sound an alarm. The alarm sounded. I mean, I wasn't aware of this because I was asleep but I know more of the facts now. The alarm sounded, my nurse came over and just silenced the alarm and he didn't check why it wasn't working properly. The alarm sounded a further two times -- so three times maximum -- and then he unplugged the machine. I've no idea why he unplugged the machine. All I can think is he was fed up

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again, it's not enough screening of potential long-term implications of these drugs, I feel.

Q. The second point that Ms Monaghan has asked me to raises is something that happened during your last hospital stay. There was a life-threatening error of some kind that was questioned by your wife.

A. So that actually falls into two different categories actually. At the moment there's a new product for haemophiliacs, a new wonder drug like Factor VIII was heralded in the '70s, a wonder drug.

Now, my Haemophilia Centre wanted me to start this new drug. It basically it will clot my blood for a week at a time. So I will need -- and I won't bleed -- it's an amazing new drug. They were pushing for me to have this, I think it was at the beginning of 2018 and, obviously, now we know I have these issues with my arteries in my heart.

If they had given me this is new drug then I would have had a heart attack on the spot and died because, as I say, it clots your blood pretty much immediately for up to seven days or more.

Now, once I would have infused this drug there wouldn't have been a way to clear my body of it or not easily anyway. But because of the arterial damage I had, I would have dropped dead basically as soon as

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listening to it. I don't know, he was very busy and didn't want to deal with me, even though I had one-to-one care with this nurse?

So I went a whole night without having any life-saving medication. I had no blood clotting medication for about eight or nine hours and I then bled profusely. I bled internally into my chest and needed to be opened up -- I think this was the third time -- for them to clear out all the blood and my lung collapsed because of the amount of blood in my chest was pressing against my lung.

That's negligence. That's disgusting behaviour, in my opinion. A highly trained nurse giving me one-to-one care just deciding to turn the machine off, it makes no sense to me at all. So I am -- me and my wife are following proceedings to find out what happened.

Q. Those are the questions that I have for you. Is there anything that you would like to add?

A. To be honest, I feel I've covered everything I wanted to. As I said, I'm scared for the future. Well, I'm scared for the future of my wife and child. They just live off of my finances. If, you know, anything happens to me in a year's time, a couple of years' time, I don't know (*unclear: interference*) exactly how

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1 they would survive. My wife's been severely affected
2 by all of the implications (*unclear: interference*)
3 last few years and has quite serious anxiety and her
4 own mental health has been affected by this issue.
5 Apart from being scared for myself, I'm scared for my
6 wife and child if I was to die, basically, and, you
7 know, I can't emphasise enough the impact of having
8 two viruses.

9 It's just ... it's affected me -- it's affected
10 me in a way that -- you know, even I didn't think they
11 could from becoming undetectable to HIV when I was 21
12 and believing that life was going to be better from
13 then on, it's not been. It's been incredibly
14 difficult because of the stress my body's been under,
15 the multiple illnesses I've had over the years. I just
16 don't think it's going to end. I'm lucky to have
17 a very supportive wife and a fantastic daughter and my
18 whole family supporting me.

19 Q. Thank you.

20 Sir Brian?

21 **SIR BRIAN LANGSTAFF:** It was important evidence to hear
22 your story for someone as anxious as you are. Having
23 overcome so many difficulties and challenges, it has
24 been particularly impressive that you felt able to
25 come here and give it and for that I am really very

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1 otherwise ordered and I may vary or revoke the order
2 by making a further order during the course of the
3 Inquiry.

4 Mr AI, would you come forward, please.

5 **MR AI, affirmed**

6 **Questioned by MS RICHARDS**

7 Q. You were diagnosed with severe haemophilia A when you
8 were a baby in 1980?

9 A. Yes.

10 Q. And you were treated thereafter at the Birmingham
11 Children's Hospital under the care of Dr Frank Hill
12 until you were 17 and then you transferred to the
13 Queen Elizabeth Hospital, also in Birmingham.

14 A. That's right, yes.

15 Q. Now, when you were very young you had a lot of
16 bleeding episodes?

17 A. I did, yes.

18 Q. Three to five a week you have suggested in your
19 statement.

20 A. That's right, yes. I would be treated quite often
21 because of multiple problems, often surrounding my
22 ankles to begin with but as I grew, I had an awful lot
23 of bleeds related to my growing. At the time we would
24 be having to call ambulances to be taken to the
25 hospital where they would treat me there to begin with

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1 thankful. Thank you.

2 A. Thank you very much.

3 **MS RICHARDS:** If we can cut the video link now.

4 **SIR BRIAN LANGSTAFF:** There is one I thing need to say
5 before we break and we will break until 2.45. For
6 those of you who heard a name being mentioned earlier
7 in the evidence, you must remember that to you he is,
8 and will, remain Mr AH. Thank you very much.

9 (2.31 pm)

(A short break)

11 (2.47 pm)

12 **SIR BRIAN LANGSTAFF:** Our next witness will be known as AI
13 it follows on the order from AH and in his case I make
14 an anonymity restriction order in these terms.

I order that the name and address of witness
W0008 (that's AI to you and I) the name of any member
of the witness's family and other identifying
information such as the witness's image or
a description of their appearance cannot be disclosed
or published in any form unless express permission is
given by me or the solicitor to the Inquiry acting on
my behalf. Witness W0008 must be referred to only as
Mr AI.

The order remains in force for the duration of
the Inquiry and at all times thereafter unless

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1 until my mother was introduced to treating me and
2 later on having to learn how to treat myself.

3 Q. Your records show that you were first given
4 Factor VIII products in October of 1980, again as
5 a baby. You were given cryoprecipitate for a period
6 between 1981 and 1982 and then back to Factor VIII
7 products.

8 A. That's what I'm told my records show, yes.

9 Q. Then in terms of the home treatment, that began to be
10 administered, first of all, by your mother in 1986.

11 A. Yes.

12 Q. And by the age of 7 you were --

13 A. I started to learn to do it myself as well. During
14 that time, my mother would also be treating me
15 alternating because, after having the brain
16 haemorrhage I had, I was paralysed down my one side,
17 so I don't have the co-ordination to do it both ways,
18 so my mother would have one arm and we'd alternate who
19 did it so it would be on this day I would do one and
20 then my mother would do it two days later, let's say,
21 using the other hand to let my veins rest.

22 Q. Now, were your parents, as far as you are aware, ever
23 given any information or advice or warnings about any
24 risk of infection associated with the use of the
25 factor products?

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1 A. No, they were told that the -- what I was on would be
2 heat-treated. This is after my cousin had already
3 been infected and that was in 1984.
4 So after that had happened to our family, both
5 my mother and his mother were told at the haemophilia
6 unit that now they'd started using heat-treated
7 products and once they started that they said it was
8 absolutely safe. Things like that couldn't happen
9 again. So at that time I wasn't infected and my
10 parents were told it was not possible to be infected
11 after -- once you're using the heat-treated products.
12 Q. If we just take it in stages. So before heat
13 treatment was introduced, before your cousin was
14 diagnosed, from 1980 up until 1984 when your cousin
15 was diagnosed as having been infected with HIV, you
16 were receiving Factor VIII during that time, Armour
17 products, as far as you know?
18 A. Yes.
19 Q. Were your parents told in the pre-heat treatment phase
20 anything about any risks?
21 A. I don't know what my parents were told at that stage
22 about potential risks but I don't believe they were
23 told that they were taking any risks with my health.
24 If they were told anything, they were told it was as
25 safe as it could be and that's all I've never been

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1 parents will have been taking me to the hospital,
2 after the fact that my cousin was infected they were
3 obviously furious and then very scared for my
4 well-being. So testing will have been taking place
5 and for a long time I was clear of the viruses myself,
6 and that's when they were telling my parents that
7 they'd taken the precautions that they needed to, what
8 they were using now was much cleaner and heat treated,
9 therefore, it couldn't happen to me after the fact of
10 my cousin's infection.
11 Q. What you have said in your statement is your parents
12 were reassured by the hospital that heat-treating the
13 blood products was now being done and so you could
14 never be infected in the same way, the products would
15 be safe and free of viruses?
16 A. Yes, that's what they were told. They said the entire
17 point of the heat treating is to get rid of the
18 viruses. If there was ever anything like that in the
19 products, it would kill them.
20 Q. You had contracted hepatitis B --
21 A. Yes.
22 Q. -- in early 1985 when you were about four years old
23 but you naturally cleared that virus.
24 A. Yes. That was during the time I was still at the
25 children's hospital that I actually naturally cleared

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1 told that they were -- that was said to them at that
2 time.
3 Q. And then as you've already referred to, in 1984, it
4 was discovered that your cousin, who was very similar
5 age to you, I think six weeks older than you --
6 A. Six weeks apart, we were.
7 Q. He was four at the time and the family was told that
8 he had been infected with HIV.
9 A. Yes.
10 Q. But you were tested and at this point you had not been
11 infected with HIV.
12 A. That's right, yes.
13 Q. The test results were negative.
14 A. Yes.
15 Q. Then as you have just said --
16 A. Sorry, the testing was happening quite often after
17 that stage, once they'd established that some had been
18 infected. I don't know how many other episodes prior
19 to my cousin's infection episode, the incident that
20 infected him, and I don't know how many others it
21 infected at that time, but I don't know how many other
22 incidents of other infection times they had already
23 had.
24 But I do know that from that time onwards we
25 were being regularly tested. I know this now and my

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1 it.
2 Q. Then in around August or September of 1986, your
3 father was told by the hospital that there was
4 a problem with a batch of product?
5 A. Yes, that they'd been giving to me and that they --
6 I don't know how it was explained to my parents.
7 I know that my father wrote at the time about what
8 he'd been told and how they were told. I do know that
9 my mother was told eventually that I was infected over
10 the telephone.
11 Q. We'll come on to that. Again, we'll take it in
12 stages.
13 A. Okay.
14 Q. Around August or September of 1986 there was a recall
15 of an Armour product your father was told and, as you
16 say, your father wrote a letter and we're going to
17 look at that.
18 Paul it is 0008004, please.
19 We can see the date of it. It's
20 14 November 1986. It refers to you and -- you being
21 a severe haemophiliac.
22 A. Yes.
23 Q. Then it says this in the second paragraph:
24 "There are over 100 young patients receiving
25 treatment at the Children's Hospital Birmingham and

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each were recalled and tested for the virus. Unfortunately, a large percentage were found to be already carrying the AIDS antibody. It was then announced that the Factor VIII was to go through another process by which it was heat treated and, of course, we thought our worries were over. Not so, two patients were found to have contracted the antibody even after this safeguard. Our fears have returned and we no longer feel secure using the above mentioned product."

Which was -- in the first paragraph it mentions it's Armour. Then over the page your father continues:

"Following this the hospital called in Armour Factor VIII and we were issued with a product made by Alpha."

Then it says:

"At the present [and names you] is free from the virus but he has to have fortnightly blood tests to keep check on his condition. Obviously this lack of guarantee of what is the life saving product worries us, as you will well imagine."

Then if we just go down towards the bottom of the page your father says this:

"We understand that we could well produce

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Factor VIII here in Elstree but sadly the Government fails to fund to a correct level to make this country self-sufficient. Although at present we produce a limited amount, funding to a higher level could give us all peace of mind. Dr Hill, the head of haematology at the Children's Hospital says we need urgent resources to fund the following: (1) research to produce a synthetic Factor VIII which would be 100 per cent safe; (2) for health education; (3) for a counselling service so necessary particularly at the present when all the patients and their relatives are at their lowest ebb. At present we haven't a single counsellor either at the Children's or at the Queen Elizabeth where the young patients continue their screening and treatment after reaching 16 years. We can only wait for our twice-yearly consultation with Dr Hill. It is quite dreadful that we can't get advice when we are all so anxious. The only way we can get this much needed chance to talk through a particular problem is through the parents' self-help group."

That, for the sake of completeness, was a letter that was being written to your local MP Peter Snape.

That is 14 November 1986. Up until that point, you had tested negative of the virus.

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- 1 A. Yes.
2 Q. But that changed and your records suggest that you
3 first tested positive on 19 November 1986 --
4 A. Yes.
5 Q. -- only a few days after that letter was written.
6 A. So they worked out later that it was probable at the
7 time that was being written I'd already received the
8 treatments that were infected. So my parents are
9 thinking I might have dodged a bullet if you like and
10 they are writing with hope and it wasn't long after
11 that, although there were, I now understand there were
12 unacceptable ways that they found out about the fact
13 that I'd been infected, at that point they didn't
14 think I had been and I feel for them.
15 Q. Your understanding from what is set out in your
16 medical records is that you sera converted in around
17 October/November 1986 when you were six years old?
18 A. Yes.
19 Q. And critically at a point in time at which the only
20 product that could have infected you with the HIV
21 virus were the heat-treated Armour products that you
22 had been receiving.
23 A. Yes, at the time the batch numbers of what I was being
24 treated with were being recorded by the hospital,
25 which I've managed to keep -- get a list of to

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- 1 yourselves to show that it was those products that
2 I was on at the time. So, as far as I understand it,
3 it can only have come from that source.
4 Q. We can see from a statement that your father made in
5 subsequent litigation -- Paul, it is 008009, please --
6 this is a statement prepared by your father I think
7 for the purposes of either the HIV haemophilia
8 litigation or litigation that was taken against Armour
9 itself but we can see about halfway down the page it
10 says:
11 "In about August 1986 I was informed by the
12 hospital that a particular batch of Armour
13 heat-treated product was faulty and that there was
14 some sort of problem. I received instructions from
15 the hospital to return all the remaining supplies of
16 heat treated Armour Factor VIII to them. After the
17 product had been returned [you, Mr Al] had to attend
18 hospital approximately once every fortnight for blood
19 tests. My wife has informed me that on one occasion
20 she went to the hospital and managed to catch sight of
21 the file in relation to you. The file indicated that
22 the results of the fortnightly tests had proved
23 negative up until November 19, 1986, when the word
24 'HIV positive' was indicated next to the results of
25 the test. We were not actually informed of the

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position until January 1987. To the best of my knowledge and recollection the only treatment our son ever received was with un-heat-treated and heat-treated Armour Factor VIII. He most definitely sera-converted at a time when he was receiving the heat-treated product."

That was the statement your father gave in the litigation.

A. Yes.

Q. The reference to your parents not actually being informed of your diagnosis until January 1987 is a reference to a telephone call your mother received. What can you tell us about that?

A. Yes, my mother, when this was explained to me when I started to become a lot older, I would be around about 15 to about 17 when I was told more, but my mother explained to me that one of the things that really hurt them and angered them was that she was only told over the phone and it stressed her massively, to which point they immediately fled up the hospital with me to try and find out what the hell had gone on and how it was that they'd been -- it wasn't just being told over the phone. It was the extent of everything she'd already read, I now understand this information was kept in these boxes for years and

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doing sport or physical activities with the other kids, just in case there is any kind of school ground accidents that would threaten the other kids. So I can imagine they were deeply stressed with wherever I was, whenever I was out of sight.

Q. You have described it in your statement as, as you got a little older, your parents essentially broke the news to you in stages?

A. Yes.

Q. First of all, you've got something in your blood. It means other people can't touch your blood. You need to be very careful when you are playing with your friends.

A. Yes, when I was relatively -- at the beginning I would probably be about 13 when that was proposed to me.

Q. Then they said to you a little later on you needed to be very careful in PE and careful of accidents.

A. Yes, that would be at school, in junior school. That was when I was younger.

Q. Then you say it was when you were aged some time between 14 and 16, so your mid-teens, when you finally were informed and understood that you had HIV?

A. HIV, yes.

Q. You had also been diagnosed with hepatitis C?

A. Yes. What I understand of that is I wasn't actually

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because I was so young I wasn't aware of all the information found out at the time until much later and it's only in recent months even that I've ever seen this document from my father and my father's statement.

I didn't know the details of how it was that they were told over the phone and I didn't know that it was months later that they actually had been informed that I'd actually become HIV positive.

So obviously the more I find out about it the more upset I become about how they were treated and how they were told what had happened to me. So although I don't know because I was very young, I was six, so because I was that young I didn't know what was happening and I think my Dad references in one of his letters that they didn't tell me that I was HIV positive to try to shield me from the strain of that, given that it's becoming a very famous deadly disease and they didn't tell me until I was older but whilst I'm at school they were telling me to have to be very careful how I play with other children.

Trying to move the focus on to remember you're a haemophiliac you might hurt yourself, but I then later in life come to understand we were also protecting the other children and that's why I'm not

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tested and diagnosed until the early '90s and I understand that -- I believe that to be because the testing wasn't available until that period. So although it all stemmed back to the dirty products that we were given, I believe we weren't confirmed as having hep C until later because the testing wasn't available. That's as far as I can recall.

I do remember my mother telling me that but I don't -- I didn't know what year specifically, whether it was 1993 or 1992 that she remembered that it was asserted when I was finally diagnosed with that as well.

What I do remember about that is that she pointed out that my cousin didn't get that but that may have been because my cousin died in 1992 when we were both 12, so it may have been that he hadn't had the test yet but I don't know. I do know there was something I got which I believe was the hep C that he didn't get diagnosed with but I think that may be because he died.

Q. As you say your cousin died at the age of 12 years old --

A. Yes.

Q. -- from AIDS?

A. Yes, he developed double pneumonia and died because

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1 his immune system collapsed.

2 **Q.** You yourself in terms of the hepatitis C cleared it

3 naturally when you were in your late teens.

4 **A.** Yes. I would have been about 18 to 19 when they told

5 me that because I know that I'd already transferred to

6 the Queen Elizabeth Hospital by that time and I didn't

7 transfer to the Queen Elizabeth Hospital until I was

8 17. It was normal that you went earlier but because

9 we were haemophiliacs and the bond with where we were

10 being treated was quite strong, a lot of haemophiliacs

11 didn't transfer until they were a little older so that

12 there was a better picture of how -- where our health

13 was before we moved over, so I will have been 18 or 19

14 by the time they tell me that I've naturally cleared

15 the hep C.

16 **Q.** There's a long-term health consequence of the hep C

17 which we will come on to at a later stage.

18 **A.** Yes.

19 **Q.** You have said in your statement that by the time you

20 transferred to the Queen Elizabeth Hospital you were

21 receiving what you have described as a proper

22 education from the hospital about HIV and hepatitis

23 and what it could do and you understood about

24 transmission and risks of transmission.

25 **A.** Yes.

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1 immediately talked to as an adult and my social

2 worker's help, because I had a lot of trouble with

3 staying at school and social interaction, was -- it

4 was critically important to me and it was how

5 I understood how do you live with this deadly virus

6 and how do you protect other people. It wasn't just

7 about things like becoming adult and becoming sexually

8 responsible, it was obviously you fantasise -- having

9 a bleeding disorder, any accident like a crash or

10 anything threatens everybody else, so you're always

11 wanting to know the extremes of the precautions you

12 need to take.

13 So we had to learn how to behave as adults with

14 the viruses.

15 **Q.** I know you wanted to say a little about your cousin

16 because there's no-one else to speak for him.

17 **A.** Yes.

18 **Q.** He was just 12 when he died.

19 **A.** Yes, he was infected when he was four years old. We

20 were both four, and at that date they infected my

21 cousin and he didn't survive that long more than the

22 Government's guideline time-frame which was something

23 like five years. My cousin made it to 12 years old

24 and he developed a cold at school which then developed

25 into a much worse form of flu-like symptoms and then

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1 **Q.** You were given, you have said, at the Queen Elizabeth

2 Hospital very helpful advice in relation to sexual

3 partners, taking precautions and they were very

4 supportive and didn't try and discourage you from

5 forming normal relationships.

6 **A.** That's correct. Everything that I learned about

7 living with it, and the goal was not to necessarily

8 let it completely destroy your life, came from help

9 I got from both my social worker which I was put in

10 touch with as soon as I came to the Queen Elizabeth

11 Hospital, and I'll explain the importance of that

12 later and also at the Queen Elizabeth Hospital, the

13 staff there were used to dealing with the patients as

14 adults, no longer as children as you would be spoken

15 to at the Children's Hospital.

16 Although they did see us as becoming adults,

17 they'd spent years dealing with your parents and

18 explaining things to them and then it developed into

19 you'd have things explained to you together but they

20 are really more talking to your parents to make sure

21 that it's kept straightforward.

22 At the Queen Elizabeth Hospital, they

23 immediately are speaking to you as an adult and they

24 did have some significant differences in philosophy as

25 regards how they dealt with you. So you were

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1 that escalated into double pneumonia and that's what

2 he died of.

3 I do remember both going to the hospital when he

4 was dying and, basically, being told to say goodbye,

5 and also at school there was a vigil at the school

6 where everybody was encouraged to hold a candle

7 because my cousin had died and they'd all been told

8 but obviously not been told why.

9 **Q.** You yourself didn't know the exact reasons why he died

10 at the time because you were only 12.

11 **A.** At the time I didn't know what was wrong but I found

12 out later, you see.

13 **Q.** You found out what he died of at the time you were

14 being told that you had the very same condition.

15 **A.** Yes, I was not told at the time he died that he died

16 because he was HIV positive, because I was also HIV

17 positive and my parents were trying to protect me, but

18 I was told that he died of double pneumonia. I wasn't

19 told why that was.

20 So I knew at that stage that he'd become really

21 ill and died but I didn't find out until I was older

22 when it's been explained to me that I am also HIV

23 positive and that was the reason my cousin had died of

24 what he died of. So obviously that impacted me quite

25 hard because you then think, well, if that's how

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extreme things can get and how fast it was, what can you do with that?

You just are waiting for something random because my cousin -- it didn't take him long to become that sick. One thing that was the case at that time, I was not on treatment for HIV when I was at the Children's Hospital and I would believe that that would mean that my cousin wasn't, because the reasoning there was because at that time there were only the very early drugs for the HIV, they would tell us that they would only keep, I found out later in the years, round about 17, round about the age of 17, that they tended to only keep the treatments for when things got really bad because they didn't want us becoming resistant to them. That was the mindset of the Children's Hospital.

However, when I transferred to the Queen Elizabeth Hospital, their philosophy was completely different and I was put on treatment immediately as soon as I got there, so the difference in the style of the way you were treated was completely different.

I don't know whether anything they could have treated my cousin with could have helped him to not become sick in way he did because I do not know what of those drugs was available when we were both

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because I was worried about him.

Q. You were frightened that if he helped you you might infect him?

A. Well, we'd all been working with tools so I'm thinking he doesn't know if he's cut himself anywhere. So I'm extreming the situation. I don't want -- he wasn't wearing gloves and I didn't want him messing with me whilst he'd obviously been using the same kind of large blades that we were using on the trees if he had any kind of cuts on himself. He didn't know that I was HIV positive.

I told the office there and they were aware of it and were comfortable with me working with them but he himself didn't know, so I kept him away from me the only way I could. But it was basically my own built up walls and trying to keep it away from everybody else.

Q. You talked about having a breakdown at the age of 17 and until the age of 24 you became what you described as a very closed off person. You didn't leave the house.

A. I didn't go anywhere. I'd spend almost all my time in one room and it just was an easier way of dealing with everything. It's already difficult enough for us to socialise with everyone else given that we are

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12 years old in '92 but I do know that if they had anything, is it AZT was the very early form of treatment that they could use, but I think that would be the only thing they could have possibly done to try to help him but there was nothing they could do to help him at all. His mother was obviously destroyed by that.

Q. You have described in your statement once you became aware of the diagnosis and you began to understand the implications of it, you've put it this way, that you began to build mental walls. You thought you were dangerous and you became terrified of infecting others?

A. Yes. Initially, because I wasn't sexually active it was just the point of view of interacting with other people, and one of the things I did do because I wasn't very capable but one of the things I did do was I did voluntary conservation work for a short time until the bleeding issues that I got were causing too much trouble and it had to stop. But during one of the episodes I was working with them, I managed to cut my hand whilst we were working on some of the coppicing we were doing and at that time I remember a medical staff member coming towards me trying to help me and I ended up kicking him away from me

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physically to damage ourselves being haemophiliacs and keeping up with the normal pace of normal people always injures us, but as I grew up and I start building barriers between me other people as far as, getting girls and girlfriends there was just nowhere I could go in my mind to justify going along that path. So yes, I became very closed off from everybody and eventually it was even disruptive to my family.

Q. In terms of the physical effects you have talked in your statement about feeling seriously fatigued all the time, constantly being on drugs with side effects. Can you tell us a little about that?

A. Yes, you see, a lot of the drugs we have to take are very toxic, so you're always dealing with extreme levels of nausea just with -- and you're having to take anti-sickness pills just to combat the nausea, just so that you can eat, because you are endlessly feeling nauseous. But you are also weak and drained because they basically knock you about. It's almost like they toxify you to toxify the virus enough to keep it down.

I don't know how it works but it seems to have to beat you up in order to combat the virus and I've heard it described many times as like being on a mild form of chemotherapy all the time because you're so

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1 wiped out, you're tired, you feel sick all the time
2 and it really affects your ability to have any energy
3 whatsoever and, on top of what we're already doing, it
4 just makes life three times as hard.

5 **Q.** You had recurrent serious infections that required you
6 to be hospitalised over the years.

7 **A.** Yes, I had several occasions where I would have to go
8 into hospital because I developed some kind of lung
9 infection or something similar where I would be
10 choking up whatever this infection was. But what
11 would often happen, it wasn't every single time, but
12 it often was the case that they couldn't even diagnose
13 it and the policy at the time, for example, with
14 antibiotics is if we can't diagnose it then we can't
15 work out which type of antibiotic you can be treated
16 with, therefore, we can't provide you any treatment.

17 So several times I was in hospital they would
18 just leave me there and hope I'd get over it. I have
19 actually signed myself out of the hospital because
20 they were not willing to provide me any treatment and
21 I was getting better care at home. That was purely
22 policy-based.

23 Often it also had things to do with the weekend
24 skeleton crew of staff they were having, no doctors
25 around to intervene. But it was usually because they

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1 being shot to pieces. So although I did naturally
2 clear the virus, the hep C virus, by that time,
3 I found out later it is one of the things that hep C
4 can lead to and, as regards The Skipton Fund, it's one
5 of the illnesses that they accept that you will and
6 can suffer having been infected with hep C as well.

7 So I believe it to be very much related to the
8 hep C and, obviously, my HIV impacts everything.

9 **Q.** You had to undergo chemotherapy?

10 **A.** Yes.

11 **Q.** Because of the B cell lymphoma and you started that
12 pretty much straight away after the diagnosis in July.

13 **A.** Yes, as soon as they could get me into it. I had to
14 have five courses of the chemotherapy. I was supposed
15 to have six but the sixth course, during the testing
16 they said that the levels of the test that they were
17 doing, which was showing how stable my own condition
18 was, if I had had the sixth set it would have killed
19 me. So I was unable to have the sixth set and they
20 basically just had to wing it whether I would get
21 through it or not. They didn't know whether I would
22 survive it because the cancer I had was -- when they
23 started the chemo it was 11 cms across inside my
24 chest. They said it was like a large orange in there.

25 The chemo I was doing was both intravenous and

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1 couldn't tell us what it was. It wasn't a matter of
2 waiting for the tests when they sent off samples.
3 They said they didn't know what it was so that
4 because -- they explain it because your HIV is so
5 bizarre in what it can allow to happen to you, we
6 can't diagnose every illness that we come across, so
7 they would then not treat us and in my case they
8 didn't treat me several times and I essentially just
9 about got through what I was dealing with at those
10 times.

11 I can tell you that happened -- four times I can
12 remember distinctly when they couldn't diagnose what
13 had happened to me. It was some kind of infection.
14 I was coughing my guts out, not just coughing but
15 literally bringing things up and there was nothing
16 that they were able or willing to do.

17 **Q.** In July of 2005 you were diagnosed with B cell
18 lymphoma cancer in your chest.

19 **A.** Yes.

20 **Q.** You understand that to be a direct result of the
21 hepatitis C --

22 **A.** Hep C, it --

23 **Q.** -- or both infections?

24 **A.** It has to be related to the hep C but it could have
25 had an impact from both because of my immune system

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1 also through lumbar punctures into my spine and each
2 time I went there, there were five sets that I had and
3 I believe three of them were lumbar punctures.

4 So later on we'll explain that that had its
5 problems. It caused problems for me later. But I did
6 get through it, but it was blind luck. They said
7 that -- they weren't even remotely sure it would be
8 enough because it wasn't gone by the fifth stage but,
9 fortunately enough, it had shrunk enough after that
10 fifth stage for me to get away with not having the
11 last cycle.

12 **Q.** In terms of treatment for HIV, you're on a triple
13 therapy treatment but you have had problems with the
14 treatment over recent years because you've become
15 resistant to particular medications and combinations
16 have had to be changed.

17 **A.** Yes, I'm told there are four groups of treatment that
18 can be provided -- not four independent drugs, it's
19 groups of drugs and I am now resistant to one whole
20 section and then half of another section. So, as
21 I explained to you, what that means to me is I'm
22 running out of options. It means that I keep becoming
23 more and more resistant to what is available and that
24 cuts down what they are able to treat me with. It
25 doesn't matter what drugs are available if you are

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1 resistant to those drugs because it won't work
2 anymore.
3 So, yes, I do feel like I'm running out of time,
4 if you like, as regards what will help me suppress the
5 virus.

6 **Q.** You have experienced side effects from the drugs in
7 previous years.

8 **A.** I've had some amazingly difficult times having been
9 taken off one drug that they call getting old or less
10 efficient often because they are saying I'm beginning
11 to become slightly resistant to it and they have
12 a newer drug that they think will work better.

13 One of the episodes I had with that was
14 I developed a major form of migraine because I had
15 just gone on to this one new drug and it was called
16 efavirenz and I developed an immense type of migraine
17 that initially floored me. I then had to be taken
18 back to the QE, they booked me in and they had to take
19 me off my pills under my insistence that this new pill
20 had to be *why*.

21 There is a culture of, "Don't be silly, it can't
22 be the drugs, the drugs do no wrong", within
23 hospitals. They are very positive towards the form of
24 treatment you are on but I was adamant because it was
25 the only new thing I'd done that it had to be that and

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1 my doctor's advice at the time but I told them this is
2 wiping me out and I had to come off it and I was off
3 treatment for five years, and during that time,
4 believe it or not, it was completely free and it was
5 like I was a different person. It's only then that
6 I've realised how badly affected I was on the
7 treatments.

8 **Q.** You went back on to the HIV treatment in 2005 because
9 you met your partner, now wife.

10 **A.** What happened was, basically, simply because I met my
11 wife, my equation -- let me put it that way -- in my
12 mind changed completely. All of a sudden it becomes
13 about protecting someone else. That's all I was
14 concerned about. So I'd basically somewhat given up
15 prior to that. I'd had enough. But when I met *[my*
16 *wife]* I just needed to change what I was doing because
17 it then isn't just about me. Even if we're not
18 together it affects someone else directly, so there
19 was a massive need to change what I was doing.

20 **Q.** You have talked in your statement about how -- and
21 we've touched on it already but I just wanted to ask
22 you a little more -- how you lived life like a hermit
23 as a form of self-protection.

24 **A.** Yes.

25 **Q.** You would push friends away because you feared things

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1 they did take me off the drug and although I did have
2 one additional spike of the major migraine I've got --
3 I'm lying in the hospital bed with a latex glove
4 filled with ice on my head just so that I can open my
5 eyes and I was like that for days and although it
6 flared up once more, once they took me off that drug,
7 it went away. So we confirmed that I couldn't
8 tolerate that drug and this was all about trying to
9 modernise the treatment I was on when they were moving
10 things around and changing what drugs I was on.

11 Some of it is because I had become resistant to
12 other forms, some it's because these were newer drugs
13 at the time. But, yes, I've had major problems with
14 a lot the drugs, even in more recent times.

15 **Q.** To the extent that there was approximately a five-year
16 period 2000 to 2005 when you took no HIV medication at
17 all.

18 **A.** I decided to come off the treatment at that time
19 because I was being beaten up far too much by the
20 treatment. I was zombie-fied by it. It was so
21 aggressive that I had no life because of it. The only
22 way I can explain to you, it was like going on
23 holiday. As soon as I come off the treatment, which
24 I did. I decided I just couldn't continue taking
25 things that were being so hostile and it was against

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1 would go wrong for them.

2 **A.** Yes. Every time I had made friends eventually
3 I became a burden to them. I'd had -- at school
4 I didn't really make that many friends but I was
5 always one of the disabled kids in the class so
6 everybody was nice to you.

7 But after school when you are developing your
8 own friends, whenever they would arrange to do
9 anything or go anywhere I would be invited because
10 I was part of their group but in some way I'd ruin it.
11 Something would always happen that either stopped me
12 going there or I would break whilst with them and be
13 a burden because they were trying -- for example, just
14 normally going out with people I am physically
15 breaking down and they are having to rush to where
16 they are going and I'm slowing everybody down. But
17 I'm also carrying, if we went anywhere big, I'm
18 carrying lots of medication with me as well which
19 doubles the workload for everyone and I have gone to
20 places where my friends have had to pack all my gear
21 away because I've been taken away in an ambulance and
22 they have been left to clean up my mess.

23 So whenever I would try to go anywhere with
24 anyone, something about my health would destroy
25 everything.

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1 So I ended up basically just not interacting
2 with everybody because I am a problem to everyone. So
3 I spent years just in my bedroom staying there because
4 it was the least problem I was.

5 Q. You've been with your wife now for a number of years.
6 A. Yes. That did change my life significantly --
7 Q. You have described --
8 A. -- with that support.
9 Q. You have described her as a godsend to you. She's
10 taken on trying to get you out.
11 A. Yes.
12 Q. And getting you to interact more but you don't -- you
13 still don't leave the house unless you are with her?
14 A. That's it. I still am only interacting with outside
15 because I'm taken to places and it's very purposeful.
16 It's still not let's go and have a nice time
17 because -- well, apart from my social problems because
18 of isolating myself for so long and the reasoning
19 behind having to have a social worker because
20 I interact badly because I spent years being really
21 locked away, so I don't friendship well, if you want
22 to put it that way, it's -- there's so many problems
23 that I'm dealing with that whenever I go anywhere it's
24 designed behind get what you are going to it and then
25 come back and when my wife's tried to make it so that

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1 been socially really awkward and difficult and the
2 more I know that it's because of the way I close
3 myself off, but it's the -- the only way to explain it
4 is it's the only place everything is safe. I can deal
5 with what happens to me so long as it's just me, but
6 when it's affecting other people I become immensely
7 strained by it.

8 Q. The fact that you have made a much longer journey to
9 come here to give evidence is a very unusual
10 occurrence for you?
11 A. Yes. Yes, I don't normally go out. When -- my wife
12 goes out for herself with her friends whenever it is
13 arranged for them. I don't go with her and I don't
14 interact with anyone. I had had friend groups but
15 over time every time you dent what they're doing
16 because you then become ill in the middle of it and
17 then just become a problem, you stop being willing to
18 burden them with what you deal with.

19 I've ruined several trips for a lot of people,
20 including my parents, trying to carry me as part of
21 whatever your group is, whether it was my family or
22 those friends I had back then, eventually erodes their
23 ability to -- well, it really erodes my willingness to
24 put them through it and eventually I just gave up on
25 it all and shut myself away.

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1 I could be more outgoing but I'm still immensely
2 reluctant all the time because I'm expecting problems
3 all the time.

4 Even doing this has been a huge stressful task.
5 So we never know what's coming. I've got a whole
6 suitcase full of medical equipment full of
7 just-in-case possibilities just because I've come to
8 this and I'm always thinking about the times when I've
9 gone places and that's resulted in -- just because
10 I went I've ended up in hospital. Whether it's
11 because I'm interacting with people and picking things
12 up or whether it is the other side, which is the
13 haemophilia side, with your body breaking down because
14 you are trying to do what everybody else is doing.
15 That led to me using a mobility scooter, which we'll
16 talk about.

17 Q. You've said in your statement that when you and your
18 wife do go out it's really, as well as having
19 a purpose to it, it's a short trip so you will go to
20 the bank or the shopping centre and then you go back
21 home.

22 A. It's like a straight line journey. I know that that's
23 difficult for [my wife] because [my wife] would prefer
24 to explore more but I don't want to be there. I'm
25 always thinking back to safe zone. So it's always

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1 Q. One of the individuals who has been very important to
2 you in terms of providing you with practical support
3 and assistance is the social worker who you've
4 mentioned. Your statement describes a number of
5 significant practical interventions by the social
6 worker Mark Simmons based at the Queen Elizabeth
7 Hospital in Birmingham, from helping you to get a flat
8 that you and your wife could move into together,
9 through to assisting you with applications to the
10 schemes, which we will come back to --
11 A. Yes.
12 Q. -- and providing general everyday support and advice.
13 A. Yes. My social worker was golden. He was the only
14 way for me to have any kind of independence because
15 I'd boxed myself into a single room box and his entire
16 motivation was trying to help me out of that cage
17 I put myself in and he not only helped me with my wife
18 but it started well before that, from the age of 17
19 onwards when I first met him, he saw immediately that
20 I was hiding from the world and tried to get me to
21 interact in a normal way with it.

22 He encouraged me into college and we did that
23 for a few months until that was beaten up by my
24 health. My health collapsed that idea too. Every
25 time he's tried to do it it's also gone wrong but he

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was immensely vigilant and kept helping me with the normal instructions on what you do to have a normal life as an adult and, obviously, because I'm not outside interacting with other people, I'm not learning life skills. So he had to basically tutor me even down to basic fillings of forms of living in a home, what do you do, where do you send things, who do you get that information from, was all having to come through my social worker, aside from trying to deal with the schemes to do with this, which has been a nightmare in itself.

Q. In terms of family life, you have decided that you do not feel able to have children.

A. No.

Q. And you've put it in this way in your statement:

"My child not only could have haemophilia but could also carry and have to suffer the viruses and would still have to deal with a father that's a complete mess, a broken diseased thing. That's no life for any child. I would just never want to put any child through that."

A. I know some people would see that as unfair because a lot of people have gone on to have families but you tend to look internally and see nothing but episodes of trauma you cause everybody else, all of it really,

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you said that both those positions were currently unfilled at the haemophilia unit due to financial and staffing issues.

A. Yes. It's both that the social worker I had had to retire because he wasn't well and the main problem that they suffered is the position of being a social worker to us is so immensely complicated that they can't actually train someone to deal with the years of information that they need to absorb to deal with both the illnesses we have but the trusts that are associated with our support, as well as having to deal with our disability benefits such as the PIP changes as well as any understanding of grants that we might be able to get help from from things like the council.

All of that information plus the medical damages that we've sustained becomes impossible for somebody to be trained. That's how it's been explained to me. They can't train someone with all that information and each time they've tried the person they were trying to get to do it has gone away.

But they are also under the pressure all the time of because they haven't filled the position, the overheads of the unit who -- not those who run the unit but those who fund it say, "Well, clearly you're not using one so you don't need one so we want to

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in your own mindset, you are used to damage.

That's what we do as haemophiliacs but with things like the viruses, when you become really sick it's abnormal. So everybody they see you bleeding and you've been dealing with that so everybody knows he's going to sort that out, he's going to get over the bleeding and he's going to be okay. But when you become sick, everybody is intensely frightened because you expect to die because you keep hearing that everybody else did. Your cousin did. My cousin [redacted] died and that was a random, what started out as a small thing. He was just a little bit snivelly and then very soon after he'd died of double pneumonia.

So every time something happens like that, you affect everyone else. So when I'm thinking of things like children, all I can see is what dealing with me would be for even if the kid was healthy and I don't want to put anybody else through what I've done. I just don't.

Q. You have talked in your statement, as well as the assistance you received from the haemophilia unit-based social worker, you also received assistance from the haemophilia unit community nurse, but certainly at the time you were drafting your statement

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close the position down".

So for at least ten years they've been under threat of losing not just those positions, the community nurse at the moment has gone because of the staffing level has been taken away so they don't have anybody who can act as the community nurse anymore and the social worker became ill and was never replaced. That left people like me lost, completely lost, because all of the information, the finding out how to interact with the rest of the world, came through my social worker and they won't replace them and it's been like that now for years.

Q. I want to just ask you a little about the litigation in which your parents were involved on your behalf and the issue of financial assistance.

Your father and mother wrote, as we've seen in 1986, to your local MP and continued to raise matters of concern with your local MP. One at least of those letters was passed to the then Minister for Health, Virginia Bottomley. If we just have up on screen the response your MP received, it's 0008003. It's a letter 16 November 1990 from Virginia Bottomley. It is at the time of the court action, the HIV haemophilia litigation. It says this:

"Thank you for your letter of 29 October

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enclosing one for [Mr and Mrs X] about the current court action concerning haemophiliacs who have contracted the AIDS virus. First, there is no argument about the scale of the tragedy or the desperate plight of haemophiliacs infected with the HIV/AIDS virus. It's difficult to find words to describe the depth of the distress which both they and their families must be experiencing. The Government has never disputed our moral responsibility to pay attention to the needs of the victims and their families. We have quite uniquely paid haemophiliacs with HIV at least £20,000 each to help with their problems and we have paid more in cases of hardship. We have also always promised to keep the sums available to the Macfarlane Trust and the needs of haemophiliacs under review. Despite our promise to keep under review the £34 million already made available many haemophiliacs have decided to pursue legal proceedings alleging negligence against the last Government, the present Government, the licensing authorities, the health authorities, and the doctors who treated them. On the information before me, I have no grounds for conceding the tragedy was the fault of the NHS or of this or previous governments."

She then talks about concepts of no fault

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the Government is showing its great concern for haemophiliacs with HIV, by the *ex gratia* payments it is making. I am afraid that the question of compensation has to remain a matter for the courts to decide if some of the haemophiliacs insist on pressing their legal claim to a court hearing."

You wanted to draw that letter to the attention of the Inquiry and exhibited it to your statement. You have, I think, and you have expressed them in your statement, views on the amounts of money that were or were not made available to individuals through the *ex gratia* payments scheme?

- A. Yes. I just -- to begin with, I would like to point out that I see them as radically unfair, if I understand them correctly, that someone who was a child would not have received as much as someone who was an adult or an adult with children because it doesn't account for the fact that we -- apart from the Government's point of view that we're all going to die in five years, which was thrown around at the time, you would expect that we would grow up to become adults and then expect to try to put some kind of life together that may include a partner and, for many, may include children.

But if we're to get less because we're children

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compensation and then if we go over the page please, says this:

"There have been no substantial changes in the basic arguments since then. While no fault schemes remove the perceived unfairness between those who can prove negligence and those who cannot, they create unfairness between those disabled as a result of a so-called medical accident and those who are equally disabled through natural causes. They also generally result in individual claimants receiving much smaller amounts of compensation than would be awarded through the courts in cases where negligence could be proved."

Then she says this:

"Our NHS is greatly threatened by the increase in the number of writs that are being issued claiming compensation for allegations of medical negligence. The American healthcare system is being ruined by excessive litigation and the mounting costs of compensation. It is possible to organise powerful emotional campaigns for many groups whose treatment has failed to restore good health. All medical treatment has an element of risk and involves considered judgments of those risks in the light of current scientific knowledge.

"I am sorry if this is a disappointing reply but

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at the time than people who were already adults, it just seems completely unfair. Obviously, the first thing everybody's going to say is essentially my cousin is put to death for what amounts to £20,000 and there isn't a soul on this planet that would put up with that, being told that's what your life's worth. Nobody would have that. Just in general the idiocy of the figure that they say makes up for what was done to us is absurd in itself. But then to treat us as children as somehow less worth than those who are already adults, although I accept that they have other responsibilities but we, as children, were going to become adults and have those problems and responsibilities ourselves. So the idea that you could give less to us because we were children just seems incredibly unfair and it's just -- it seems deliberately divisive between the groups of victims.

And you then -- I'm not going to call at any time resent -- becoming resentful of any other victims in other situations. That's not where we come from. But whenever anything has been arranged for any kind of payment system, there are always ways that divide us into groups that end up being unfair figures. It's from the litigation at the start to the support systems later on (where they separate off widows from

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what they call primary infected victims), there's always differences in the way they will fund it or huge differences in the amounts that you are allowed to get, and it's almost a divide and antagonise and ultimately to try to save money.

Q. You've made a number of observations in your statement about the schemes and indeed your own experiences with the schemes and I am just going to draw out some of the themes from that and ask you about them.

You have just touched on one of them which was the cessation of payments after death.

A. Yes. One of the most vulgar things that you have to deal with when you're applying to the trusts is their stance when a primary beneficiary dies. Basically, after one year of the payments -- after one year after your death, they stop all payments to your family and they basically cross your name off a list, say, "He's not alive anymore so we don't have to pay them. It doesn't matter what happens to them now".

I've always found that to be amazingly unfair because you leave a family in immense grief. I know this for a fact because I know that my aunt would have been essentially cut off because of the policies made up by these so-called supportive trust funds and I'm left watching that and thinking every time you've paid

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Macfarlane Trust pleading for its life really but what they were highlighting was if it comes to pass that this new scheme is set up, it would be found out by the Haemophilia Society as well that the Scottish system would pay a great deal more both to primary beneficiaries and to widowed beneficiaries in the amounts. The Scottish system would pay a hell of a lot more than per month in their payments than would happen in the English system.

So basically you're getting a lot less money if you live in England just because you live in England. And I also understand that the Scottish system proposed that widows would get I believe it said 75 per cent, at the time this was all being proposed, of the payments of a primary beneficiary as an ongoing payment, acknowledging that the dead victim was a living person who had a right to life. So at least their family would be receiving something that could help them through not just their grief but their financial hardship, losing somebody who -- essentially we all received money, so it could stabilise our lives. So when we are dead, that's suddenly gone as well from that family.

So in Scotland they would receive that 75 per cent of the payment. As I've said before,

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me, that means something that you've refused to pay the families of those who have died. So they will be left with nothing but their grief, their anger and their pain with no support whatsoever.

So no, it's not okay that entire groups get completely cut off from systems that claim they are there to support the victims, even though all of those victims, whether they are parents, widows, or you as a primary infected person are also supposed to be named in the deed of the trusts themselves. It was supposed to be set up to support haemophiliacs that had been infected with the HIV virus in the case of the Macfarlane Trust, who had been infected via blood products from the NHS, but also to their families, the families of those people who have been infected. So your parents were supposed -- were named specifically as supposed to be supported, the widows were supposed to be supported all in this deed, and yet the Trust itself, when you get into what happens when you die, cuts them off and I don't understand how that's okay.

Q. In that regard, you have also drawn attention in your statement to disparities between the current system and the position in Scotland.

A. Yes. When the change to the EIBSS was proposed, we were sent letters which amounted to the

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I will not get into whether the amounts are acceptable. I'm talking about them receiving a payment that can keep them perhaps financially stable through their grief but in England you get a one-off payment when you die under the new scheme. It's not just that they cut you off, there's a one-off payment, a small amount (I believe it's something like £10,000) and then that's it. Forget about you. It doesn't matter who the person was that died.

So in England it's completely unfair compared with an ongoing payment that happens in Scotland and the difference between the two is just brutally unfair. So I don't see anything as more wrong.

Q. You have some particular concerns about the processes and transparency of those processes that you have identified in your statement. You've talked in your statement about how in the early years of the Macfarlane Trust your mother wasn't made aware of the possibility of applying for grants, and it was only later when the social worker that you've mentioned told you and told you also that he had to tell a number of people about the availability of those grants?

A. Yes. We had no idea and I say "we" because I didn't have a clue either. My mother wasn't told they did

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a wide range of grants. We're talking about when I'm 17.

When I first met this social worker, who has enlightened me to the fact that we haven't received any support from what they call the grant system within the Macfarlane Trust, despite the fact that apparently we were supposed to be able to access this ever since the MFT had been put in place.

So my parents had done without grants. My mother said she did once find out that they did a washing machine but when they applied for it, it was made absolute hell for them for having to jump through hoops to try to qualify and in the end they gave up. It was over.

So from that point onwards that would be in the very early days of the Trust, both my mother and father had no idea that they even did the wide range of grants that were available when we met Mark. And he had to educate me into not just how many things that we'd been doing without that my parents should have been receiving as support all that time and they -- my parents were poor. My father was worked for like £40 a day. So it would have made a massive difference to them and they just weren't made aware of it.

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which you got, but your application was still turned down.

A. Yes.

Q. And turned down on the basis that other organisations, such as the local authority, should fund this.

A. The initial one -- it ended up being a three-year battle in total which crossed over between when the Macfarlane Trust was taken over by the EIBSS.

I initially applied under the Macfarlane Trust rules during a period where they had made the ability to qualify for a grant a hell of a lot stricter under an undefinable phrase of "exceptional circumstances" which they refused to define to us. Bear in mind by this time I have been dealing with the Macfarlane Trust for a long time at that point. I believe we were in two thousand...

Q. Your statement suggests it was 2015 when you made your application for assistance.

A. So by 2015 we'd gone through a big change in the scheme where we had gotten the MFET payments, which were direct and automatic. But because they were direct and automatic payments, it was felt by the powers that be that we just shouldn't need the grants anymore and should stop getting them all the time.

So they made it immensely difficult for anyone

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So when my social worker introduced me into it, he had to teach me what you had to do to apply for what was a wide range of different grants. It was never immense amounts of money but it was helpful if you don't have any.

At that time, it wasn't too difficult to apply. You just then had to provide things like a lot of receipts and sometimes slightly absurd levels of receipts to prove that you'd spent the money correctly because you weren't trusted. But it was support that my parents were essentially denied whilst looking after me as a child. They didn't know because no-one told them. The Trust itself never told anyone that these grant systems existed and that left them not knowing they should have been getting support.

So I again feel bad for my Mum and Dad, and I know that my aunt would have been cut out of any of that as well because my cousin died in '92.

Q. You had particular difficulties when you made an application to the Macfarlane Trust in 2015 for funding for a mobility scooter?

A. Yes.

Q. You say that was the most difficult experience you ever had with the Macfarlane Trust. You had to get medical letters to verify your need for the scooter,

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to get any access to a grant, but then we're still being told, "These grants are there for you. We do grants for mobility equipment. We do grants for medical modifications to your home for disability needs".

So I applied because I'd developed a lot of trouble from dealing with the cancer -- I'll explain why as I get to the later stage -- but I applied to them because they told me this was available for us and I had lost my mobility. So I was saying that surely that demonstrates exceptional circumstances if I can no longer walk around anymore.

But because they wouldn't define what "exceptional circumstances" meant, they would say not good enough and during that time they outright refused me anyway even though I had sent them the medical letters from the haemophilia unit, because what would happen it would be sent directly by the unit because it had to be written and signed by the consultant by that time. And they sent it by email to the Macfarlane Trust and the Macfarlane Trust said, "Yes, you have apparently medical supporting letters but you can't have the grant because you won't give us your outgoings".

Now, we would get grants for years having only

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1 ever given them our income to prove our income, which
 2 I always did. But suddenly they introduced a rule
 3 where they wanted your outgoings as well and
 4 they'd never -- because they'd never needed it,
 5 I refused to accept that they actually needed that
 6 information to grant a grant. They had the medical
 7 information, which is what I was saying. I am in
 8 medical need of this equipment and you have medical
 9 proof that I am in medical need of this equipment.
 10 You don't need to know any more. And I was saying
 11 that because I don't believe it's acceptable for me to
 12 be means tested out of support from a medical disaster
 13 charity.

14 **Q.** Your application in relation to the mobility scooter
 15 went back and forth.

16 **A.** I sent it back to them four times at that time.

17 **Q.** And they still said no and eventually you got so
 18 desperate that you funded the purchase of the mobility
 19 scooter yourself?

20 **A.** I actually had to buy it by the second time of asking
 21 because, regardless of the Trust, I am in medical need
 22 of this equipment. That's got nothing to do with
 23 whether they will pay it and, with all the grants,
 24 it's the case that we as victims can't wait three
 25 months for them to make up their mind if we deserve it

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1 unable to get the scooter I had into any car, because
 2 I can't drive, to get to her. Although our car could
 3 fit it, I can't drive. So I needed a travel option to
 4 be able to both look after my wife but at the same
 5 time look after myself.

6 Essentially, I asked them because the EIBSS once
 7 more said, "We've got a new set of grants that are
 8 available again including mobility equipment", so
 9 I said, "Okay, then you're doing grants again. I'm
 10 going to ask you for what I've now experienced that
 11 I need" because I injured myself quite badly trying to
 12 look after my wife.

13 I applied to them and sent again medical
 14 supportive letters. Again, the unit is, although
 15 overworked being asked for these letters all the time,
 16 they fully supported it because they saw the mess
 17 I got myself into. And I was essentially told,
 18 "You're a haemophiliac and because you're
 19 a haemophiliac, that's why you need it; so you can't
 20 have it because it's nothing to do with your HIV
 21 status". I was banned from accessing disability
 22 grants because I was a haemophiliac, despite the whole
 23 reason they were set up was supposed to be to support
 24 us haemophiliacs that had been infected.

25 So I was furious. So every time I tried,

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1 or if we need it. We need it for medical reasons and
 2 we've got medical letters telling us, telling the
 3 hospitals, telling them that we medically need it. So
 4 what happens in reality is we have to buy this
 5 equipment and we have to start using it whether
 6 they've made their mind up or not.

7 But their response to that was always, "Well,
 8 you've purchased it now. That makes it retrospective,
 9 so we're not paying for it now anyway".

10 **Q.** You applied again for a mobility scooter grant three
 11 years later in 2018 to EIBSS because you wanted
 12 a machine that you could fold away and put in the car?

13 **A.** Yes. So after the fourth time of asking through the
 14 MFT, I gave up on that. I'd been trying to get it
 15 from them for something like two and a half years and
 16 then it was all changed over to the EIBSS. I had
 17 given up by that point. I'd bought it anyway, the one
 18 I was able to use. I bought a larger machine because
 19 I needed to be able to get from my house to places and
 20 we'd always had a car that could take a larger machine
 21 at that point. But that then became a new series of
 22 problems. My actual machine that I got stopped being
 23 useable for certain scenarios.

24 What essentially happened is my wife took ill
 25 and I had to look after her in the hospital and I was

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1 whether it was with the Macfarlane Trust, around this
 2 scooter that had -- I had a lot of need for it. The
 3 reason it mattered so much to me is it's the one grant
 4 where I had exceptional need in a life-changing
 5 problem that I needed this equipment and I had
 6 absolutely everybody vouching for me that I needed it
 7 and it was the only thing I could do, and yet by being
 8 banned from access for a multitude of reasons but the
 9 most insulting one is because I'm a haemophiliac.

10 They said in the new scheme they'd set up that
 11 you have to prove that it's related to your HIV status
 12 or your hep C status or the treatment of those two
 13 illnesses.

14 **Q.** Ultimately, you were able to satisfy that more --

15 **A.** They were still wrong because what actually happened
 16 to me is when I had the cancer, while I was doing the
 17 chemo I had to have lumbar puncture chemotherapy
 18 injected into my spine and then the third time they
 19 did my lumbar punctures it went kind of badly and they
 20 had to attempt it seven times, and it's that that's
 21 led to me having a lot of trouble with my back that
 22 finally put me in a position, after years of bleeding
 23 from that damaged location, which was directly
 24 associated with my cancer, which was related to the
 25 viruses that led to me needing the scooter in the

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1 first place.

2 So I basically had to send a 19-page complaint
3 explaining to them that haemophilia for a start does
4 not cause damage, it is the effect of an injury that
5 took place because of a cause of something else,
6 whether it's an accident or whether it's a fall or
7 whether it's a medical procedure (such as it was in my
8 case), wherever the locations are, haemophilia is
9 a consequence of that. I started having to explain
10 that to them and then explain to them what really
11 caused the damage which was the damage from the chemo
12 after having the cancer, which over years has caused
13 me loads of bleeding in what's become -- in
14 haemophilia turns they call it "a weak point" in
15 either one of your joints or a location in your body
16 where you bleed from an awful lot and it's persistent.

17 So I had to explain that to them and eventually,
18 because I schooled them, I actually got the scooter in
19 the end. But it was like having -- I was at war with
20 them for three and a half years just for one grant.

21 But that's not the only problem I had with these
22 grants. During the time I was talking about, when
23 I applied for the scooter the first time, I had four
24 rejected all for the same reasons, because I wouldn't
25 give them my outgoings, which I knew that they had no

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1 what had happened previously, sorry, in 2016 they
2 added a stage 1 monthly payment which was low, it was
3 like £3,000 annually but it was something, and I was
4 put on the stage 1 payment.

5 However, in 2018 I received a letter which was
6 about what they were calling a special category
7 mechanism letter which explained that they were adding
8 new illnesses to the qualifying criteria for stage 2
9 for the Skipton payments. In that letter that wasn't
10 associated to the new illnesses they added, it said
11 anybody that had suffered a B cell non-Hodgkins
12 lymphoma will already be on stage 2.

13 When I read that, obviously I've said "but I'm
14 not" and I immediately took that to the hospital and
15 asked them, "Am I reading that correctly? Is that
16 what that says?" and they said they read it the same
17 way I did. So I had to call them up and find out how
18 to apply for stage 2 because I'd suffered the
19 non-Hodgkins lymphoma.

20 I then went back through the paperwork I did
21 have from the original explanation of what Skipton was
22 from 2005 (which I keep records of everything), also
23 saw that I had no information about non-Hodgkins
24 lymphoma now qualifying but they told me when I asked
25 them that that was added in 2011, and they said that

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1 right to base their grants, the decisions on because
2 they had no right to that information in the first
3 place. Neither did they have the ability to check
4 anybody's financial status. So they couldn't base
5 their decisions on it because anybody could just make
6 them up.

- 7 Q. The two other particular issues you had with the
8 application processes that I wanted to ask you about,
9 firstly, was about your attempt to get the stage 2
10 payment, which took again a significant period of time
11 and you ultimately got it from EIBSS not having
12 managed to get it through Skipton.
13 A. So when Skipton first was introduced -- I believe that
14 was around 2005 -- and at that time I understand
15 everybody that had been infected with hep C was put
16 through with the Macfarlane Trust liaising with the
17 hospitals about all the patients they knew about and
18 as it was set up, we were all put through it and our
19 medical records were checked and then, in my case,
20 I was put on stage 1 at that time. At that time, the
21 stage 1 payment was only a one-off payment, which they
22 gave to me and then I essentially didn't hear anything
23 else about it for a long time.

24 So I was considered to be on stage 1 until 2018
25 because they didn't know any different. In 2018 --

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1 coincided with the stage 2 payments becoming monthly
2 payments.

3 So basically I had to reapply to the Skipton
4 scheme to try to get put on the stage 2 payments.
5 I had all my medical letters arranged by the hospital
6 again, using the notes from when I was treated for the
7 cancer in 2005/6. They sent that to The Skipton Fund
8 and they said, "Ah, we see you do actually qualify for
9 Skipton stage 2 and that will mean that you'll receive
10 the one-off payment for being on stage 2" which was
11 a £50,000 one-off payment "and that means you also
12 qualify for the monthly payments for stage 2" which is
13 much higher.

14 I believe that's the same payment as for HIV
15 under the new scheme. I think that's 15,000 per year.
16 So they said, "So you do qualify for that and you
17 have -- we can see you've qualified for it -- well, it
18 will be since 2005/6 when you suffered the cancer but
19 the actual payments, the monthly payments, weren't
20 introduced until 2011 so we can only do that from
21 then".

22 However, they said, "Actually, we know you
23 qualified from then but we're only going to pay you
24 from 2018 onwards from when you applied because that's
25 the way it works. We can't back pay you". So this

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1 meant to me a difference of I think it was £94,000
2 that I would have gotten from 2011 because they'd
3 explained how long I would have received the payments
4 for, but they said they're not paying it. They won't
5 back pay it.

6 So I had to again go back to the earliest
7 paperwork I had where it said that I could force them
8 to have it reviewed in a court, a judicial review
9 I think it was called of the decision, and it wasn't
10 until I actually threatened to take them to court
11 about this decision -- they said I qualified and they
12 themselves had said I'd qualified since 2006 but they
13 weren't going to back pay me to the 2011 when they
14 told me the payments I should have been receiving had
15 started from.

16 Q. And your statement explains that it was once you'd
17 threatened to take them to court, you say, you got the
18 letter that said that they would make the back payment
19 to 2011?

20 A. I already had received -- once I'd qualified they sent
21 me a letter that said that I did qualify from the
22 period I explained, when I had the cancer, but they
23 would only pay me from 2018 onwards in the first
24 letter they sent me, and it was that that I challenged
25 and I went back to them and told them, "That can't be

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1 was refused to those people as well. But because
2 I fight them about things, I've eventually got through
3 to them. But in that case, literally having to
4 threaten to take them to court and then all of
5 a sudden they decide, "Actually, you were always
6 entitled to it, we were just trying to stop you
7 getting it", it's absurd and it's obstructive and
8 every element of the support systems is designed to
9 stop you getting access rather than to support you.
10 And I've experienced it over and over again.

11 Q. Mr AI, those are the questions I had for you. Is
12 there anything else you would like to add?

13 A. Okay. One of the things I do need to say, it does
14 relate to the potential consequences of the Inquiry
15 itself.

16 It's pretty much been established that the
17 Government keeps saying that it doesn't really want to
18 pay out compensation. So I just want to put it on
19 record that the Government seems to have a financial
20 incentive not to pay out to us because their current
21 situation in all the schemes is if we die, the way
22 they've written the stipulations the payouts stop. So
23 essential it's better for them if they wait for us to
24 die.

25 That can't be allowed to continue. If there is

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1 right. You've already qualified me from that period.
2 You can't disqualify me for a period you yourselves
3 have just qualified me for. You're telling me I was
4 entitled to it from that point, so you can't take it
5 away from me".

6 And I said that I wanted them to do this court
7 review of my application because it was unfair, and it
8 wasn't until I actually threatened to take them to
9 court that they suddenly sent me another letter
10 saying, "Actually, we will back pay it and we'll back
11 pay it all back to 2011 like you are correct that you
12 were owed".

13 So again, you don't -- it's like you can never
14 get what you're supposed to be entitled to until you
15 reach such a point that you're willing to take them to
16 court to get it, and in that case I went that far
17 because it was an extraordinary amount of money. So
18 if I hadn't challenged them about that, I wouldn't
19 have received it. If I'd just swallowed that I'd
20 would have lost £94,000 and I'm sure there's many
21 others who haven't known or who haven't had the old
22 paperwork that established that you had the right to
23 challenge them who they've told the same thing to.

24 I know that there are others who've tried to get
25 the same things I have, such as the scooter, and that

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1 going to be any kind of whether you call it
2 compensation or whether you don't call it compensation
3 and they just raise the support payments, they have to
4 make -- someone has to make it so that they're not
5 allowed to only deliver them to the people that are
6 still alive because, while they only have to pay out
7 to people who are still alive, they can always keep
8 refusing to pay it hoping that we'll die off so that
9 they can save money. It has to be paid out in the
10 names of the victims that have died as well, to the
11 next of kin of those victims and the families that
12 were also immensely damaged. I know their deed said
13 in the Macfarlane Trust's deed that those people were
14 supposed to be being supported every bit as much as we
15 were as primary infected (in my case, kids) but
16 infected haemophiliacs.

17 Someone needs to clarify that it's not okay for
18 you only to support the ones that are still alive
19 because when the victims have died, their families are
20 devastated, they are going through financial hardship
21 as well as the grief but the Government is saying, We
22 don't need to support them anymore, that person died,
23 cross-them off the list, their life doesn't matter.
24 The fact that they were killed doesn't matter. To
25 hell with them.

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1 That can't be allowed to carry on. So whatever
2 is done must include widows -- there's a major problem
3 around where there were parents because they didn't
4 necessarily call them widows, so parents weren't
5 really thought of within the schemes in a way. There
6 were some payments that some widows could get access
7 to through the MFT, but they were minuscule, but there
8 were no categories for parents, even though many of us
9 were children when we were infected and when we died
10 when we were young, they will always be classed as
11 your next of kin, and yet there was no category to
12 help them.

13 So whatever happens in the compensation system,
14 it has to include the families of those that have died
15 in the name of the person who was infected and who has
16 died, because otherwise the Government still has
17 a financial incentive not to pay out because it's just
18 waiting for us to die off to reduce how much it costs.
19 It's just not right.

20 **Q.** Thank you. Sir.

21 **SIR BRIAN LANGSTAFF:** Mr Al, during the course of your
22 evidence you said how you described yourself to
23 yourself as a broken, diseased thing. Let me tell you
24 I do not see you that way. I rather see somebody who,
25 despite having the fears that you have, despite never

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1 coming out of your house except to go to particular
2 events for a short time, and despite having the fears
3 of anonymity you have, have been prepared to come here
4 for the length of time that you have to give us the
5 full value of your experiences and thoughts which you
6 have, despite your saying that you have no social
7 skills, mainly about other people and how things might
8 be improved for them, and for that and for what you
9 have told us, I'm very grateful.

10 **A.** Thank you as well.

11 **SIR BRIAN LANGSTAFF:** Tomorrow?

12 **MS RICHARDS:** Sir, tomorrow we hear in the morning from
13 Susan Delglyn and Tara Allen and then from Janice
14 Whitehorn-Cox and then we have two anonymous
15 witnesses.

16 **SIR BRIAN LANGSTAFF:** We start at 10.

17 **MS RICHARDS:** Yes.

18 **SIR BRIAN LANGSTAFF:** So tomorrow at that stage. In
19 relation to tomorrow, as you leave you may find that
20 there is a leaflet of information which has been
21 handed out. Please read it and take note if you are
22 intending to be here tomorrow. Thank you very much.

23 (4.30 pm)

24 (Adjourned until 10.00 am the following day)
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