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(10.03 am)

SIR BRIAN LANGSTAFF: Good morning.

MS RICHARDS: Good morning, sir.

SIR BRIAN LANGSTAFF: The first witness this morning,
Clair Walton, wishes to be known as Clair, I think.

MS RICHARDS: That's right, sir.

SIR BRIAN LANGSTAFF: Mrs Walton -- Clair, I'm sorry.

CLAIR WALTON, affirmed

Questioned by MS RICHARDS

MS RICHARDS: Clair, I'm going to ask you, first of all,
about your husband Bryan and what happened to him and
what happened to you, and then I'm going to ask you
about the dealings that both you and Bryan had with
the Macfarlane Trust.

So you are the widow of Bryan Walton?

A. Yes.

Q. Bryan was treated with Factor VIII products over
a number of years?

A. Yes.

Q. He was infected as a result of that treatment with HIV
and with hepatitis C?

A. Yes.

Q. He died in 1993 of AIDS-related illnesses?

A. Yes.

1 Q. You yourself were infected with HIV?

2 A. Yes.

3 Q. Can I start by asking you to tell us a little about
4 Bryan and his childhood and medical conditions.

5 He was a haemophiliac?

6 A. Yes, he was a severe haemophiliac with less than
7 1 per cent factor -- blood clotting Factor VIII,
8 clotting factor. He was diagnosed when he was about
9 18 months old after they discovered much bruising on
10 him, and he was educated not at a normal school. He
11 went at the age of four-and-a-half to
12 Stratford-upon-Avon at an old hospital, the old
13 hospital there, and he was a weekly boarder, and then
14 when he became of age to go to secondary school, the
15 Warwickshire County Council wouldn't -- refused to
16 sort of have him in the schools and so he went down
17 to, Lord Mayor Treloar school. I would think that was
18 around 1969 because he was born in 1958.

19 Q. So the weekly boarding was from about 4 -- the age of
20 4/4 and a half until he was 11 or so?

21 A. Yes.

22 Q. I think his parents didn't even have a car to be able
23 to take him there but they relied upon volunteers to
24 take him and bring him back at weekends?

25 A. Yes. Well, his father would have been working anyway

1 but they were, you know, I don't know whether they had
2 a car but he wouldn't have been able to drive him
3 there because he would have been at work. But I know
4 there were hospital volunteers. In fact, the very
5 first day I'm told by his mother, who sadly died last
6 October, that when he was going to go to the school
7 she went to get into the big black car with her son of
8 four and a half and sort of the lady said, "Oh no, you
9 can't come in", and she said, "I'm going. I'm taking
10 my son".

11 He would go from Monday and come back on
12 a Friday.

13 Q. Then he was at Lord Mayor Treloar School for his
14 secondary education then as a term time boarder?

15 A. A term boarder, yes.

16 Q. So he would return home just for the school holidays?

17 A. Yes.

18 Q. He was there from the age of about 11 through to the
19 age of 16?

20 A. Through to 16, yes.

21 Q. You have explained in your witness statement that as
22 a child his haemophilia care was with the Coventry
23 haemophilia unit. I think he described that as being
24 not more than a corridor?

25 A. When I first used to go with him, when I first met

1 him, it was basically a corridor. I think his name
2 was Mr Livingston or ... used to come out and produce
3 the Factor VIII, give the Factor VIII. It wasn't
4 a centre that we learnt about later.

5 Q. He had brief periods with the Birmingham Children's
6 Hospital?

7 A. Mm-hm.

8 Q. And his haemophilia care also as a child would have
9 been undertaken in Stratford-upon-Avon at the hospital
10 effectively where he spent his primary years?

11 A. I presume so, yes.

12 Q. As an adult, Coventry Haemophilia Unit as you
13 described and then for a period of time in Exeter
14 Wonford Hospital in Exeter, back to Coventry and
15 then -- and we'll come on to this in due course -- in
16 the early 1990s his care moved to the Oxford
17 Haemophilia Centre?

18 A. Yes.

19 Q. You have explained in your statement how Bryan was
20 treated with Factor VIII products from the 1970s or
21 late '60s onwards.

22 A. I think it would have been the 1970s. I think that's
23 when -- when I first met him in 1978 he was using
24 factor, and it was a recent introduction.

25 Q. Paul, could we just have up on screen an extract from

1 Bryan's records. It's 1589008.

2 Clair, it should come up on the screen in front
3 of you.

4 Could we go to the second page of that document.

5 We can see there, Clair, from 1969 onwards there
6 are references, if you look in the right-hand side, to
7 Bryan being given, first of all, cryoprecipitate, then
8 FFP, presumably fresh frozen plasma, cryoprecipitate
9 and then we see Factor VIII (BPL) starting in the
10 1970s.

11 Then if we could go on to the first page please,
12 Paul.

13 Then we can see 1979 Factor VIII (BPL) and then
14 cryoglobulin is the factor product he was given then
15 in 1979/1980. Factor VIII (BPL), cryoprecipitate, and
16 then the Factorate which was the Armour product and we
17 can see the period.

18 That represents the different range of factor
19 products that Bryan was being given throughout that
20 period for his severe haemophilia A?

21 A. Yes, as far as I was concerned it was just
22 a Factor VIII in a bottle, so ...

23 Q. Do you know if, in the time before you met Bryan, if
24 Bryan was ever given any information or advice about
25 the risks of infection associated with factor

1 products?

2 A. No. The only thing that he ever said to me was that,
3 and quite proudly he's been told, that he'd been
4 subjected to hepatitis so much through the blood
5 products that he had developed antibodies for them, as
6 if that was a good thing and so ...

7 Q. That was based upon the doctors having told him that
8 as if it were a good thing?

9 A. Yes, yes.

10 Q. Then in the time when Bryan was receiving factor
11 products when you knew him, which I think was from
12 1978, late 1978 onwards --

13 A. Yes.

14 Q. -- were there ever any discussions you were aware of
15 between doctors and Bryan with risks associated with
16 factor products?

17 A. No.

18 Q. Were there ever any discussions about the reason for
19 giving different products at different times?

20 A. No. I wasn't aware that he was given different
21 products.

22 Q. Do you know if he was ever given any choices about the
23 products that he was given?

24 A. No, I think that by that -- I mean, he told me about
25 the history in terms of cryoprecipitate and how he as

1 a young boy had developed and how it used to be and
2 how it was now with the Factor VIII but, no.

3 Q. So you and Bryan met in November 1978?

4 A. Mm-hm.

5 Q. How old were you?

6 A. I was 17.

7 Q. How old was Bryan?

8 A. He was 20.

9 Q. You've described him in your statement as quite
10 a character.

11 A. Yes.

12 Q. In what way?

13 A. He had a real love for life, a real zest for life. He
14 loved to read, he loved to, you know, have -- you
15 know, he had great aspirations for what he wanted to
16 do with his life.

17 We were part of what was known as the biker
18 scene in Leamington Spa, we were with British bikers.
19 So we loved motorcycles, we loved that sort of that
20 way of life and he had -- yeah, he had ambition.

21 Q. You became engaged when?

22 A. In -- on my 21st birthday in -- that would have been
23 1982 and we had a party for that, so ...

24 Q. You brought your first house together in Leamington
25 Spa?

1 A. Yes, in the later part of 1982 we bought a three
2 bedroomed semi-detached house with a 120-foot long
3 garden. It was a beautiful new start to our life.

4 Q. You talk in your statement about how you both felt so
5 proud of that.

6 A. Yes, we were very proud. We'd scrimped and saved. We
7 made a lot of sacrifices but that's was how -- that
8 was what you did to secure a home, secure a house.
9 And put all our savings and all our income into that
10 in order to establish and this was a place we could
11 have a family.

12 Q. The way you put it in your statement:

13 "This house was going to be the start of our
14 future and our family."

15 A. Yes, yes. It was -- we weren't expecting -- we
16 weren't planning to have children straight away. We
17 had careers we wanted to develop but, you know, I was
18 only young still. We thought of having children maybe
19 four/five years down the line, but we wanted to
20 establish ourselves, establish our careers, establish,
21 you know, our home.

22 Q. When did you get married?

23 A. 21 May 1983.

24 Q. Again, in your statement, you've said you were young,
25 in love:

1 "... starting out with all the joys of young
2 newlyweds with a long life ahead of us. As far as we
3 knew we had a bright and happy future together."

4 A. Yes, absolutely.

5 Q. Around that time, perhaps later on in that year, you
6 applied for a new job. What was that job?

7 A. Yes, I was to be the -- there was a senior post. I'd
8 qualified as an archive conservator and I wanted
9 a senior position so there were positions in Preston
10 in Lancashire and there was one down in Exeter in
11 Devon so I -- well, I got both jobs but I decided to
12 go to Devon and start a new life down in Devon.

13 Q. You moved down there to start work and there was a bit
14 of a delay before Bryan moved down to join you in
15 1984?

16 A. Yes, when I went down there in January 1984 and, you
17 know, it was busy running a collection. I was
18 responsible for the archive collection of the whole of
19 County Devon Records Office and so, you know, there
20 was quite a lot to do and then Bryan, he came around
21 about April time.

22 Q. Then what happened in early 1985?

23 A. He was called in to -- he'd registered with the
24 Wonford Hospital in Exeter where the haemophilia unit
25 was and he went for a regular, what we thought was

1 a regular testing, and he was -- I remember going --
2 he had -- I think I went with him and then sort of six
3 weeks later we went back again and he was told that he
4 was positive for what was HGLV3, which later became
5 known as HIV, and that he had AIDS and that he would
6 die. You know, he had a matter of two or three years,
7 whatever, it was a matter of years to live and that he
8 would die.

9 Q. That was the prognosis that was given to him when he
10 went back with you to get his test results?

11 A. Yes.

12 Q. Can you recall anything else about that meeting?

13 A. There was -- it was a strange meeting because at some
14 point the nurse handed a box of rubber gloves like for
15 me to protect myself and I just to this day find it
16 a little bizarre and odd, you know, that I'm having to
17 protect myself from my husband.

18 We were advised that if we were to have sex we
19 should use condoms and then that was it. That really
20 was it. We were just left and we went home back to
21 our home that we just moved into, we'd bought a house
22 down in Devon, and we were left completely isolated.
23 We had no friends or family down in Devon and we were
24 just left to sort of work it out for ourselves.

25 Q. You've said in your statement that you believe that

1 Bryan was tested without his knowledge, and I just
2 wanted to ask you, first of all, tested for what?
3 Tested for HIV, you think?

4 A. Tested, probably tested for a range of things but sort
5 of years later, looking back, I realised that there
6 was testing going on from other stories. So I think
7 that it's likely that he was tested.

8 Q. There is one document that you have drawn to our
9 attention in Bryan's records.

10 Paul, it's 1589007, please.

11 We can see there the date first positive is
12 given as 15 June 1984. It is not clear from this
13 document when the test was carried out but, in any
14 event, Bryan was only told of the diagnosis in early
15 1985?

16 A. Yes, and I only found that out last week.

17 Q. In terms of this document?

18 A. This document.

19 Q. So the advice and information that was given to you
20 and Bryan at that stage was essentially to use condoms
21 and that Bryan would die within a short number of
22 years?

23 A. Yes and at that same time for some reason the Sun
24 newspaper was being delivered through our letter box.
25 We didn't order it. I think it was being misdirected

1 to the wrong house and so we were seeing, you know,
2 the coverage about AIDS and about the panic and,
3 obviously, seeing reports on television and it was
4 incredibly frightening, incredibly frightening.

5 We knew, really, that the best thing was to keep
6 quiet, to be silent, because we were witnessing how
7 other people with HIV were being stigmatised, how
8 people were losing, you know, over the coming years,
9 how people were losing their jobs, how people were
10 having AIDS scum daubed on -- even though that wasn't
11 happening to us we were still part of that collective
12 who it could happen to. So we really didn't know who
13 we could talk to and who we could confide in. So it
14 was kept very, very minimal, to just parents and very,
15 very close family.

16 Q. The emotion you described both of you experiencing at
17 that time in your statement is terror. You were
18 terrified?

19 A. Terror, terrified and traumatised by it all.

20 Q. At this point, you had been married I think for less
21 than two years.

22 A. Yes.

23 Q. You decided, I think in part because you didn't have
24 anyone around you to support you and Bryan, to move
25 back to Leamington Spa?

1 A. Yes.

2 Q. And that was later that year, late 1985?

3 A. It was Bryan's choice. He said, "If I'm going to die,
4 I want to be back with my family", and so this kind of
5 career and this move, this whole, you know, life ahead
6 of us was just bluntly cut short. But there was, you
7 know, as many times over the years, there were times
8 when things just happened magically, if you like, and
9 I applied to a job that had been frozen at the
10 Coventry City Records Office and said, "When are you
11 going to open it", they said, "Oh, we'll open it now",
12 and I got the job. Bryan was able to get a job back
13 running petrol stations back in Leamington Spa and we
14 moved.

15 So we moved back, so we were in the house --
16 we'd bought the house in January 1984. By September
17 we had sold it and actually made a profit on that
18 selling. It as -- I started my new job in November
19 of, sorry, 1985. So we were back in Leamington Spa
20 then.

21 Q. You described in your witness statement that it was,
22 at least start with, an unhappy move because it was
23 forced upon you rather than being your own choice.

24 A. Yes.

25 Q. You started off staying with Bryan's parents but you

1 then found a house that you both fell in love with.

2 A. Yes, yes. So, you know, aside from everything that
3 was going on and the AIDS we still, I think probably
4 the resilience of being young, we still felt we're
5 going to carry -- you know, try and carry on as best
6 we can and we found a house. It was on the edge of
7 a village in Warwickshire and it was just a magical
8 house. It just needed some work doing on it and we
9 sort of threw ourselves into that for a while.

10 Q. That gave you a focus. You were both still able to
11 work at that time?

12 A. Yes, yes.

13 Q. You were able to tell some friends?

14 A. A few friends, like you know best men at our wedding
15 and Bryan's boss, who was a friend. So it was a very
16 small group of people but otherwise we kept it secret.
17 Neither of us were showing any signs of, like,
18 I wasn't positive, but Bryan wasn't showing any signs
19 of illness at that time. It was only his mental
20 health started to deteriorate.

21 Q. You've talked in your statement about his character
22 starting to change at that point.

23 A. Yes.

24 Q. Can you tell us a little about that.

25 A. I think because he just wanted to live and he knew

1 that, again, the prognosis was there, that everyone
2 was telling you you're going to die. People were
3 dying. People were dying of AIDS.

4 One friend he tried to track down from Lord
5 Mayor Treloar and he knew he lived in the Oxford area.
6 By the time he tracked him down he'd just died. This
7 had a massive effect. He went to his funeral.
8 I think that might have been something that triggered
9 an awful lot in him when he saw that, because we
10 didn't really mix with the haemophilia community at
11 all. We were completely isolated. It was just the
12 odd people he might have met in the corridor at
13 Coventry but generally we weren't part of any
14 community. But we were aware of what was happening
15 and, yes, it had a significant impact on his
16 character.

17 Q. He became obsessed with living for the day?

18 A. Yes, yes.

19 Q. That led to a temporary split up between the two of
20 you in 1986?

21 A. Yes, and that broke my heart because I could
22 understand why he was like that. I could understand
23 why he was angry and, you know, traumatised but that
24 didn't stop him. But that lasted a few months and
25 then we returned back together again.

1 Q. When you got back together, you had a discussion, the
2 two of you, about what you wanted to do with whatever
3 time was left for Bryan and what was the outcome of
4 those discussions?

5 A. Well, that was it. It was really what was it that we
6 wanted out of life and our dreams that we'd had of
7 having children were still there, you know. I was
8 negative and we were questioning why -- you know, we'd
9 had sex, why is it that I hadn't become positive? And
10 so we were questioning that and so we went to the unit
11 at Coventry and we had a conversation with the then --
12 I don't think he was director of haemophilia. He was
13 in charge of haemophilia, the doctor, the consultant,
14 and he -- we said we'd like to have a baby and he
15 said, "Well, that's not very good idea but if you want
16 to go ahead, we'll monitor you", and so we did.

17 Q. What now is your understanding or your belief about
18 what was meant by you being monitored at that period
19 of time?

20 A. They were watching whether I would turn from HIV
21 negative to HIV positive. That was it. There wasn't
22 any advice around. You know, it seems incredibly
23 innocent and naive at the time, you know, but there
24 was no -- it's only afterwards that -- there was no
25 discussion around ovulation, about whether either of

1 us were actually you know fertile in any way. There
2 was nothing around that. It was -- or the dangers of
3 it. Again, we were living isolated with this.

4 Q. You would be tested monthly there as to whether you
5 were HIV positive?

6 A. Yes.

7 Q. You weren't given any information on an ongoing basis
8 about the risk of infection?

9 A. No.

10 Q. Or about pregnancy or the prospects of becoming
11 pregnant?

12 A. No, no.

13 Q. June 1987 you had another of these regular tests at
14 the hospital in Coventry and what was the outcome this
15 time?

16 A. I think it was either June or July. It was June I was
17 ill. I was very ill for a week, which was most
18 unusual for me, and then I had a test. The test came
19 through, the result came through, and they said we're
20 concerned this -- I can't remember the term they used
21 but --

22 Q. Inconclusive?

23 A. Inconclusive, that we needed another second test and
24 so they did another test again.

25 Q. The result of that second test was that you were HIV

1 positive?

2 A. It was but they didn't tell me.

3 Q. They didn't tell.

4 A. They told my husband and I found out on -- because

5 I was the whole of August, July, while we were waiting

6 for the result to come back it started to stir my

7 guard, I had become positive. My whole life was

8 thrown and we decided to have an unplanned holiday to

9 America, to Santa Barbara, where actually we had been

10 before where we knew friends and I was -- as we were

11 flying across the Atlantic I said to Bryan, "Actually,

12 they never gave me the result back", and he said, "Oh

13 yes, they did. You are positive. They told me", and

14 I thought that was ...

15 Q. They told Bryan that at an appointment that he had

16 gone to for his health?

17 A. Probably for his own, yes. They'd told him, not me.

18 Q. So you were in your 20s still?

19 A. Mm-hm.

20 Q. Your husband had been diagnosed with HIV, now two

21 years later you'd found out you were HIV positive.

22 You had been on your holiday. I think you'd just got

23 a dream job?

24 A. Yes. That was it. Because I thought, oh, I can't

25 have children, you know, the career -- you know, I was

1 at the Coventry City Records Office and at that time
2 if you wanted maternity leave, you had to have been
3 working with that company, I think it's changed now,
4 but at that time you had to have been working with
5 that organisation for so many years, so I was there
6 and I could have taken maternity leave had I got
7 pregnant. And once I got that inconclusive.
8 I thought, you know, I'm free to look -- I'm free to
9 look at other things in my life.

10 As it turned out, I was called to the -- I was
11 called in for some advice from the Shakespeare
12 Birthplace Trust because they were thinking of setting
13 up an archive conservation unit, and so I'd given them
14 some advice. But then when I found out that I might
15 be positive, I said, you know, I'll apply for the job.
16 So I applied for the job and I was interviewed just
17 before we went to America and, again, because of my
18 connections in conservation I had wonderful tours of
19 the Getty Conservation Unit in Los Angeles.

20 So when I came back it was like I had been
21 diagnosed with HIV but, you know what, I've got this
22 wonderful ... you know, these things happened that
23 took me out of not worrying about being HIV positive.
24 It was a new job. It was somewhere to focus and over
25 the next 12 years I set this conservation studio up

1 and set up the conservation there of these collections
2 of archives and I -- it was like my baby, I think,
3 looking back, you know. That was my baby that I'd
4 been denied.

5 Q. Can I just ask you about a conversation that Bryan had
6 had late 1985/early 1986 with doctors about, or
7 a doctor, about factor products. He was told
8 something particular about the factor products he was
9 going to be given.

10 A. Yes.

11 Q. What was that?

12 A. It must have been 1985, I think, because it wasn't
13 long after he was diagnosed, and I don't know whether
14 it was in Exeter or by the time we had come back to
15 Coventry, but he was told -- I have a feeling it's
16 Coventry -- he was told that there was a shortage of
17 the Factor VIII, of the old stock, and that they were
18 keeping the good stuff for the little boys, the boys
19 that hadn't been given or hadn't received HIV and
20 Bryan accepted that. He accepted it and I think
21 that's a mark of the man he was, that he -- but he was
22 put under that emotional blackmail, you know, and to
23 continue to take what potentially was old stock
24 infected blood products.

25 Q. You've said in your statement you believe that you and

1 Bryan were both used for research purposes.

2 A. I think that now.

3 Q. What is it that has led you to that conclusion many
4 years later?

5 A. Because I was, you know, Bryan was a haemophiliac,
6 a severe haemophiliac. He had been -- they knew that
7 he had been given HIV through his blood products and
8 I was a healthy young woman who was negative and I now
9 think, from what I'm hearing of evidence that's coming
10 out, that there may well have been -- I understand
11 there were studies on man to woman, how that -- but we
12 were never part of that, we had never known about that
13 and this is why I referred back to when I was thinking
14 about having a baby --

15 Q. And that conversation about monitoring?

16 A. -- about monitoring, that actually this was much
17 more -- I just thought it was incompetence at the time
18 but actually probably much more serious than that.

19 Q. You told us how after your diagnosis you threw
20 yourself into the job that you've been describing, but
21 Bryan's health around this time began to deteriorate
22 and he became less and less well.

23 A. I got that job in 1987. He worked for a while, yes,
24 because around -- he was still working, he still had
25 ambitions to work. He loved work. He wanted to work.

1 He had ambitions to --

2 Q. What was Bryan doing? What type of --

3 A. At that time he was running petrol stations, in places
4 in Birmingham, in Coventry, he worked for a major
5 petrol company and so he would work incredibly hard.
6 You know, they were operating seven days a week, 364
7 days of the year and some were night, some were open
8 24 hours and so he was going in, whenever the tankers
9 would come in to bring the petrol in, he would have to
10 be on duty to be there to ensure there was safe
11 delivery of petrol and diesel, and he was running
12 staff as well and that's what he did and he loved it.

13 But he had ambitions to run his own business as
14 well and particularly he was really interested in car
15 washing and car washes in petrol stations and had sort
16 of great plans to introduce that. He knew -- we also
17 looked at having a business. We looked at a business
18 down in Cornwall. He understood that the money that
19 you make in a petrol station isn't the petrol it's the
20 goods that you sell around it and so he really had
21 high ambitions for that.

22 But by 1989, he had -- I don't know why --
23 sorry, backtracking -- but I don't know why but he was
24 put on to AZT and I don't actually remember him being
25 ill but I know that he was given AZT, which was a very

1 first medication for HIV and it was hailed as a wonder
2 drug.

3 He hated it. He felt there was something not
4 right about it and I've since discovered he was given
5 megadoses as was the time and I actually think that
6 may well have contributed to the downfall of his
7 health. But certainly by 1989 he had developed
8 non-Hodgkin's lymphoma. He had developed a lump. So
9 in 1989 he had developed this -- which was said to be
10 part of the HIV condition.

11 Q. It was called AIDS-related lymphoma, colloquially?

12 A. It was also, as HIV, it was incurable and at that time
13 non-Hodgkin's lymphoma was incurable and he was told
14 you have basically got 18 months left to live, even
15 though he had been living -- you know, this will kill
16 you.

17 Q. He had to undergo a number of treatments for the
18 non-Hodgkin's lymphoma.

19 What treatments did he have?

20 A. He had radiotherapy at first. So in 1989 he started
21 with radiotherapy to the neck and it destroyed any
22 hair growth on that side of the neck. So he could
23 never grow a beard after that because his beard would
24 only half-grow, so he ended up -- he'd been for quite
25 a few years having a beard and so decided -- well, he

1 decided he had to. And then -- so that was in 1989,
2 and then that seemed to sort of work to a certain
3 extent.

4 We knew it was going to come back, we knew that
5 or so we were told, with all the knowledge around
6 non-Hodgkin's lymphoma and he -- in 1991 it came back
7 and he was -- I think it was '91 -- given chemotherapy
8 and he had to go through intensive, you know,
9 harrowing chemotherapy at the John Radcliffe Hospital
10 in Oxford.

11 Q. Around that time you'd transferred his haemophilia
12 care to Oxford as well?

13 A. Yes, because after I became HIV positive at Coventry,
14 the relationship there really -- it was untenable
15 really and we'd discovered Oxford and we'd discovered
16 this wonderful centre that was actually almost as
17 close we could have gone to all those years and it was
18 a good centre. There were social workers and there
19 were lovely nurses and it was -- and when Bryan had to
20 go into hospital into the John Warin Ward, the
21 haemophilia unit would come in and sort of support
22 you.

23 One of the things they had, there was a chair
24 that -- his friend that I mentioned that had died,
25 their family had bought a chair like a Parker Knoll

1 recliner for other patients to use, so they wheeled
2 this chair in so I could sit next to him, so it was
3 a much nicer unit.

4 Q. You relate in your statement, and this must be I think
5 before you transferred care to Oxford, around the time
6 he was having a biopsy on the lump that he'd found on
7 his neck, so probably late 1989, that he needed to
8 have a boost to his Factor VIII levels. What
9 happened?

10 A. That was in Coventry and that would have been at,
11 I think it was the Wonford it was called then -- it
12 might have been called the Coventry and Warwickshire,
13 but it was the main hospital in Coventry -- and he had
14 to go in for this biopsy and I went to see him
15 afterwards and he was quite -- well, dignified I would
16 say but obviously upset and he said that he'd had to
17 fetch the factor out of the cupboard and inject
18 himself, and I didn't understand what he meant.
19 I thought, oh, they just forgot you, but he knew in
20 his mind that they didn't want to touch him.

21 Q. The nurses didn't want to touch him?

22 A. No. Because he needed the booster, obviously. He had
23 Factor VIII to boost him before the surgery and he
24 needed that after the surgery and he had to fetch it
25 himself.

1 Q. And he had to inject it himself?

2 A. Inject it himself, which was a normal thing for his
3 home, he was used to home treatment, so he was used to
4 it. But it was the first time he felt that sort of
5 lack of care really or their fear. I mean, this is
6 1989 still, you know, so the fear that, you know, was
7 throughout even in the medical profession who should
8 really know better, though they were scared.

9 Q. In 1991, Bryan having been told that he probably
10 didn't have very much longer to live, he decided to go
11 on a road trip.

12 A. Yes.

13 Q. What can you tell us about that?

14 A. Yes. He decided to buy a Land Rover, a long wheel
15 base Land Rover, and kit it out. We had it kitted out
16 as a camper van and I made the cushions and I sewed --
17 saved a little bit of money, I made the cushions and
18 sewed the curtains and he took off on a trip to
19 Iceland that took in driving all the way to Scotland.
20 I can't remember the different -- I think it was
21 Shetland, the Orkney Islands, the Faroe Islands and
22 then into Iceland. That was the way it had to be and
23 then you had to get the last ferry out.

24 I couldn't take five weeks off work at that time
25 so I flew in to Reykjavik and we travelled around

1 Iceland. It was again, sort of, how he was. He
2 wasn't going to -- I think he was on AZT then
3 actually. He certainly was in between having the
4 radio therapy and it was then afterwards he had to
5 have the chemotherapy.

6 But when he came back he'd recorded that trip.
7 He recorded it on tape and he recorded it in a small
8 book that I had actually made and bound for him where
9 he's saying he's missing me, he's missing Clair, you
10 know, because I'd flown back the safe way and he had
11 to make that journey back. But when he came back he
12 was emaciated, he was ill. It was really the
13 beginning of the end for him.

14 Q. You've described that trip and the fact that he wanted
15 to do it and the way he did it as true to his spirit?

16 A. Yes, absolutely, yes.

17 Q. You've still got the log book and tapes at home.

18 A. Yes. I haven't heard them for a while but ...

19 Q. So when he came back late summer 1991 that was the
20 beginning of the end is the way you've put it in your
21 statement --

22 A. Yes.

23 Q. -- for Bryan. He had chemotherapy. He had surgery.
24 Did he ever get offered, did you ever get offered, any
25 counselling or psychological support?

1 A. No, but I do remember in the John Radcliffe Hospital
2 his consultant said to me once "and how are you", and
3 it just broke me because it was like I'm here being
4 strong, I have to be strong and, you know, it was like
5 chinking my armour to ask me how I was. He was
6 concerned but that was the consultant.

7 We didn't have the -- as I say, the Oxford, the
8 nurses and things -- the social workers were very
9 nice, very lovely, but we weren't getting what you
10 would class as, you know, proper psychological
11 counselling and support that we obviously needed now
12 looking back.

13 Q. Some time around this time, perhaps not long before
14 his death, Bryan asked about hepatitis C and whether
15 he had hepatitis C or somehow found out he had
16 hepatitis C; is that right?

17 A. No, the conversation went that, as far as I knew, he
18 didn't have hepatitis C, as far as I knew, and it was
19 only in recent years, we are talking seven or eight
20 years ago, that I found out through his medical --
21 going back to Oxford that he had hepatitis C.

22 His attitude was, you know, I've got AIDS.
23 I don't need to know anything else. That was it, he
24 was dying. That was the biggest -- HIV was just the
25 most horrendous thing to have and to have AIDS was

1 horrendous. Looking any further was -- that's how he
2 said it to me and I don't know whether he was ever
3 told and if he was told, he would have told me. He
4 would have told me. We didn't, sort of, have secrets
5 like that, so yeah.

6 Q. You nursed Bryan and cared for him during his dying
7 months. I know you wanted to talk about that, Clair.

8 A. Yes. It was -- you know, I was a young woman. I was
9 watching my husband become more and more emaciated.
10 He went through -- I saw his bravery as well.

11 In his final months, he was getting severe pain
12 in his jaw and it turned out the radiation he'd had
13 previously back in 1989 had actually destroyed his jaw
14 and that he had to undergo the most painful surgery in
15 Oxford, a wonderful dentist, actually, that I still
16 see to this day -- no, I don't, she's retired -- but
17 I continued to, but she -- so he went undergoing, you
18 know, painful operations while he was dying and, you
19 know, even in January, he died in the March, he was
20 still going through this.

21 And the other thing in the hospital I felt that
22 you needed someone -- you need someone in hospital
23 with you. You need someone at your side because, you
24 know, whatever work they are doing things go wrong.
25 Medicine wasn't delivered on time. His food wasn't

1 there. He needed me around there. He needed someone
2 to support him, to give him the love that he needed.

3 It was very, very frightening.

4 Q. There was a moment the two of you stood in your
5 kitchen and hugged.

6 A. Yes. We'd had -- we'd been having -- he was worried
7 for me, he was concerned about me, and he also said,
8 "I don't want to die. I'm too young". He said, "I've
9 got so much I want to do", and he was at this
10 point 34 years old -- 34, yes -- and he said, "I don't
11 want to die".

12 Then he said he was worried for me if he died,
13 you know, "What's going to happen to you", and I just
14 said, "It's okay, I'll be all right", and I don't know
15 whether I lied or whether I -- but I just -- it was
16 something he needed to hear and he died within a week.
17 I think he needed permission, if you like, to die.

18 You know, I ...

19 Q. That was 13 March 1993.

20 A. Yes.

21 Q. Briant died aged 34.

22 A. Yes. He was in -- he died late at night on a Saturday
23 evening and again sort of miraculous things happened,
24 that I was busying myself as I always did with my
25 own -- I was studying with the Open University,

1 I studied physics and that particular module was
2 around calculus, mathematics, and I was studying that
3 and so in the periods of time when Bryan was lying in
4 bed asleep, whatever, I'd sit at the end of his bed or
5 comfy in a chair and either read or in this case doing
6 an Open University course, and I think the doctors,
7 the consultants, became quite concerned for me because
8 I was looking, at those days you had to have a video
9 or watch television to look at the coursework, and
10 I said, "Can I use your room to watch the video about
11 calculus".

12 At that point I realised they'd become concerned
13 for me because I think what it was it was my mode of
14 survival to distract myself and the consultant came
15 in. I'd never seen him before and he said, "Do you
16 know he's going to die", and I said, "Yes, I've known
17 for a long time he's going to die". They said, "No,
18 he's going to die now. He's going to die in the next
19 few hours", and at that point, you know, we got hold
20 of his brother. He had to race from Nottingham. We
21 got hold of his parents. My mother turned up.
22 Everyone got to the hospital in time and just as he
23 was taking his last breath, but just before he was
24 dying, the nurses tried to take me out because he'd --
25 he'd wet himself and we didn't want him to be -- his

1 brother said, "We cannot leave him in that dignity",
2 so they were trying to to shove me -- I mean, quite
3 rightly, they were trying to make me go out of the
4 room but I wouldn't go and he was changed and at that
5 point his brother and I and his parents, you know,
6 held his hand while he took his last breath. It was
7 10.00 Saturday night.

8 That morning as I was helping him in the bed,
9 there was a magpie that came to the window and he
10 went, "One for sorrow", and by that evening he had
11 died and I was just numbed.

12 One of is his -- somebody took me back in the
13 car and I afterwards thought, "Oh my God". Afterwards
14 I was feeling who's going to be there for me? And
15 that was the trauma the beginning of trauma,
16 a traumatic time for me.

17 Q. You were about 30, 31?

18 A. I was 31.

19 Q. And Bryan had died and you knew you had the same
20 condition that had killed Bryan?

21 A. Yes.

22 Q. So how did you manage over the following years?

23 A. I thought I'm going to survive this, that I'm going to
24 have to stay as healthy as I can. So I sort of
25 engaged in more healthier -- I'd already started that

1 anyway, but being healthy, trying to understand.

2 Also I looked at this quite logically. I looked
3 at it that we were as HIV positive people, the
4 haemophilia community who were HIV, pioneers, we were
5 the pioneers of HIV. We were the test tranche of
6 people that were given this.

7 We don't really know what the long-term was and
8 I thought, you know, we don't -- so I had to sort of
9 put on a very positive level that, you know, maybe
10 I won't. And I was well. I mean, despite all this,
11 I was incredibly -- I was a 31-year old -- I was well,
12 I had no symptoms, except for the mental health
13 issues, and I thought if you -- logically, as my brain
14 works, is that if you tell someone they're going to
15 die and then you ostracise them from society, which
16 was happening to the HIV community, and you take away
17 their sexual needs, their rights and their
18 reproductive needs, then, you know, that's not a great
19 recipe for life, and I recognise that on a sort of
20 intellectual level and thought, you know what, I'm
21 going to sort of mitigate those and live as best as
22 I possibly can. I was doing yoga. You know, I just
23 lived positively, I tried to eat well.

24 That wasn't always the case, you know, but
25 that's how I felt and for many years that support and

1 helped me and again I threw myself back into my work.

2 I gave my first ever presentation at a conference the

3 following year and I, again, carried on.

4 Q. You were working at the Shakespeare Birthplace Trust

5 and you returned to work there.

6 A. Yes.

7 Q. Doing work conserving Shakespearian folios?

8 A. Shakespearean archives and of Stratford-upon-Avon. So

9 it was sort of anything back to the 12th century,

10 basically, which was what my skills were and I -- it

11 was a wonderful job and it was a very dignified and

12 very serene world that I -- privileged, if you like --

13 world that I worked and lived in and the people

14 I worked with, there were very few people I confided

15 in, in fact, probably one or two at work. They didn't

16 know. Again, when Bryan died and people all assumed

17 he died of cancer because that's what I told them he

18 died of. So I had the sympathy around cancer.

19 I could never have told people that he died of AIDS

20 and it's only in recent years that I'm beginning to do

21 that. It was such a stigma.

22 So most people didn't know, you know. I had,

23 you know, letters. I've got letters of the time of

24 condolences for the loss of my husband which, to this

25 day, are very sweet and -- I'm trying to think of the

1 word -- consoling for me, how people respected me and
2 how they said how I'd been resilient over the years
3 and how they praised me for my courage kind of thing.
4 So it was nice. There was that nice world that I went
5 back into.

6 But I was hiding a truth. I was hiding, you
7 know, my own health and my own issues and, you know,
8 the mental anguish that goes along with having HIV in
9 a world that's so hostile, because we're talking about
10 hostility.

11 Q. Having focused on your work and I think you said there
12 came a point on which you embarked upon a post
13 graduate course, an MA course --

14 A. Yes.

15 Q. -- which you were very proud to be doing.

16 A. Yes.

17 Q. There came a point at which your health gradually
18 began to deteriorate.

19 A. Yes.

20 Q. What kind of problems did you experience? What
21 physical health problems?

22 A. Around the 2000s, early 2000s, I started to develop
23 skin problems and I'd also -- I didn't want this to
24 happen. You know, didn't want to admit anything was
25 happening because it was frightening and so I probably

1 just carried on. When I was doing my post graduate,
2 it was a position -- it was studying at the V & A, the
3 theatre museum within the V & A, and I was -- it was
4 a mid-career development, if you like, that I would
5 be -- that would then led me on to many, many better
6 ways, lead me -- advance my career.

7 So when I started to become ill, I didn't want
8 to admit this illness and I was becoming more thinner.
9 I was hiding the fact that I was HIV from my tutors
10 from the course because, again, it wasn't something
11 you discussed. But eventually I had to tell them what
12 was happening to me.

13 I got so -- I'm trying to think of what -- I was
14 just basically the walking dead, if you like. I was
15 becoming more and more ill and I ended up having to
16 take time out of it, sort of admit, look, I'm not
17 well, I need to take time out of it. And during that
18 time I was admitted within five days into the Royal
19 Free Hospital and I had what was PCP, which is
20 pneumonia, which is an AIDS-defining illness. I was
21 told if you don't come into hospital, you're going to
22 die and then I also developed what was CMV,
23 cytomegalovirus.

24 Q. It's a brain infection.

25 A. A brain infection. It was an infection that can go

1 into the eyes and many people did and they went blind.
2 I was very fortunate it went into my brain, I was
3 told, and not my eyes, that I didn't become blind.

4 After that, I was in hospital for many, several
5 weeks and then I was eventually sort of going into
6 a respite into the Mildmay Hospital which is in East
7 London, which was the AIDS kind of hospital. It was
8 all so very, very frightening, it really was.

9 The point that I was -- something happened to me
10 just before I was going into hospital, and the
11 consultant at the Royal Free said to me, "Clair, if
12 you do not come in, you will die" and I sort of
13 shrugged my shoulders. It was kind of like I really
14 didn't care. You know, I'd gone to that stage that,
15 you know, I'd lost everything so -- I'd lost the sort
16 of spirit, you know, to live but, you know, again
17 I was fortunate that it was caught at the right time
18 and I began to recover again.

19 Q. You described at that point in time your life falling
20 apart is the phrase you've used in your statement.

21 A. Yes.

22 Q. You'd been resistant to/reluctant to take any form of
23 anti-retroviral medication?

24 A. Yes.

25 Q. Was that in part because of the experiences Bryan had

1 gone through?

2 A. Absolutely, because I had seen what AZT had done to
3 him and I was watching the medication was doing to
4 other people and I just thought while I'm healthy
5 which I thought -- I mean, I was healthy. I was
6 incredibly healthy until -- I thought it was maybe
7 until the early 2000s and I thought it was just the
8 course, you know, it was a bit tough on me.

9 I thought maybe I just need to have a rest
10 because I was living in London at that time. I was
11 travelling on the Piccadilly Line down to South
12 Kensington every day and it was quite intense and
13 I thought it was really just that and all I really
14 needed to do was kind of have a bit of a rest but it
15 was more serious than that.

16 Q. You had -- you'd told your consultant, Professor
17 Johnson, that you'd only be willing to have that
18 medication at the very last moment that it became
19 absolutely necessary and what did she say to you?

20 A. This was the last moment, basically, "You're going to
21 die. You know, you will die. You've got to go into
22 hospital. We've got to sort this out", and that's
23 when I went on to medication.

24 Q. The experience of being on the AIDS ward in the Royal
25 Free Hospital?

1 A. Yes.

2 Q. You found that experience demonstrating to you that
3 there was still stigma still discrimination, even on
4 an AIDS ward, a specialist ward in a hospital?

5 A. Yes and particularly me as a woman, as a woman,
6 a white woman, it was assumed that I was a drug user
7 or I was a prostitute. There was assumptions there
8 and I didn't want to have to sort of explain who
9 I was. I shouldn't have to, where, you know --
10 because the implications of saying you are a drug user
11 they assumed I was taking drugs, which I wasn't.
12 I didn't have a problem with drugs. I wasn't a drug
13 user and I felt -- I was at the end of some abuse.

14 One of the nurses just screamed at me and
15 shouted at me, you know, and I just thought how can
16 you treat people like this? You know, oh obviously
17 distressed, obviously traumatised and dying, so
18 I wasn't -- it again fed into my fears around being in
19 a hospital and being on my own and it took me back
20 again to what it was like that Bryan had me there at
21 the hospital, he had me caring for him. I didn't have
22 anyone caring for me in the hospital.

23 Q. When you went on to the medication, that treatment
24 programme, what was that like?

25 A. It was -- the side effects were awful. There was

1 diarrhoea, then you had to take medication to control
2 the diarrhoea, my stomach became extended so I looked
3 like I was pregnant, which was an even bigger insult.
4 So there was changes. I remember saying, you know,
5 I feel my stomach, you know, was too big. It was
6 like, "Oh, it's because you are eating healthy". No,
7 it was the side effects of the drugs. It's known that
8 Kaletra it was -- and later on I developed and have
9 what is incredible fat around all my organs, which is
10 a dangerous thing to have.

11 Yes, you know, I just didn't want to be on this
12 medication but, you know, it was a question of take it
13 or die.

14 Q. You started to improve a little and you wanted to
15 resume your post graduate course?

16 A. Yes.

17 Q. But I think you became ill again and had to go back
18 into hospital.

19 A. Yes. Despite all the side effects and the medication,
20 you know, I sort of had this kind of like, right, back
21 into life, back to life and I think that's what
22 happens when you have a life when you are so close to
23 death. I think you really -- and you come out of it,
24 you really -- well, I did -- experience this kind of,
25 you know, that you're alive, you want to make the most

1 of that life. Again, I loved what I was doing.
2 I loved the work that I did. It was great. I wanted
3 to continue that course, so I went back.

4 But again whatever was happening, I became ill
5 again and I was given deadline after deadline instead
6 of just stopping the course and I ended up in
7 a hospital. I was seriously all through July and
8 August of 2005 and in September of 2005 I went back
9 into the Royal Free for a period I think it was
10 either -- it was three weeks I was in there recovering
11 again. But this time I had had a mental breakdown,
12 I had. Everything had just become just too much. So
13 yes.

14 Q. What happened in terms of your own physical health, in
15 terms of your own mental health? Since that time from
16 when you came out of hospital again, what can you tell
17 us about how your health has developed since then?

18 A. I was right down to about 6 stone. I'm small anyway
19 but I was really, really emaciated and when I came out
20 of hospital, I started to improve, my health was
21 getting better, and I moved back eventually back to
22 Warwickshire to be close to my home, close to my
23 mother who had been an enormous strength and support
24 and my only support, actually. She was elderly then,
25 you know. She's 91 now. She was in her late 70s and

1 80s supporting and helping me.

2 I was fed up -- I was fed, you know, given good
3 meals and I was sort of nursed back to health and
4 I started to sort of gradually get back to the point
5 that, you know, I became much more healthy again
6 because I was taking it easy, I wasn't going back into
7 anything that was too strenuous at that time.

8 Q. You continue to take anti-retroviral medication to
9 this day?

10 A. Yes.

11 Q. And presumably for the rest of your life?

12 A. Well, that's it. HIV it's not curable. It's only
13 maintained by this medication that is actually in
14 itself potentially -- you know, we're constantly being
15 checked. I have five appointments this week that I'm
16 going to, to look at your parathyroid, to look at your
17 kidney function, to look at, you know, because of
18 problems that are associated with HIV, the long-term
19 living with HIV and also the drugs that we have been
20 taking.

21 For me, I wasn't taking many of the earlier
22 drugs so I didn't -- you know, so -- but those drugs
23 have had an effect themselves and we don't know the
24 long-term effects, you know, and I don't know how long
25 I will live but if I have to take drugs for the rest

1 of my life then ... that's something I need to just --
2 I try not to think about, you know.

3 Q. Your statement describes very powerfully the stigma,
4 the discrimination, that you found that you
5 experienced, that Bryan experienced throughout the
6 second half of the 1980s, throughout the 1990s?

7 A. And to this day.

8 Q. I was going to ask you really to describe that in your
9 own words and also to say the extent to which it's
10 different if at all now.

11 A. I think we live in a different world and my attitude
12 towards telling people has changed. We were
13 encouraged to be quiet. We were told to keep it quiet
14 and even amongst families, you know, not to tell
15 members of your family. We were encouraged by --
16 encouraged to do that but also we felt, I personally
17 felt I had to keep it quiet because of what I was
18 seeing and the destruction that other people had at
19 the hands of people finding out that they were HIV
20 positive, and the damage to their careers, the damage
21 to their family units, and so I took the attitude, and
22 it was that I had to just be silent. I was silenced,
23 basically, and to be silent about it.

24 But again being sort of pragmatic about it,
25 I had to think of it as sort of like as

1 a professional, you know, in a way a professional may
2 have to hide confidences about themselves and it was
3 only after I met a woman when I was in Greece
4 on holiday and she wouldn't tell us what she did for
5 a living and in the end she confided in me that she
6 was a police officer. She thought, you know, if
7 I tell people I'm a police officer, I will get all
8 sorts of stick. So I kind of thought, "Ah, that's how
9 I have to live". You take this as people don't need
10 to know and it's only on a need-to-know basis did I
11 tell people.

12 Actually, I don't want my business discussed,
13 you know, and to be defined by that, she's the woman
14 with AIDS, she's the woman who's HIV positive.
15 I didn't want that. But on the other side of that, it
16 was the fact that we couldn't ... you know, you
17 really, really led this dual double life, if you like,
18 but as the years have gone by and I think particularly
19 with this inquiry and because I got involved more with
20 campaigning, I felt our voices aren't being heard.
21 HIV voices are not being heard and I felt that I'd
22 started to do pieces with newspapers but saying, "Oh,
23 don't mention where I live. Don't mention who I am.
24 Don't mention my name", and I gradually sort of
25 realised that actually the world has changed to

1 a slight -- slightly but, more importantly, is my
2 attitude is that if I tell somebody and they reject me
3 that's their problem, you know, and that is how it has
4 to be, that if I'm shown any sort of discrimination
5 I will come back at them. You know, I won't allow it
6 to happen whereas before I was so frightened and I was
7 so, you know, that's how it was.

8 MS RICHARDS: Clair, I am going to ask you next to talk
9 about your dealings and Bryan's dealings with the
10 Macfarlane Trust but you have been giving evidence now
11 for over an hour and wondered whether this, sir, might
12 be a convenient moment to take the morning break?

13 SIR BRIAN LANGSTAFF: I think it would be a convenient
14 moment to take a break. I am sure you could do with
15 one following what you have been telling us. We will
16 take a break for half-an-hour.

17 Can I just say something which I will say to all
18 witnesses where there's a break in the middle of their
19 evidence and that's this: please don't talk about your
20 evidence either what you have already said or what you
21 are yet to say, to anyone, whoever they are, lawyer,
22 member of the press, member of the public, me,
23 Ms Richards, anyone.

24 You can talk about anything else you like.

25 A. I'll talk about the weather, okay, thank you.

1 SIR BRIAN LANGSTAFF: It's just 11.10. Shall we say
2 11.45.

3 **(11.09 am)**

4 **(A short break)**

5 **(11.48 am)**

6 SIR BRIAN LANGSTAFF: Yes, Ms Richards.

7 MS RICHARDS: Clair, I am going to ask you next, as you
8 know, about your dealings, yours and Bryan's dealings,
9 with the Macfarlane Trust. What was the Macfarlane
10 Trust?

11 A. It was the organisation set up by the Department of
12 Health in 1988 to support haemophiliacs and their
13 families who had been infected with HIV. It was -- it
14 had -- the board of trustees of appointed by the
15 Department of Health and also by The Haemophilia
16 Society.

17 Q. You at some point found out about it you think either
18 through The Haemophilia Society or possibly through
19 your local haemophilia centre?

20 A. Yes.

21 Q. Your first application to the Macfarlane Trust was
22 because you needed money because you'd purchased
23 storage heaters to keep warm.

24 A. Whether that was the first I don't know but, yes, we
25 we'd purchased storage heaters. We lived in this

1 house was on the edge of a village and we needed
2 storage heaters. There was no other heating; so yes.

3 Q. Your debts were beginning to rise and so you made an
4 application or Bryan I think at that time made an
5 application to the Macfarlane Trust for a grant to
6 cover the cost of those storage heaters?

7 A. Yes.

8 Q. You received or Bryan received a letter from the Trust
9 suggesting that you needed to undergo debt
10 counselling?

11 A. Yes.

12 Q. What was Bryan's response to that?

13 A. Bryan wrote a letter, handwritten letter back, as it
14 was the process in those days, and he expressed quite
15 clearly that we didn't have a problem with debt that
16 needed -- we had a problem because of what had
17 happened to us, that we'd accumulated debts because of
18 the cost of living and his own health presumably by
19 that time and it wasn't -- we did not have a debt
20 problem.

21 Q. You've related in your statement a conversation you
22 had. You called one of the social workers at the
23 Macfarlane Trust in desperation because you needed
24 some financial support.

25 Can you recall that particular conversation?

1 A. Yes, I can recall it. I remember where I was, where
2 I was sat at the time. He said to me, basically, they
3 were going to give me the money but he said, "There
4 ain't no more where that's coming from", emphasising
5 the "ain't".

6 Q. How did that make you feel?

7 A. It was like again a stabbing. I was shocked. I was
8 utterly shocked the way I was spoken to and the way
9 I was treated, given this was the organisation set up
10 to support and help us.

11 Q. You managed to get some small grants for assistance
12 with things like a cooker and other essentials?

13 A. Yes.

14 Q. How did you and Bryan find at that time the
15 application process?

16 A. Lengthy, you know, complicated, not in any way
17 supportive. Unnecessary, in our minds, bureaucracy in
18 terms of having to get three quotes or whatever it was
19 at the time when things were needed desperately, and
20 the delay that it took, and often these would then go
21 to a meeting that was set some several weeks down the
22 line, so when you are desperately in need of something
23 it was unnecessarily difficult.

24 Q. You've said in your statement that what bothered you
25 the most was how they spoke to you. They seemed to

1 forget that they were dealing with desperate and dying
2 people.

3 A. Yes, absolutely. Yes, it's as if we were, you know,
4 weren't entitled to apply, as if we were, you know --
5 as if we were dirt, basically. That's how -- it
6 wasn't appropriate language and approach that you
7 would expect from an organisation that was set up to
8 support you.

9 Q. As you've told us, Bryan's health started to decline
10 with the diagnosis in late 1989 of the non-Hodgkin's
11 lymphoma and the radiotherapy and the knowledge that
12 Bryan would have to stop working and there came
13 a point where you, from I think a phone box at the
14 hospital in desperation, phoned the Macfarlane Trust
15 and you spoke to John Williams, who was then the
16 administrator.

17 What can you recall about that conversation?

18 A. Bryan had been told he had the non-Hodgkin's lymphoma.
19 He'd been told he had probably 18 months left to live
20 and he needed to undergo therapy radiotherapy and we
21 knew that he had to give up work.

22 He was still working and although while he could
23 take off a certain amount of sick leave in those days
24 it was a limited amount of sick leave he was
25 statutorily entitled to but after that we would be

1 desperate for -- to keep the basic household income.
2 We suddenly recognised -- this was one of my main
3 concerns. So I rang John Williams, and it was a phone
4 box in the hospital, and I told him this. I said, you
5 know, "He's ill. He needs to -- he's going to need to
6 give up work and we need to sort out the financial
7 situation", with, you know, hoping that they would
8 give us some grants to help us along the way, which is
9 what they were set up to do.

10 Q. What was John Williams' response?

11 A. He was very matter of fact. He was a very matter of
12 fact man and he just said, "Yes, okay, I will be back
13 in contact with you shortly", and there was
14 a conversation, it may have been a later phone, it
15 might have been a later phone call, that I stressed
16 that he needed to give up work but he was going, "Oh,
17 yes, they do like to work", this kind of upper -- I
18 said, "No, he likes to work but he actually needs to
19 give up work, you know, he's too ill".

20 True to his word he then came out -- he then
21 arranged a meeting to come and see us, but it was --
22 this was November by this time so the months in
23 between, the couple of months in between, were quite
24 desperate for us because we didn't know what was going
25 to happen.

1 Q. You described you and Bryan both being stressed out in
2 the intervening months?

3 A. Yes.

4 Q. Worrying about the mounting bills and the fact that
5 Bryan could not work.

6 A. Yes.

7 Q. What do you recall about Mr Williams' visit to your
8 house?

9 A. It was a dark winter's night, it was November, I think
10 it was the end of November, and he arrived in the
11 evening, and we lived in a -- it was a detached house
12 on the edge of a village and he came in and his first
13 remarks were "Rather large, isn't it", which I just --
14 it actually wasn't rather large. It was a two
15 bedroomed, two up, two down, detached house on the
16 corner of the village but it's the way he said it, as
17 if that -- what does that mean? We shouldn't be
18 having a nice house? We don't -- I don't know. But
19 it was -- it struck in my mind as a very strange thing
20 to say.

21 Q. What did he tell you was on offer from the Macfarlane
22 Trust in terms of assistance?

23 A. He said that he would take away the mortgage by way of
24 an investment in equity in our home and that the Trust
25 would then like buy equity, that meant that they would

1 have our house valued and they would give us the money
2 that would be for the mortgage and then they would
3 take X per cent, as it turned out 58 per cent I think
4 it was, of the home in exchange.

5 Q. So they would advance you the money to pay off the
6 mortgage?

7 A. Yes.

8 Q. They would put a charge on yours and Bryan's house for
9 the value of that?

10 A. Yes.

11 Q. And the percentage based upon the valuation would be
12 a percentage that they would reclaim from you whenever
13 the house was eventually sold.

14 A. Yes.

15 Q. It could be if the house had gone up they would claim
16 more than they had originally loaned you, they'd claim
17 a percentage of the increase in value of the house; is
18 that right?

19 A. Yes, and they also said they could lose out that way
20 as well but, actually, the house prices were going up
21 but it seemed to be a sort of -- I don't know what
22 would you call it. It wasn't what we were expecting.

23 Q. What was it you and Bryan had actually wanted?

24 A. To get some support on a monthly basis to help us with
25 the bills. It was the household bills we needed to

1 and keep the roof over -- the mortgage being a major
2 piece of that, was to keep the roof over our head for
3 a period. We knew he was going to die, you know, and
4 to just deal with it as that. But that wasn't an
5 option. There was no discussion. This was the
6 option.

7 I do not know whether you would call it an
8 option if there's only one but this was it, this was
9 the deal, take it or leave it, basically.

10 Q. You have said that there was no negotiation and the
11 Macfarlane Trust knew that you couldn't go to your
12 building society and say, "Sorry, my husband is dying
13 of AIDS. We can't make the mortgage payments".

14 A. Yes. It was not an option in those days. This is
15 1989, probably not an option now, but it certainly
16 wasn't an option then. There was no way we'd have
17 done that.

18 Q. Did you feel you had any choice whatsoever?

19 A. I had no choice. I had absolutely no choice.

20 Q. You had to go through then an application process for
21 the loan?

22 A. Yes.

23 Q. Was the fact that you filled out the application form
24 for the loan something that was raised with you
25 subsequently by the Macfarlane Trust?

1 A. Yes.

2 Q. In what way?

3 A. Until very recently, "You knew what you were doing.
4 You applied -- you came to us and asked for a loan for
5 this charge upon your property", and we didn't -- and
6 there was an application process because that was the
7 only option so we had to go through an application
8 process but no.

9 Q. You put it this way in your statement. I am going to
10 read out two sentences from your statement and want to
11 see if this is something you stand by now:

12 "We were forced to make the application because
13 there was no other option. Bryan was dying and we had
14 very little money coming in. The Macfarlane Trust put
15 a man who was dying of AIDS, he had been told he had
16 only 18 months to live, under extreme duress to sign
17 over our home to keep a roof over our heads."

18 That's a powerful way of putting it but is that
19 how you think about it?

20 A. That is correct, yes. That is absolutely correct. We
21 had ...

22 Q. Having put in the application in the circumstances in
23 which you describe, was it dealt with promptly?

24 A. No. It then became delayed and delayed, and there
25 were arguments because they had to value the house and

1 obviously they were valuing the house at a valuation,
2 rather than a selling point it was a valuation at --
3 so it was a lower valuation so that they were getting
4 more, if you like, but the deal at the end, whenever
5 the end was going to be, which is on our death, would
6 have been to sell it, a sale.

7 So there was arguments about the value of the
8 house and how -- because there were different
9 valuations on it. It was a unique little property, as
10 they would say, as the estate agent said, and so there
11 was -- so, yes, there was that but also they just
12 delayed the process, just the whole process, the usual
13 slow process of the Macfarlane Trust and how they
14 operated.

15 Q. Did you and Bryan chase them?

16 A. Yes, I chased them. I chased them, I wrote letters
17 and said, "Do you know what's happening", and
18 eventually it was settled and it was June of 1990 when
19 it was drawn up.

20 Q. You described that in your statement as nine harrowing
21 months after your initial approach for financial
22 support.

23 A. Yes, and it wasn't the option that we -- it wasn't the
24 outcome that we wanted but it was the only option. It
25 was the only option.

1 I didn't agree that they should be profiting
2 from -- the charity set up to support haemophiliacs
3 and their spouses should be profiting from people
4 dying. It made no sense to me and I didn't think was
5 legal. I don't know, but it didn't seem -- it
6 certainly was immoral and I actually I said that on
7 several occasions then and since.

8 Q. We'll come back to the subsequent history in relation
9 to the loan but you continued from time to time to
10 make or Bryan made applications for small grants. So
11 he made an application for a few hundred pounds for
12 some gym equipment that he could use at home?

13 A. Yes.

14 Q. Why was that important to him?

15 A. You know, prior, some years earlier he used to go to
16 a gym at a friend's house, he had his own gym, and he
17 really loved it. He didn't want -- he was quite puny
18 in his stature and he didn't like being in a gym and
19 he found kind of -- he found that it was better to do
20 it in a gym in your own home, and there was this thing
21 out at the time, this piece of equipment called
22 multi-gym and you assembled it and had it in your
23 living room and it did lots of things, being able to
24 do weight training, and he felt that that was just
25 what he needed in order to build his body up, and he

1 really thought that they would you know help him with
2 that, not only for -- also for his health, for his
3 well being.

4 Q. Again, you put it in your statement this way:

5 "This would allow him to build up his strength
6 without the embarrassment of attending a public gym
7 with his puny body", that being the consequence of the
8 stage the illness had reached?

9 A. The illness but I think also he was a thin -- through
10 his haemophilia as well he had actually -- because he
11 was born in 1958, he'd got quite -- he'd had many
12 bleeds in his legs and so he was quite puny and
13 I think that -- that's the only word I can describe
14 but also the health, the illness had brought that on
15 as well.

16 Q. He felt it would also allow him to manage his bleeds?

17 A. Yes, he knew how to manage his bleeds, you know, of
18 all people.

19 Q. What was the Macfarlane Trust's response to that
20 application?

21 A. That it's not good for haemophiliacs. That they --
22 I can't remember -- I think they might have had advice
23 from a doctor or something that, no, it's not a good
24 idea for haemophiliacs, as if he was a child who
25 didn't know what he was doing.

1 Q. What was Bryan's response on receiving that rejection?

2 A. He was devastated. He cried. There were very few
3 times that Bryan cried. He cried and he felt that
4 his -- his autonomy was taken away from him. His own
5 decision-making as a man, being able to decide, "This
6 is what I want to do and actually I'd quite like a bit
7 of help if you can give me this piece of equipment",
8 that actually would help him and his body image, if
9 you like, I think you'd call it now, would have --
10 and, yeah, he was devastated.

11 Q. You and Bryan continued to make applications for small
12 amounts of money for things like respite care and
13 transport costs and so on.

14 What was the process? What did you have to get
15 in terms of supporting evidence, not just the quotes
16 but medical evidence and so on for the applications?

17 A. Quite often you had to get medical evidence, which
18 meant going to a, you know, a very busy doctor,
19 consultant, and ask them to legitimise, if you like,
20 us having anything we needed.

21 It was often just absolute basics that a doctor
22 shouldn't have to -- it should have been just general
23 knowledge this is what you needed, whether it was
24 a washing machine to wash clothes that probably, you
25 know, through you know having to do laundry from night

1 sweats that he might have had, on a more regular
2 basis, just unbelievable red tape that we went ...

3 Q. I think at one time, perhaps this was a little later
4 on, but at one time the Macfarlane Trust made
5 a complaint about your HIV consultant because a few
6 weeks had elapsed between them asking for a piece of
7 information and the information being provided by
8 a consultant, as you say a busy consultant, and they
9 complained about her.

10 A. Mmm. It was one of the trustees of the board actually
11 happened to work at the Royal Free and she had been
12 trying to help me in some way by getting this
13 information. I didn't realise it was happening
14 because I was actually very ill at the time, but in
15 doing so, the Chief Executive took it upon himself to
16 make an official complaint about my HIV consultant.

17 I did not know anything about this but she
18 mentioned to me like in passing, like yes you've had
19 a complaint made against her. That's a serious thing.
20 It was not on my -- it was not something I'd asked him
21 to do. He took it upon himself to make a complaint
22 about actually a top consultant in the HIV world
23 because she hadn't filled a piece of paper in for him
24 in time.

25 Q. You have explained in your statement about some of the

1 early *ex gratia* payments that were made. You've
2 talked about the £20,000 that was given as *ex gratia*
3 payments to haemophiliacs with HIV in 1990. You
4 didn't receive that sum.

5 A. No.

6 Q. What you've said in your statement is that the Chief
7 Executive Officer, subsequently, of the Macfarlane
8 Trust had said it was only given to haemophiliacs.
9 You have said you don't believe that to be true.

10 A. Oh, I've since found out that it was actually given to
11 Eileen Trust, who were recipients of HIV through blood
12 transfusion, and so it wasn't just to haemophiliacs as
13 the Chief Executive had told us.

14 Q. And then in consequence, you've said in your
15 statement, of the 1991 HIV litigation settlement Bryan
16 received a sum of £32,000. That sum was calculated on
17 the basis he was married but without children.

18 A. Mm-hm.

19 Q. You I think only found out about your own eligibility
20 for Macfarlane Trust payments from The Haemophilia
21 Society?

22 A. It was part of the -- I think that's how we found out.
23 I think that was the general source of information,
24 unless it was the hospital, more likely The
25 Haemophilia Society because I think we were getting

1 their newsletters.

2 Q. Although you were married you were classed as a single
3 person for the purposes of calculating the payment?

4 A. Mm-hm.

5 Q. Did you ever understand why?

6 A. I never really questioned it, to be honest. It's not
7 until years later I thought, "Hang on, why was my
8 husband a married man and I'm a single woman attached
9 to him as a married man?" I didn't understand it and
10 so it was a lesser amount of money, but it was also an
11 insult at the time. I felt that, you know, my husband
12 was being given money because he hasn't got children.
13 We don't have children, you know, it was a double
14 whammy, we didn't have children because of the HIV.
15 You were literally that generation when we got
16 married, that's when it hit us, the HIV, so we hadn't
17 had children prior to this and so that was an insult.

18 Q. After Bryan's death, there came a point I think in
19 about in 1995 or thereabouts where you wanted to move
20 house and you made contact with the Macfarlane Trust.

21 I just want to show you a handful of documents
22 from your file.

23 The first, please, Paul, to put on screen is
24 1589003.

25 This is a letter from the Macfarlane Trust, not

1 sure who it is to but it's about you, 29 March 1995.
2 If we look at the second paragraph we can see you are
3 described there as hoping to be able to sell the
4 house, buy something around the same price in
5 Stratford. It's noted that your earnings around that
6 time gross were about £15,000 and then it says:

7 "As you know, she pays no rent to us in respect
8 of our share of the property ..."

9 How does seeing that in print make you feel
10 about the charge that was on your house?

11 A. That was it. It was taken away. They basically
12 invested into our home.

13 Q. If we could have the next paragraph, please, Paul.

14 It says someone had discussed with you the
15 possibility of an ordinary commercial mortgage instead
16 of transferring the equity, various calculations there
17 about the kind of mortgage you would need to raise.
18 There's a reference there to the Macfarlane Trust's
19 original investment. Then it says this:

20 "This assumes that you could find a mortgage
21 company willing to advance a sum nearly four times
22 [your] salary."

23 Then could we have the next paragraph, please.

24 This is what's said about your response:

25 "She [that's you] is adamant she is not prepared

1 to take on a mortgage and that if this is the only
2 option open to her she will stay put. This is said by
3 her in a semi-threatening way, i.e. 'If you don't
4 agree to transfer the loan you won't get your money
5 back anyway'."

6 Do you regard that as an accurate
7 characterisation of the discussions that were going
8 on?

9 A. I think that was a show of the power that they had
10 over me, and they were talking to someone, I don't
11 know what the date is but it's less than two years
12 since I lost my husband, and it showed the attitude
13 towards me.

14 Q. Did you think you were being threatening in being
15 unwilling to take on a mortgage?

16 A. No. I just made them the fact that, "This is it. I'm
17 stuck here. I'm stuck here".

18 Q. Then if we just have the last paragraph on this page,
19 please, Paul.

20 There's reference there to a loan agreement. It
21 shows quite clearly that:

22 "Repayment of the loan will be required
23 [emphasis in the original] upon sale of the property."

24 Then if we can go over the page, could we have
25 the first paragraph (a) highlighted. Two options

1 identified:

2 "The first is we require repayment of the loan
3 on the sale of the property and refuse a further loan.
4 We could then attempt to arrange a mortgage with the
5 Nationwide, although I suspect they would balk at
6 a four times salary multiple."

7 Then this:

8 "Given this woman's poor money management track
9 record, this [that's presumably the refusal of
10 a mortgage to you] would not be a bad thing."

11 What do you say about that option?

12 A. Well, it shows the -- to me, it shows the contempt
13 that they held me in again as a woman living with HIV
14 grieving for a dead husband and this is how they see
15 me, not understanding, having a complete lack of care
16 or understanding of the situation that we were in and
17 they are able to talk to each other.

18 I don't even know who the letter is to but this
19 is how they spoke about beneficiaries.

20 Q. Then, Paul, could we just have option (b). Option (b)
21 is requesting repayment of the loan on sale of the
22 property and offering you a further loan:

23 "This should be offered on condition that all
24 costs are borne by her especially in view of the loss
25 which we would suffer ..."

1 A. Mm-hm.

2 Q. What's your view of that characterisation of the
3 second option?

4 A. Again, it seems to be that they are more interested in
5 their investment, their speculation on the property
6 market, and not in -- the language to me it talks
7 about how they hold me, how they think about me.

8 Q. Then you have referred in your statement to a letter
9 that John Williams sent to trustees and I think we
10 will just have that up on screen, please.

11 Paul, it's in 1589002. If you could put that up
12 on screen and then it's page 101. So it's towards the
13 end of that tranche of documents, please.

14 I think this is the letter that you quote in
15 your statement. If we could have the third paragraph
16 beginning "I'm afraid" highlighted:

17 "I am afraid the lady [that's you, Clair] wants
18 to eat her cake and still have it. She conveniently
19 forgets the rent-free living she has enjoyed for seven
20 years. It is not true that our decision prevents her
21 from moving. It may well prevent her from buying
22 outright so that she can continue to live rent-free,
23 but that is not really our concern."

24 How does seeing that letter which you refer to
25 in your statement make you feel?

1 A. I obtained that letter through data protection some
2 years ago and that's when I realised just how -- the
3 contempt that they had had for me in those years when
4 I was, you know, grieving, living with HIV myself,
5 traumatised and this is how they treat me. It was of
6 their making. It's their making, the equity loan. It
7 was the only option and so then they continued to beat
8 me -- it was like used to beat me with a stick every
9 time I tried to sort it out. There was never any
10 support and help.

11 The attitude was -- obviously seeing the
12 internal documents and how they treated me, that
13 that's actually how they saw it. It was an investment
14 that they wanted to return.

15 Q. Can we just have the next paragraph, please, Paul.

16 Again, you have quoted this in your statement
17 Clair:

18 "This is about the fifth go/stop on sale since
19 her husband died. If account was taken of this
20 mortgage subsidy or even to the lost interest by the
21 Trust this couple [Bryan of course was dead by this
22 time] would rocket to the highest paid beneficiary.
23 In my letter, please note I have expressed my doubt
24 the trustees would consider any further concessions.
25 I believe that if the current offer (which is really

1 quite generous and was made with justifiable
2 reluctance on the part of most trustees) is not taken
3 up by the end of February deadline, our future policy
4 should definitely be the contract -- no more, no
5 less."

6 You were trying to, I think, to move house, to
7 move out of the home in which your husband had died,
8 to make a little bit of a fresh start.

9 A. Yes.

10 Q. How did the Macfarlane Trust's response to your
11 requests to them impact upon your life at that time?

12 A. It was preventing me from moving on. So what I wanted
13 was a dialogue about the actual -- the origins of that
14 charge on my property and to try to come to some
15 resolution. I was shackled and I've used that word
16 "shackled" to this Trust. I couldn't move.
17 I couldn't develop my career. I couldn't live unless
18 they wanted me to pay it back, and "it" being the
19 profits they made out of my dying husband, a man dying
20 of AIDS who had had to sign and was forced to sign his
21 homes away when he was dying.

22 And that was very much for me the position I was
23 coming from and I felt there was no support, there was
24 no understanding of that, there was a complete
25 reluctance -- and they are using this -- this was

1 their investment and there are other -- I'm not sure
2 of the other letters but I mention it in my statement
3 where John Williams talks about giving the original
4 loan and says that these two are both -- you know, we
5 were both -- I'm not saying the exact words but
6 basically we were both HIV positive and that they
7 would see a return of their investment soon; so they
8 were expecting us to die. They did not expect that
9 30 years later I'd still be alive.

10 Q. You have recounted in your statement not just the
11 letters that you received from the Macfarlane Trust
12 but phone conversations and one particular phone
13 conversation that you had with John Williams when
14 discussing your request to move and for the issue of
15 the charge on the property to be sorted out.

16 What was John Williams' response and how did he
17 communicate it?

18 A. He was brutal. He was a matter of fact man and he
19 just said, "Mrs Walton, you would have been thrown out
20 on your ear if it wasn't for the Trust", and that's
21 how he spoke to me, and then we ended the conversation
22 and the next day he wrote a letter. It was charming,
23 "It was really nice to meet you -- speak to you on the
24 phone". His ability to write things down in writing
25 was not a true reflection of what happened in the

1 conversation when he was speaking to me, when he was
2 writing to me.

3 Obviously through data protection I found out
4 that it was a different story and what I suspected was
5 happening, that they had an opinion of me as someone
6 challenging them, for someone who is basically trying
7 to move on, who didn't want this situation and never
8 wanted this situation, but all I ever wanted was to
9 try and talk and have a reasonable conversation but
10 they were so just brutal and without any care for what
11 I was going through and, you know, who they were
12 dealing with.

13 Q. You've put it this way in your witness statement:

14 "It was a mess created by the Macfarlane Trust.
15 Instead, with the Macfarlane Trust unwilling to help
16 resolve the situation, I stayed in the house trapped
17 for years after my husband died."

18 That's how you felt?

19 A. Yes. Well, I did for seven years.

20 Q. And then after Mr Williams had left the Trust, there
21 was a new Chief Executive, you approached them again.
22 Did you get anywhere with that approach?

23 A. Not really. I think by the time there was a new Chief
24 Exec, I eventually got a meeting with some trustees
25 and I said, "I want to move. I want to move",

1 I wanted to come to London and to live in London.
2 I had opportunities. It was preventing my life. It
3 was holding my life, and had held it for a good
4 I think about seven years by this time, six years, and
5 at that meeting the Chief Executive said to me, it was
6 a woman -- can I say her name?

7 Q. Yes.

8 A. Ann Hithersay was the Chief Executive at the time.
9 She just turned to me and she just said, "Don't worry
10 about it", like, "don't worry about it. It will just
11 go". You know, and I said, "Well, it can't just go.
12 It's a legal charge on my property set in a deed.
13 Unless you take it off", but it's almost like it will
14 just get wiped off and it didn't. They agreed that
15 I -- finally agreed that I could, they would take the
16 charge, the original charge, and put it on to
17 a property wherever I go so the charge followed me
18 round and I was still shackled to this Trust. It was
19 never resolved in any way.

20 Q. So in I think approximately 2000 you moved, you sold
21 the house and you moved to a small house in London?

22 A. Mm-hm.

23 Q. But with the charge, as you say, having followed
24 you --

25 A. With all its --

1 Q. -- and having been placed upon the new property?

2 A. Yes, with all the money, the profit they had made, so
3 the equity still stayed, but it was just newly
4 written, newly drawn up.

5 Q. Then it was a few years after, that about 2003, having
6 started to make a life for yourself in London, you say
7 you became very ill and your condition developed into
8 what was then usually referred to as full-blown AIDS.

9 A. Mm-hm.

10 Q. There came a point you decided you wanted to move away
11 from London to be close to your mother.

12 A. I did not want to move. I loved being in London.
13 I didn't want to move at all, but I knew that the
14 reality of my health I needed support and I needed
15 care and I needed to be back closer to family,
16 particularly my mother who was helping and supporting
17 me, as I say, in her late 70s at that time. So
18 I asked them, you know, "I want to move again, I just
19 want to move".

20 Q. And there was a visit that took place to your house?

21 A. Yes.

22 Q. Your mother was there?

23 A. Mm-hm.

24 Q. And you were expecting the social worker and the then
25 Chief Executive Officer Mr Harvey to attend but, in

1 fact, the social worker didn't attend and Mr Harvey
2 was accompanied by one of the trustees, Mr Spellman?

3 A. Yes.

4 Q. What can you recall about that meeting which we know
5 took place in about August 2005?

6 A. It was a very unpleasant, unpleasant conversation.
7 I was very ill at the time. I, at the time, was
8 recovering. This is in August of 2005.

9 Q. 2005.

10 A. I was recovering from -- as it turned out I ended up
11 back in hospital a month later but all I was
12 interested in was trying to sort of settle and try to
13 get back to some -- to be able to move the home, move
14 the house, sort this mess out again, if you like, so
15 that I could move, and Mr Harvey and Mr Spellman
16 were -- they were two like businessmen, if you like,
17 coming into my home and trying to do deals and were
18 not very pleasant to me. I wasn't well. My mother
19 was there. She was, you know, pleasant.

20 And then they started sort of doing negotiations
21 around knocking -- they, agreed the profit should come
22 off, from the -- should come off, they would stop the
23 profit they made, because that was my biggest thing to
24 them, "You've been making profit. You've been making
25 profit out of a dead man who died", and Martin Harvey

1 agreed, "We won't have that then. We'll move the
2 charge without profit". I thought this is some kind
3 of result and so they then went away.

4 Q. But what actually happened when you saw the papers
5 that were drawn up subsequently?

6 A. They agreed to just knock the profit that was made,
7 I can't remember which way round, from the London --

8 Q. What you have said in your statement is they took the
9 profit off the profit from the London house, which you
10 hadn't owned for so long, but not from the original
11 property?

12 A. Yes, and actually looking back now and I think if
13 I'm -- there was something that happened in charity
14 law I think around that time and I think it was about
15 profiting and making profit from people. I think
16 there was something about profiting that I looked --
17 I found out only very recently and I thought that's
18 very interesting. That's very interesting that they
19 did that at that point.

20 Q. You have supplied us with a photo. It's 1589005.
21 This is taken from around that time just to show your
22 general state of health.

23 A. Yes and who they were dealing with at that time.

24 Q. So that's you then?

25 A. Yes.

1 Q. You, subsequent to that meeting, you've seen a note
2 that was prepared by Mr Spellman and a memorandum that
3 he prepared for the trustees.

4 A. Yes.

5 Q. I'll take you to that in a moment but I should just
6 say it is right to note that Mr Spellman has made
7 a witness statement, you've seen it. It will be
8 published along with your statement and along with
9 a number of other witness statements that comment on
10 matters that you have set out in your evidence.

11 Is there anything that you have read in
12 Mr Spellman's statement that causes you to doubt your
13 recollection of the meeting?

14 A. No, it doesn't cause me to doubt. I disagree with
15 what he's saying or his -- I just disagree.

16 Q. If we could have on screen, please, Paul, 1589002 and
17 go to page 97, please.

18 So this is Mr Spellman's note, there's a date at
19 the very end of it, 10 August 2005. You have said in
20 your witness statement, you -- reading this you find
21 it unpleasant to read what you think is the contempt
22 in which you were held.

23 A. Mmm.

24 Q. We will just look at it, if we may, briefly. Third
25 paragraph, it refers to your mother staying there as

1 your daughter had been ill, and then it says this:

2 "Indeed, throughout the interview 1823A [that's
3 the number applied to you] looked and behaved in
4 a poorly fashion and needed to make frequent trips to
5 the toilet."

6 A. Yes.

7 Q. Is there anything that struck you about that
8 observation?

9 A. I find it, when I saw -- I just thought it was
10 so ... why was he saying that? What was ... and also
11 the 1823, that's how they refer to you, you were
12 a number. You were ...

13 Q. Then the next paragraph, please, Paul.

14 There's a reference there to the MA that you had
15 been doing and you had at that stage been unable to
16 complete?

17 A. Yes.

18 Q. "Her tutors wish her to end her studies and she is
19 reluctant to do so as her current student status
20 exempts her from council tax."

21 A. Mm-hm.

22 Q. Was that the reason you --

23 A. That wasn't the reason, but why give up -- I needed to
24 see how well I was and whether I needed -- was able to
25 go back and being off ill, that did exempt me, so it

1 was a bill I didn't need to pay.

2 Q. Then if we could have the paragraph beginning "1823A
3 was distressed ..."

4 "... was distressed to learn we did not think it
5 would be a simple matter to transfer the equity in
6 Wood Green home to a higher priced property in
7 Warwickshire."

8 Then this:

9 "We pointed out that she is currently in hock to
10 the MFT to the tune of over £168,000 ..."

11 What does that phrase "currently in hock to the
12 MFT", how did that make you feel?

13 A. Again, that they are including all their profit that
14 they are making as well and just, again, the language
15 "in hock" and "we pointed out to her", and above that,
16 you know, "was distressed to learn that she did not
17 think it would be a simple matter". Why couldn't it
18 be a simple matter, you know? Why were they making it
19 complicated?

20 Again, it shows the contempt, the lack of care,
21 the fact that two men, one a trustee, one chief
22 executive, you know, much older than me, came into my
23 home when I was dying or seriously ill and without any
24 support whatsoever, without the support that I need in
25 a professional way, to discuss financial --

1 a financial transaction which I was not in a fit state
2 anyway but also -- and took offence to me actually
3 challenging them about it, you know, which I have and
4 always will.

5 Q. You had been in receipt, by 2006 you had been in
6 receipt of some monthly subsistence payments from the
7 Macfarlane Trust.

8 Paul, if we could just have on screen again,
9 page 27 of that exhibit and if you could just
10 highlight, please the, the third paragraph beginning
11 "The entire meeting".

12 So those regular payments had been agreed
13 following an assessment by a social worker which we
14 see set out here that you were in need both of some
15 immediate financial assistance and some longer term
16 support?

17 A. I think that was a financial adviser to the Trust that
18 made that, yes, she'd met with me and realised that my
19 current state without any income needed some immediate
20 support and the Trust agreed to it. She came up with
21 some figures that would help me through -- pay the
22 monthly bills and stuff, and so they gave me a certain
23 amount of figure -- a certain amount of money that
24 would obviously get reviewed at some point, so ...

25 Q. In about 2006 you were told without warning that those

1 payments were going to be stopped; is that right?

2 A. Yes, they just stopped them but it was -- yes.

3 Q. You wrote to the Macfarlane Trust querying that and
4 received a letter in response from the Chair, Peter
5 Stevens?

6 A. Yes. Because I had this letter that sort of out of
7 the blue came saying, you know, "We're going to take
8 this money away from you", without actually reviewing
9 it with me, actually, you know, it wasn't that --
10 I didn't object to what was happening. I just
11 objected to the process.

12 I spoke, I had a telephone conversation with
13 Martin Harvey, the Chief Executive, and you know
14 I told him this was no way to deal with people, "You
15 need to have a proper review. You need to contact me.
16 You need to ask me what my situation is", and left it
17 at that and then within a few days I received a letter
18 from the chair.

19 Q. Paul, that's page 15, please, of this exhibit. Can I
20 just ask you to highlight the date, first of all.

21 13 March 2006. Is that a significant date?

22 A. It's the significant date. It is 13 March 1993, so
23 13 years after my husband had died and it is
24 a significant time of the year that, during those
25 particularly those early years, were those huge

1 markers and remembering him dying. So this was
2 sent -- I think I received it a day or two later.

3 Q. Then if we could have the first two paragraphs please
4 highlighted, Paul.

5 It says this:

6 "I understand from Martin Harvey that you have
7 asked that the Trustees review the decision he
8 recently communicated to you that we would cease
9 paying the additional monthly sum [et cetera]. It is
10 rare for me as Chairman to write outside the normal
11 protocols but the circumstances of your particular
12 request and the level of support we have given you
13 over the years persuade me to do so on this
14 occasionally."

15 And then:

16 "Your reaction disappoints but does not,
17 I confess, greatly surprise me."

18 What was your response to seeing this letter?

19 A. I'd not long come out of hospital, so I was not --
20 I was in a very sensitive state and it just -- it just
21 was as if someone had stuck a knife in my stomach. It
22 was just like -- the pain it took, the pain, the
23 timing of it as well and the surprise that he should
24 write to me. I hadn't even had a conversation with
25 him, that he should take it upon himself to write to

1 me and talk to me in that manner.

2 I'd known Peter Stevens through the partnership
3 groups that we used to go to and I couldn't believe
4 it. I couldn't believe somebody would do that to
5 someone who's ill, write that to someone who he's
6 supposed to be supporting. If he had a problem there
7 were other ways of dealing with it and it wasn't --
8 yes, so ...

9 Q. Could we have the next paragraph, please, Paul. First
10 sentence:

11 "Over the years the trustees have lent over
12 backwards to assist you.", and a suggestion you are
13 receiving more by some multiples than other
14 beneficiaries and then the next paragraph, if you can
15 highlight the last two sentences, please, from
16 "... but I must point out":

17 "... must point out that the majority of those
18 whom we help have haemophilia, you do not, and are
19 infected with hepatitis C, you are not, so they might
20 be said to deserve at least equal treatment. That is
21 of course something that we are not unable to give."

22 Then the next paragraph, please:

23 "You know that the Trust has never been funded
24 sufficiently to enable us to put everybody in the
25 state they would like. All we can do is give them

1 a measure of assistance, which we know is generally
2 inadequate. Your frequent criticism of the Trust
3 appears to ignore this and to assume that we have
4 unlimited resources that we can apply to each and
5 every case -- or at least to your own."

6 Was that ever your assumption, that the Trust
7 had unlimited resources to give you?

8 A. No. I had been a trustee of an organisation myself,
9 I understand what goes on. I understand the
10 limited -- but that's not -- it's not for him to write
11 to me about that. It's -- whatever his frustrations
12 were, and I don't know why he wrote that letter.
13 I still to this day don't know why he felt able to
14 write that letter to me.

15 You know, again, the fact that he showed his
16 contempt for me. He told me that I was not
17 a haemophiliac, so my HIV status, the fact that
18 I contracted it through my husband was somehow lesser,
19 was somehow less important? "You do not have
20 dependent children." You might as well have just
21 punched me in the face. I didn't have children
22 because my husband had died. I mean, it was the
23 language. It's the level of how he thought about me
24 and why, why did the chair of the organisation that's
25 set up to support feel able to write to me? You know,

1 why?

2 Q. If we could just look at the second --

3 SIR BRIAN LANGSTAFF: The information he appears to be
4 giving is that your request is going to be acted on at
5 the next Trustee's meeting. It is going to be put
6 before the trustees and the rest of it is simply
7 expressing views about you, isn't it?

8 A. So he is, yes, expressing views about me that I think
9 is, you know, why should he write to me like that?
10 I mean, I don't know.

11 MS RICHARDS: If we could just pick up the second page of
12 this letter, please, Paul, just help make sense of
13 your response to it:

14 "You are of course entitled to ask us for help.
15 You are not entitled to receive it anymore than
16 anybody else does", then there's a reference to
17 limited resources.

18 Then he says this:

19 "I do suggest that you might give some
20 consideration to the fact that you are but one of some
21 hundreds of people who look to us for assistance, many
22 of whom are less articulate than you, do not have the
23 benefit of owning any property as you do, have
24 dependent families which you do not, and whose health
25 is much more compromised than your own."

1 And then the reference that the Chair has picked
2 up there:

3 "We will be in touch again after the Trustees
4 have undertaken the review you request."

5 A. To me that's brutal. To me that is, "You've stood out
6 of line. We're going to give you a good thrashing".
7 That is how I see it. That was a -- that's how I see
8 it, I think, and I cannot see any justification for
9 that language, that attack on me, attack on -- and
10 particularly given, you know, the state -- it's just
11 downright wrong, but also given the state of health
12 that I was in.

13 Q. Just one passage I think from your response to that
14 letter, Clair, it's page 18, please, Paul. The
15 paragraph towards the bottom of the page beginning,
16 "I would like to point out to you ..."

17 You said this, Clair:

18 "I would like to point out to you that I do not
19 have dependent family because my husband is dead. HIV
20 and his death put a stop to us having children and now
21 I face this world alone. Forming new relationships
22 when you have HIV is not easy. Coincidentally, your
23 letter was dated 13 March 2006. My husband died on
24 13 March 1993. It is an appalling letter to receive
25 at any time but worse so close to the anniversary of

1 his death. Your reference to dependent family is
2 crass beyond belief and shows your lack of compassion
3 to and understanding of people living with HIV/AIDS,
4 in particular to me as an infected childless widow
5 with very advanced HIV infection."

6 I think you go on in your letter, we won't go to
7 the rest of it, but to point how does he know what
8 your current state of health is?

9 A. Yes, actually, I think he may well have known because
10 the photograph that, you know, I had been in hospital
11 but also he said, you know, "You don't have
12 hepatitis C". He didn't know how I had hepatitis C or
13 not, you know. But it is, it's -- you know, even sort
14 of whatever it is, you know, 13 years later, it's
15 still a letter I find so utterly disgusting.

16 Q. We won't go through all the remainder of the exchange
17 of documents but there was a further letter to the
18 case worker I think at the Terrence Higgins Trust who
19 was helping you with the grievance and complaint that
20 you subsequently lodged which said that the trustees
21 and the Chief Executive had felt that you've shown
22 little appreciation of the extent to which you'd
23 received exceptional treatment over the years.

24 Did you feel you'd received exceptional
25 treatment over the years?

1 A. I don't -- I mean, I was aware that I had been
2 supported in some ways. I don't know how that
3 compared to anybody else. They make the decisions.
4 They know who they are supporting. It's their
5 decisions. You don't go in there and grab the money.
6 If you ask for something they give it to you, so
7 I have no idea.

8 But the talk about exceptional conditions, you
9 talk about the sort of rocket to the highest paid
10 beneficiaries, the language they use. You have to
11 remember my husband was HIV positive and died. I was
12 a widow and I was also infected so my situation was
13 quite exceptional amongst the community as well.

14 So I don't know and I don't -- I just feel that
15 whatever they were doing it was their choices that
16 they were making? It's their decision-making. They
17 have to back up their own decisions. They thought
18 I was given exceptional help then it was because
19 I needed that exceptional help, if they felt that way.
20 It wasn't for me to doff my cap and thank them, and
21 this is the -- I think they were expecting me to be
22 grateful and, as I pointed out, I appreciate the sort
23 of concern -- I appreciate those that made efforts and
24 were supportive, people like the financial adviser,
25 et cetera, but you know what did he want in terms of

1 gratitude.

2 Q. I think if we just go, please, to page 82 of the clip
3 of documents, Paul, the penultimate paragraph
4 beginning, "I have to ask", could you just highlight
5 that.

6 So this is a letter, Clair, again you obtained
7 from your files. It is a memo 2 October 2006 from the
8 Chair to the Trustees and it says this:

9 "I have to ask for the board's guidance ... it
10 is of course wholly inappropriate that Martin [that's
11 the Chief Executive officer] should be in any way
12 criticised. If it is felt that I behaved improperly
13 I am willing to apologise to 1823A. The primary
14 objective should I think be to bring to an end the
15 waste of Martin's and others' time on this matter. It
16 would be good if as a secondary objective we could
17 attain a satisfactory ongoing relationship with 1832A
18 but that I fear is beyond us."

19 What is your response to that document?

20 A. It wasn't Martin I was complaining, I think it was
21 about Peter Stevens, because I actually asked Martin
22 for a -- I wanted to make a complaint. I said,
23 "What's the complaints procedure", and he said, "We
24 don't have a complaints procedure because no-one ever
25 complains".

1 So it took -- I think it was the determination
2 that I had in actually trying to put right a wrong,
3 trying to hold them to account, that put me in
4 a difficult relationship with them, the relationship
5 I had with the Trust was not -- it wasn't unique but
6 it was certainly rare that we had this -- they were --
7 I was basically shackled to them because of the charge
8 on my property and I was trying to get that resolved
9 in some way, I think because I was also called them to
10 account that they didn't like. You know, we tried so
11 hard some of us tried so hard to call them to account.
12 They were unaccountable.

13 Q. You ultimately received a letter of apology from the
14 successor chair.

15 A. Yes.

16 Q. We've got that at 1589006, please. This is
17 16 May 2007. You had attended a meeting and explained
18 your concerns?

19 A. Yes.

20 Q. If we have the second page, please, the second
21 paragraph highlighted. The chair sets out a number of
22 matters and said this:

23 "Whatever sense of frustration or exasperation
24 may have been entertained and even accepting that
25 Mr Stevens saw and I know you did not, that its

1 contents were factually correct, the letter of
2 13 March 2006 was entirely misguided and misdirected
3 in its tone and approach; in short it should never
4 have been written at all. It is too late to withdraw
5 the letter itself but I expressed at our meeting and
6 I repeat now, for myself and on behalf of the Trust,
7 my deep regret the fact that it was and also for the
8 impact you described to me and your particular
9 circumstances at the time it was received."

10 Now, did the issue in relation to the charge on
11 your property ever get resolved by The Macfarlane
12 Trust in the years that followed?

13 A. No. At this time, I had no support in terms of
14 a member of parliament around this period or anyone
15 I could go to to get the support, but by about
16 2012/2013 through partnership groups, meeting up with
17 others within the Macfarlane Trust community, we
18 started to sort of the like swap notes, if you like,
19 on how the Trust was behaving towards them, towards
20 each of us, and I decided to go to my member of
21 Parliament and ask him for help.

22 I wanted to raise the way we were being treated
23 but also on a separate matter I wanted him to look at
24 the charge on my property. So in 2013 my MP embarked
25 on what he was not expecting, a long period -- can

1 I just say, sorry, can I go back to that actual letter
2 of apology.

3 Q. Yes, of course.

4 A. That was a year. It took a year afterwards to extract
5 that apology. They talk about Martin's wasted time.
6 What about my wasted time? That's what -- this is,
7 I think, you know, I was not someone who they could
8 just beat and I would go away. If it's wrong, it's
9 wrong, and it needed to be resolved.

10 So in 2013 I explained the problems of the
11 Macfarlane Trust and there was -- there were debates
12 in Parliament and the issues of the Macfarlane Trust
13 were raised. But on a separate matter, Nadhim Zahawi,
14 my MP, he wrote to the then chair, Roger Evans, and
15 said, "Could you explain the circumstances of the
16 charge on Mrs Walton's property" and it was as simple
17 as that. It was quite a -- you know, instead of
18 trying to -- I am going to ask them to explain.

19 And he wrote back and said, "I can't explain.
20 None of us were around at the time". The letter's
21 there and basically "you don't want to deal with this
22 woman", you know, and "we've had lots of meetings with
23 her" which wasn't true, I'd never met with Roger Evans
24 over my house and, you know, "you'd best spend your
25 time as a member of Parliament raising, you know,

1 awareness and funds for us". That was basically the
2 gist of the letter. You've actually got the letter.

3 Q. There was a point in time at which your MP made
4 a speech and a debate in which he criticised the
5 Macfarlane Trust.

6 A. Yes.

7 Q. Called it unfit for purpose. It was a few weeks after
8 that that there was a board meeting at which the
9 Macfarlane Trust maintained the position that you
10 would have to pay the charge if you sold your house.

11 A. Yes. Actually, no, it was just that because I'd been
12 able to move -- they had moved me, you know, it took
13 a long time, seven years, years from one property to
14 the next and they'd moved it -- I needed some kind of
15 like -- you know, I needed some resolution over this
16 charge in some way that I had to go and ask them
17 whether I could move.

18 You know, this was a curtailment of my freedom
19 to think, "oh, you know, I'll apply for a job. Oh
20 yes, I'll sell the house". I needed something in
21 writing from them or to at least resolve it, at least
22 to talk about it, have a discussion about it. That
23 was, at that period, my approach. But the letters
24 that my MP was trying to get -- the Trust was being --
25 there were delays in responding back. They were just

1 confusing and not answering the question. But he then
2 said to me, you know, this charge needs to be taken
3 off your property, it should never have been put on,
4 you know, the way it was. So I wrote -- so he said
5 just write to them and ask them to take it off. So
6 I did.

7 But also we wanted assurance that in the
8 meantime that actually we would be able to at least
9 move property as they'd let me do before. At that
10 meeting three weeks after the Westminster debate,
11 where the Trust was criticised (and actually I was
12 named as someone who said the Trust neither cares nor
13 understands), they made a decision, that board
14 meeting, no, she's not going to be allowed to move.
15 If she sells the property, she has to give all this
16 money back. So basically they made a situation worse
17 and put it in writing and made that board decision.

18 Q. That was late 2013.

19 A. Yes.

20 Q. You'd had some support from a social worker at a
21 Birmingham haemophilia centre and he provided some
22 information, and you've set this out in your statement
23 in some detail, but he provided some information to
24 your MP in early 2015 where he said as far as he was
25 aware other individuals had been treated differently.

1 Can you recall what Mr Simmons, the social worker, was
2 saying to you?

3 A. That needed to be corrected. It was 2017 and actually
4 I didn't correct -- that needed to be corrected. It
5 was 2017 he wrote that email to -- he wrote the letter
6 to -- yes, basically he was saying that there was also
7 inconsistencies in that they had written off people's
8 charges on properties and he said in one case he got
9 banks to write off properties, but the Trust would not
10 entertain even talking or discussing. Again, my MP
11 had asked to meet with the Trust. They refused to
12 meet him. They refused to meet with a member of
13 Parliament.

14 So 2017 -- this is four years later when we're
15 still trying to get the Trust to meet -- this is what
16 the social worker wrote to Nadhim to inform him and he
17 said that he, in his negotiations, he'd actually
18 managed to negotiate -- like, he'd actually managed to
19 get grants. He said some people were given grants and
20 others were given loans. Some of those loans were
21 then secured against people's property. It was all
22 inconsistent.

23 But one of the things he said was that he'd
24 actually managed to get a grant for one beneficiary
25 for 50 -- one 30,000, but £55,000 in one year alone

1 for one particular beneficiary and it was a matter of
2 if your face fitted.

3 So that person probably needed that whatever but
4 it's the point that he was making the point that it
5 was inconsistent, it was not equal and it was a matter
6 of if your face fitted.

7 Q. Now, there came a point in 2018 when the Trust finally
8 agreed that they would meet with your MP and that
9 meeting took place on 2 May 2018 and you were hopeful,
10 I think, with your MP that there would be some kind of
11 dialogue or discussion or progression of the matter.
12 Was that the outcome?

13 A. No. Again, the Trust refused for almost five years to
14 meet and they agreed to meet in early February 2018,
15 which is just when the Inquiry started back at -- that
16 was the time. It was a long process of, you know,
17 they'd agreed in February but maybe people's diaries
18 whatever, it was May. It was exactly a year ago today
19 we met. We met in Portcullis House and I just let
20 them do the talking. I just thought let my MP
21 finally, you know, talk with the chair of the
22 Macfarlane Trust and, you know, Mr Zahawi thanked him
23 for coming and sort of pointed out that it had been
24 five years, many years in the making but he was
25 pleased that he finally came to talk and he said we

1 need to sort this property out and this is an anomaly
2 that should never have happened, and the chair just
3 said, well, no, it has to be paid. It's only fair;
4 it's only fair that, you know, people who had loans
5 should pay them back.

6 So some time into that conversation that was
7 getting nowhere, I actually pointed out that nothing
8 was ever fair, you know, equal at the Macfarlane Trust
9 and that, you know -- they were closing as well. They
10 were closing down and I was frightened that they might
11 sell the loan on to someone. I didn't know what would
12 happen. I was really, really at a very desperate and
13 very scared state. But I pointed out that there had
14 been a document that I'd somehow obtained through Data
15 Protection Act -- I don't know why because it wasn't
16 really relevant to me -- but it came through with the
17 bundle and it was a document that was -- it was an
18 internal document about the loans and about the loans
19 register that they had and how it had got lost in
20 between the change over from one Chief Executive to
21 the other and that actually this meant that they
22 really weren't sure what the loans were.

23 I pointed this out to him. The chair went away
24 saying, well, in light of any information, we will
25 just -- you know, "I'll have a little think" and

1 I thought, well, maybe he will think about it and then
2 discuss it. But he came back -- you know, this
3 is May. He came back in sort of -- there was
4 a trustee's meeting in July. It was September before
5 he came back and said, "No, we've done" -- you know,
6 that they'd done this thorough investigation and that,
7 you know, they knew what they were doing. They even,
8 you know -- we told them to have legal advice. They
9 knew what they were doing back in 1989 and that the --
10 so this again was the attitude. Again, not
11 understanding, you know, and not calling me for any,
12 you know, to give any information about my
13 recollection of what went on and the fact that they
14 said, you know, you knew what you were doing.

15 Q. You say in your statement that you were informed that
16 your request for the charge to be removed was refused
17 on the grounds that you and Bryan had approached the
18 Trust for a loan and explicitly agreed to the terms of
19 it.

20 A. Yes and, again, we didn't approach the Trust for a
21 loan. We approached -- we certainly didn't -- we
22 didn't need that happening. There is other
23 correspondence where the chair says that, you know,
24 that we -- they gave us this charge because it was
25 very difficult to get mortgages in those days. We had

1 a mortgage. We had a mortgage. Again, it was a total
2 not understanding the historical facts of what it was
3 like living with HIV, you know, not being there,
4 making judgments on what happened, and to say that we
5 knew what we were doing, that we approached the
6 Macfarlane Trust for this loan was just false. It
7 wasn't true.

8 Q. You knew at that time, as you said, that the
9 Macfarlane Trust was closing down.

10 A. Mm-hm.

11 Q. And one of your worries was who was going to have this
12 charge on your property.

13 A. Yes.

14 Q. Towards late the end of 2018, it became known that the
15 transfer was going to take place to the Terrence
16 Higgins Trust.

17 A. We were not told that it was Terrence Higgins Trust
18 until we received a letter in the middle of
19 December -- I think it was 14 December -- last year
20 and they said, the Macfarlane Trust said, "the charge
21 on your property has been transferred to the Terrence
22 Higgins Trust, contact this person" and I was just
23 horrified. All the way before that there had been
24 hope that they would just -- as they closed down, they
25 would just, you know, wipe the charges off. There was

1 no need for them to be moved anywhere. I always had
2 doubts that would happen. I thought that they would,
3 if they could, transfer it. So it went to the
4 Terrence Higgins Trust. I immediately contacted the
5 Terrence Higgins Trust and I was met with, you know,
6 care and kindness and people who seemed to really,
7 like, understand that this was a woman that was
8 petrified about what was happening to her, and they
9 assured me that the Chief Executive would get in
10 contact.

11 So I wrote an email on the Saturday -- this was
12 a Friday night I'd actually contacted them. It was
13 about 3.45. So again we received a letter on
14 a Friday, a week before Christmas, to tell us this
15 with no -- you know, no forewarning.

16 Fortunately, very fortunately, the Chief
17 Executive of the Terrence Higgins Trust did email me
18 at something like 8.45 on the Monday morning. He'd
19 obviously got the email, and he said, "Can we leave
20 this until after Christmas?" and I just said "No" and
21 he rang me within a few minutes. You know, again, a
22 very, very different approach -- a very different
23 approach -- and he said that they were just getting
24 all this information in now of the charges being
25 transferred, and told him these were toxic loans.

1 You know, I told him as much as I possibly can
2 about what had happened to me and what I'd been going
3 through for years and this could have been relevant
4 with the Macfarlane Trust as it closed but it decided
5 not to, and now I had a whole new group of people
6 I had to sort of deal with.

7 Q. At the time you drafted your statement, you were
8 concerned because there was an ongoing process of
9 review by the Terrence Higgins Trust that was not
10 happening as quickly as you hoped it might.

11 A. Yes.

12 Q. I think you were told by the Chief Executive that
13 there was going to be a trustees' meeting in
14 March 2019 and you described that you were frightened.

15 A. Yes, I was frightened.

16 Q. Can you explain why.

17 A. Because I didn't know who I was dealing with. I mean,
18 it was very warm the initial sort of contact I had
19 with the Terrence Higgins Trust, but this delay just
20 frightened us because -- it frightened me, it
21 frightened the others that had loans because we didn't
22 know what they were going to do about it. And already
23 by the 5th -- I looked, I got through to the
24 Land Registry and already, I think at the beginning of
25 January, the charge had been removed as the

1 Macfarlane Trust and it said the Terrence Higgins
2 Trust on the Land Registry. So they had already taken
3 possession of the house and that really scared me,
4 that it was very quickly done.

5 But we did eventually -- we did meet and we had
6 a meeting on 8 March. A few of us went down to the
7 Terrence Higgins Trust and actually -- who had loans
8 and we, you know, explained the situation. They'd had
9 time to speak with lawyers, talk about what they might
10 do about it and to make a decision.

11 Q. You received the communication of the Terrence Higgins
12 Trust decision I think this week?

13 A. Officially I had the letter on Monday night.

14 Q. Could we just get that letter on screen, please,
15 1589004. Could we have the second paragraph
16 highlighted, please. It refers to:

17 "We've undertaken a review to consider the
18 financial and emotional impact of the loan. We are
19 grateful to you for assisting with these
20 enquiries~..." and it refers to an report prepared by
21 an independent consultant.

22 Then could we have the next paragraph, please.
23 We can see there, it says:

24 "I am pleased to advise you that we have decided
25 to accept the recommendations in the report and,

1 therefore, your loan is being written off with
2 immediate effect. We do not consider that you are
3 currently or are likely to be in a position to repay
4 the outstanding loans without causing financial and
5 emotional hardship or distress and writing off your
6 loan clearly meets the charitable objectives of the
7 Macfarlane Trust."

8 A. I mean, I've spoken with Ian Green who is the Chief
9 Executive of the Terrence Higgins Trust and I'm
10 grateful to the way he has managed that and what he
11 did in the matter of a few months. Obviously, there
12 was a period in the middle where I was very frightened
13 and he understood that and he had a process to go
14 through, a legal process. He sought legal advice and
15 he and the trustees made a decision.

16 It took a matter of months, three months,
17 whatever. It took me 30 years of Macfarlane Trust
18 to -- the Macfarlane Trust it shows could have dealt
19 with it but chose not to deal with it in my case and
20 the case of a few others.

21 Q. It's been pointed out I think by you, Clair, that this
22 writing off of the loan has not been done because it
23 meets the charitable objectives of the Terrence
24 Higgins Trust although it might well do so but because
25 it meets the charitable objectives of the

1 Macfarlane Trust?

2 A. And they could have done it. They chose not to do it.
3 They could have done it to all the loans that they
4 had.

5 Q. I am just finally going to ask you about your more
6 recent experiences with the replacement scheme for the
7 Macfarlane Trust. You have said a little about it in
8 your witness statement. Before we do so, I won't take
9 you to the document because it's a phrase you are
10 familiar with but there is Macfarlane Trust
11 documentation which identifies the category of
12 beneficiary into which you were regarded as falling
13 and it's "infected intimate".

14 How has that phrase made you feel over the
15 years?

16 A. It's a really crass -- it's not -- it put us into
17 a sort of different category, as short of secondary
18 category. I mean, the haemophiliac community were
19 treated pretty second-class but we were sort of beyond
20 that. But it was actually through -- it's strange
21 because through the chair it was only in, I think,
22 2007 or something -- no, it's much later. There was
23 a time when some of us complained about this term and,
24 actually, the fact that we were being treated
25 differently, not only treated differently but actually

1 financially treated differently as infected intimates
2 in terms of what we could receive that a haemophiliac
3 beneficiary would receive and there's much evidence
4 about that, but the -- it was changed by Christopher
5 Fitzgerald, who was the chair, to primary beneficiary.
6 So we became equal in every term alongside others that
7 had been infected with HIV in the haemophilia
8 community, which was a huge -- you know, I'm grateful
9 for him for doing that and I think it was a good move.
10 But I've noticed it, and I was trying to find this
11 last night, that the new scheme EIBSS have actually
12 taken it upon themselves to use that term again and
13 I don't know why and they need to ...

14 Q. You have had some general concerns about the new
15 scheme. You have detailed them in your witness
16 statement. There's only one I really wanted to ask
17 you to and expand upon which is your sense of the
18 extent to which they are familiar with and
19 knowledgable about the situation of those who are
20 suffering with HIV.

21 A. Yes. I was at a meeting last year with the I'm not
22 sure what she is but [GRO-D] and I was questioning the
23 fact that I had applied, I decided to apply for
24 a funeral plan. I thought, well, there's a funeral
25 plan there. I might as well get that paid up in

1 advance and I was rejected and I was told you can't
2 because you're HIV positive and only those with
3 hepatitis C stage 2 can receive a funeral plan.

4 I said, well, is that because actually in every
5 other way the level is the same, the HIV is the same
6 payments, it's the same ... and she said it's because
7 it's a -- HIV is a manageable condition, and I sort
8 of -- I challenged her. I said, "Well, where do you
9 get your information from", and she said, "Oh, we have
10 a doctor", this doctor that they referred to, an HIV
11 consultant, and I said, well, can I have that, you
12 know, evidence that that's what she's saying and it
13 turns out she didn't -- she hadn't -- through the
14 conversation she sort of admitted, well, actually she
15 got the information off the internet.

16 This is a scheme and, as I pointed out to her,
17 if you look up HIV now it becomes a manageable
18 condition if you are a newly infected and that, you
19 know, and even then it's still, you know, not
20 a curable, it's not something people want to receive,
21 having HIV, because it's still not curable and you
22 take medication for the rest of your life. But we're
23 talking about a community that have been infected for
24 35 years who have gone through chronic illness, who
25 have got mental health and anguish and all sorts of

1 the drugs that they have been taking and you cannot,
2 you cannot, sit there and just get the information off
3 the internet and say HIV is a manageable condition.

4 But because there are few people that are HIV
5 within the scheme, you know, that are specifically
6 HIV, that voice isn't always heard and I made it quite
7 clear to her but still the appeal came back and, "No,
8 you can't have it".

9 So in the grand scheme of things, I just -- it
10 needs to be dealt with in some way and they need to be
11 have education around HIV as it stands and advocacy
12 for those of us who have been living with HIV for
13 decades. That's what they need.

14 Q. Clair, those are the questions I wanted to ask you.
15 We've got your statement which deals with a handful of
16 other matters but that is part of the Inquiry record
17 and you know, I think, that we are looking, the
18 Inquiry will be looking more generally at the
19 operation of both the old and the current trust and
20 schemes.

21 Is there anything else you wanted to add to your
22 evidence at this stage?

23 A. Yes, just one thing.

24 Q. Yes, of course.

25 A. During the course of trying to get the

1 Macfarlane Trust trustees, and I take the whole board
2 as responsible, this is a board decision which the
3 chair relayed, is that they said that the reason they
4 wouldn't write off the loans is because it would only
5 be fair and equitable and also at the same time they
6 had been refusing to meet my MP, finally meeting my MP
7 and then saying the same thing to him.

8 Through the process of reaching out to the
9 others who had loans with -- that were transferred to
10 the Terrence Higgins Trust, I met a widow and she told
11 me that only last year the Macfarlane Trust had
12 renegotiated through this social worker her loan.
13 They had renegotiated it down by several -- tens of
14 thousands of pounds. So whilst they were saying that
15 they were being fair and equitable and that is
16 information I hope will come out, that actually even
17 to its dying days, even in its last year it was still
18 saying one thing and doing another.

19 Q. Clair, I am just going to ask Mr Snowden, who as you
20 know represents you, if there's anything else he would
21 like to have asked. *(Pause)*

22 There's one further document from the
23 Macfarlane Trust material relating to the 2006 letter
24 that Mr Snowden asks that I draw your attention to.

25 Paul, it's 1589002 and it's pages 20 and 21.

1 I don't know whether you can put 20 and 21 side by
2 side, please.

3 So we've looked, Clair, at the letter that was
4 eventually sent to you from Mr Stevens but through the
5 Freedom of Information Act requests that you have made
6 you've had access to a lot of your file and that
7 includes I think this which is communication between
8 Mr Stevens and Mr Harvey about how that letter should
9 be phrased.

10 A. Yes.

11 Q. Mr Snowden draws attention in particular to two
12 passages, if you look on the right-hand side of the
13 page, second paragraph, last sentence, it says this --
14 so this was Mr Stevens' first draft, I think, of the
15 letter that we're seeing and we've got the terminology
16 we see in the final letter and then this:

17 "I must advise you that I do not expect the
18 discussion to be long or to conclude in your favour."

19 If we can then look at the left-hand document
20 and if we could have highlighted, please, paragraph 2
21 you will see the suggestion being made in response
22 that:

23 "You shouldn't give even the impression of
24 prejudging. It will only come back and bite us."

25 Do you see that?

1 A. Mm-hm.

2 Q. Then returning to the third paragraph on the
3 right-hand side, please, beginning:

4 "Over the years the Trustees have bent over
5 backwards to assist you ..."

6 You will see the passage there in brackets:

7 "I cannot imagine what the reaction would be in
8 the partnership group which you must have attended
9 from time to time where the amount that the Trust has
10 been paying you known to others in that group ..."

11 Then, Paul, if we can look at the left-hand
12 column, the bit that says paragraph 3, you will see
13 the suggestion that comes back:

14 "I think the bit about the partnership group is
15 a possible hostage to fortune. I agree with it but
16 she may have told one or two about the funding; the
17 point is, I cannot be sure she has not."

18 Mr Snowden asked me to draw that draft to your
19 attention. I think you have seen these documents
20 before, in any event.

21 Can I invite you to say whether you have any
22 particular observations or comments to make about that
23 drafting exercise that was undertaken between
24 Mr Stevens and Mr Harvey?

25 A. It was under data protection that I got it, not

1 freedom of information.

2 Q. Sorry.

3 A. When I saw this some years later, again I suppose it
4 resolved -- it sort of fired up inside my belly, if
5 you like, what had been what I thought was going on
6 all the time really was going on and that the
7 reference to the partnership group, this is what they
8 did, fighting of beneficiary against beneficiary.
9 This is what snippets of information so, yes, that's
10 all I can say.

11 MS RICHARDS: Thank you. I have no further questions for
12 you, Clair.

13 Sir?

14 SIR BRIAN LANGSTAFF: Thank you very much indeed, Clair,
15 for giving such powerful evidence and drawing the
16 attention of the Inquiry to the correspondence to
17 which you have been subject. Thank you very much.

18 A. Thank you.

19 SIR BRIAN LANGSTAFF: Clair, quite rightly, took all
20 morning and little bit into what would normally be our
21 break.

22 We will take a break now, shall we, until it
23 will be 2.20. That is a little bit shorter than usual
24 but I hope no-one minds before we come to the next
25 witness.

1 room or anyone are quite serious. I am making what
2 the law permits me to make, which is a restriction
3 order. This is known as an individual restriction
4 order in the case of an individual, as the name
5 suggests, and it is the case with witness W0140, which
6 is the numerical version of Mrs A. You will
7 understand why we don't use it in the hearing room.

8 I order as follows: that the name and address of
9 Mrs A and any other identifying information such as
10 the witness's image or a description of their
11 appearance cannot be disclosed or published in any
12 form, unless express permission is first given by the
13 Chair of the Inquiry or the Solicitor to the Inquiry
14 acting on my behalf.

15 She must be referred to only as Mrs A. The
16 order remains in force for the duration of the Inquiry
17 and at all times thereafter unless otherwise ordered.

18 I may choose to revoke or vary the order but
19 only by making a further order during the course of
20 the Inquiry. It will be a courtesy to her if those of
21 you who have mobile phones -- I notice that one went
22 off this morning, not a problem particularly -- but
23 those of you who have mobile phones, could you please
24 turn them off because they may give rise to a fear
25 that those of you who have them might use them to take

1 photographs. You won't, I'm sure, do it but please if
2 you have got phones just turn them off so that they
3 aren't operative during the period of this witness's
4 evidence.

5 Thank you very much for that.

6 Are we now -- when she gives evidence she will
7 come into the room, she has chosen to do that. She
8 has taken that brave step but the cameras will not be
9 on her. We have organised the visual imaging to
10 concentrate purely I suspect on Ms Richards and no
11 shot will be taken of her either coming in to give
12 evidence, leaving after her evidence or during her
13 evidence. Thank you very much.

14 Ms Richards.

15 MS RICHARDS: Sir, Mrs A is here in the room and if she
16 wouldn't mind stepping forward and giving her
17 evidence.

18 **MRS A, sworn**

19 **Questioned by MS RICHARDS**

20 Q. You are a retired nurse.

21 A. Yes.

22 Q. You spend some time managing your husband's medical
23 practice

24 A. Yes.

25 Q. You suffer from a condition called von Willebrand

1 disease.

2 A. Yes.

3 Q. I wonder if you could just tell us briefly what that
4 is.

5 A. Yes, factor VIII related antigen deficiency which, in
6 its mild form that I've got, usually gives no problem
7 to me but can be cyclical in nature so, therefore, you
8 could have quite a heavy fall and escape with no
9 bruising whatsoever and then other occasions I could
10 brush past a table and I'd end up with a haematoma on
11 my leg. So it's quite unpredictable but the condition
12 that I have is quite mild.

13 Q. It was discovered in your case when you were a young
14 adult, I think during routine dental surgery.

15 A. Yes. I had a tooth removed and it continued to ooze,
16 it didn't stop bleeding and I had to be admitted to
17 hospital and have it packed and sutured to stop it
18 bleeding, which precipitated me having a blood
19 clotting screen to see did I have any blood clotting
20 disorder that was when it was diagnosed.

21 Q. That was in the mid-1970s?

22 A. Yes.

23 Q. The advice you were given, because your condition was
24 classed as mild, was that you should be fine and you
25 might bleed more than normal from time to time and you

1 should let medical and dental staff know --

2 A. Yes.

3 Q. -- on any future visit or medical intervention that

4 you had von Willebrand disease?

5 A. Yes but didn't require regular treatment.

6 Q. So in April 1987 when you were pregnant with your

7 first child, you were going to have a planned

8 caesarean section because of pre-eclampsia?

9 A. Yes.

10 Q. Can you tell us what happened at the hospital?

11 A. I was admitted to the hospital and I was informed that

12 I would have cryoprecipitate. So I asked why was this

13 the case because were they expecting me to bleed,

14 because in pregnancy usually your Factor VIII levels

15 physiologically are much higher so your chances of

16 bleeding are less and I was told that it was

17 a prophylactic measure that they were going to take

18 and I was going to have pre-op and also post-op for

19 three subsequent days cryoprecipitate which I wasn't

20 particularly happy with but they more or less insisted

21 in the end that I would have this treatment.

22 Q. So it was the consultant I think who told you that the

23 you were going to be given prophylactic

24 cryoprecipitate?

25 A. Yes.

1 Q. And I appreciate you're from a nursing background.
2 You are confident that what you were given was
3 cryoprecipitate?

4 A. Yes.

5 Q. Told you you were going to have that and you
6 questioned it, I think?

7 A. Yes.

8 Q. What did you say? Can you recall?

9 A. I just wondered why I was given it prophylactically
10 and not -- it would be kept in reserve, just in case
11 there was a problem because the surgeon was aware and
12 he wasn't particularly worried and he said he would
13 just take extra care during the section of tying off
14 vessels and not just cauterising them and they would
15 just take extra attention, and that I thought that
16 perhaps if bleeding did occur, then they could give me
17 cryoprecipitate as a response to a problem rather than
18 just being given it prophylactically.

19 Q. You were given it I think on the first day by the
20 consultant and then on the three successive days by
21 junior doctors?

22 A. Yes.

23 Q. On each occasion did you raise any question about
24 whether you really needed it?

25 A. Yes, because each time they would put a new Venflon

1 in, instead of flushing it and leaving it in for the
2 next day they would remove it, so I would think --
3 they then did blood and they would be testing my
4 levels and my levels were done and they were okay. So
5 I presumed that the following day I wouldn't need it,
6 but each day a new batch would arrive and I would be
7 given it again.

8 Q. You were told, I think, when you questioned it
9 subsequently with the junior doctors it was being
10 given to you just in case?

11 A. In case, yes.

12 Q. Did you feel that you were effectively given the
13 opportunity to refuse to have it?

14 A. Not really, no, and with the level of knowledge I had
15 at the time I just presumed it had been heat-treated,
16 which I presumed most blood products were at that
17 time, so it was just more of an inconvenience rather
18 than a precipitated, you know, an infection risk.
19 I didn't think there was. That didn't enter in my
20 head. It was just inconvenient to me to keep giving
21 something that I didn't need.

22 Q. So you assumed it had been heat-treated?

23 A. Yes.

24 Q. You assumed it would be safe. That was because of
25 your general nursing knowledge and background?

1 A. Yes.

2 Q. Did the doctor, the consultant or any of the junior
3 doctors or indeed anyone else give you any information
4 or advice about the potential risks or pros and cons
5 of having it?

6 A. No, none.

7 Q. Now, after you had the caesarean section and after you
8 gave birth, I think a few weeks later you woke up and
9 something had happened. What was that?

10 A. Yes. My eyes were almost orange and my skin was
11 yellow. I was obviously jaundiced and so because
12 I was senior sister on a gastroenterology ward and my
13 consultant was the gastroenterologist with an interest
14 in hepatic diseases I went up to the ward and my
15 husband accompanied me and we had blood taken and my
16 liver function tests were grossly abnormal and they
17 took bloods for hepatitis screening which at that time
18 didn't exist for hep c. If it wasn't A or B they just
19 called it non-A non-B and subsequently that came back
20 as being positive non-A non-B.

21 Q. You had, I think, as well as the blood tests, you had
22 liver function tests and an ultrasound?

23 A. Yes.

24 Q. At a follow-up consultation you were told that your
25 liver was inflamed, virus of unknown origin, but you

1 were actually told I think by the doctor that it was
2 probably connected to the cryoprecipitate you had been
3 given?

4 A. Yes.

5 Q. Can you remember what, if any, advice you were given
6 about the condition at the time?

7 A. Well, at that time and I think the level of knowledge
8 that people had was that probably once the acute
9 illness had subsided there was a huge chance that
10 I would just clear the virus naturally and would
11 recover, which didn't happen.

12 Q. Were you given any information about any potential
13 risks of infecting others?

14 A. No, not at that stage, no.

15 Q. But you were told that you would have to tell other
16 medical professionals?

17 A. Yes.

18 Q. Was that because of your own profession at the time?

19 A. It was because I worked on a ward and I'd done lots of
20 intensive care where there's lots of invasive
21 procedures and, therefore, as most people were given
22 advice at the time to wear gloves and be extra
23 vigilant, but because of this I removed myself from
24 doing any invasive procedures just in case.

25 I did intend to return to intensive care but

1 because that involves haemofiltration and putting
2 people on dialysis machines and actually needling
3 those people, I then didn't -- I never returned to
4 that area of nursing again.

5 Q. Now, the events we're talking about had been in 1987
6 and you were told it was non-A non-B hepatitis but
7 some years later in 1993 you were tested for what was
8 then recognised as hepatitis C.

9 A. Yes. In the subsequent six years, I had periods where
10 I would develop abdominal pain and I saw my consultant
11 a number of occasions and each time my liver function
12 tests would be done and they were still abnormal, not
13 grossly abnormal, but they were still not normal and
14 my bilirubin would rise to about 40 and occasionally
15 I was mildly jaundiced, so I intermittently would have
16 ultrasounds, which just showed mild inflammation.
17 I didn't have any cirrhosis or any structural serious
18 damage.

19 So when the new test came out, the PCR test
20 which could detect hepatitis C, my consultant
21 approached me and said would I like to have it done
22 and at that time I just thought, well, why not, it
23 will probably be negative but at least I will know.
24 And so I had it done and, as a consequence of having
25 it done, it was suggested at the same time to have an

1 HIV test which was rather devastating at the time
2 because I hadn't even gone down that avenue. I'd
3 completely forgotten it because in the interim I had
4 had another baby who had severe learning difficulties
5 and took up a lot of my time, so that was just put on
6 the back burner. I never even thought of it. So it
7 was a huge shock when it came back that it was
8 positive. The HIV was negative but the hepatitis C
9 was positive.

10 Q. What was your reaction to that? Can you recall?

11 A. Quite devastated, a bit depressed, because the little
12 bit of knowledge I had at the time was that it could
13 be a death sentence and it was like the sword of
14 Damocles hanging over me that I could develop
15 cirrhosis, hepatoma, liver failure, all of which were
16 not an attractive proposition and worrying that I may
17 have given it my husband or -- suddenly, I just
18 thought that, you know, I was a leper because at that
19 time there was no treatment.

20 Q. You say in your statement you were terrified until
21 your husband was tested and came back negative that
22 you had somehow passed it on to your husband?

23 A. Yes.

24 Q. You were terrified that your children could have
25 become infected?

1 A. Yes.

2 Q. And because you were a nurse you had a degree of
3 knowledge about the condition and knew that it had the
4 potential to be very serious indeed.

5 A. Yes.

6 Q. You just used the phrase "leper". You had to tell
7 employers, you had to tell medical professionals about
8 your condition, and you said in your statement that's
9 how you felt. You felt like a leper. Is that right?

10 A. Yes, because even though my colleagues were all
11 medical professionals, there was still a degree of
12 ignorance, and still is, about blood borne viruses and
13 people just presume that your sexual and drug history
14 must be -- that there must be some sexual or drug
15 history and you are always asked about it, even though
16 you have an incidence in your life that is quite
17 obviously the cause of what is happening.

18 People still run through the routine of having
19 to ask you, which at the beginning you don't mind but
20 the 95th time you've got to go through it is quite
21 soul destroying and you end up becoming quite
22 depressed about it and worthless, and I think I felt
23 a lot less confident about myself and actually at that
24 point, there was no treatment for it and I actually
25 removed myself from clinical nursing and became

1 a teacher of resuscitation to nurses, doctors and
2 other hospital staff and I had no contact with
3 patients at all.

4 Q. You'd suffered physical symptoms as well.

5 A. Yes.

6 Q. What were the worst elements of the physical symptoms?

7 A. Tiredness, immense tiredness, which I just put down to
8 having two young children but it was a lot worse than
9 that. I still managed to work full-time but then at
10 the end I would be absolutely pole axed and I would
11 almost fall asleep driving home. I was exhausted and
12 on my days off I would try and sleep as much as
13 possible, even if it was just during the day if my
14 husband was home and would look after the children
15 I was just tired all the time, aching, like I had flu,
16 really.

17 Q. In around 1995, you'd had another child at that point
18 and you were selected to take part in a clinical trial
19 and research project for interferon in Edinburgh.

20 What can you recall about the discussions that
21 you had with your consultant and the circumstances in
22 which the trial commenced?

23 A. Well, I arrived in Edinburgh pregnant and the
24 consultant obstetrician informed, because of the
25 von Willebrand's disease informed the haematology

1 department who then informed the hepatology department
2 and I went round the houses and saw everybody and, at
3 the time, because of the high incidence of drug
4 addicts in Edinburgh I think that they had
5 a particular interest in trialling interferon A. So
6 asked that when I had delivered the baby would I be
7 willing to go into the trial and I, obviously, because
8 there was no other treatment at the time said, yes,
9 I would and so I was entered into the trial of
10 interferon A which at the time wasn't an oral
11 preparation. It was a three times a week subcut
12 injection.

13 Q. Just before we talk a little about the interferon
14 trial, whilst you were in hospital, having had your
15 newborn baby, you were put in a side ward and you
16 weren't allowed to have your newborn baby with you to
17 ensure that you didn't have -- that she didn't
18 contract hepatitis C and you weren't allowed to breast
19 feed, you said in your statement.

20 A. No, the delivery, I was originally on the beginning of
21 the list. They were going to do me first, and then
22 information filtered down that I was hep c positive.
23 So then I was put on the end of the list as a dirty
24 case and had to wait until everybody else had been in
25 and then at the end I went down to theatre only to

1 find -- I'd chosen to have an epidural so I could
2 remain conscious but, in the end, when I went down to
3 the theatre I wish I'd chosen to have a general
4 anaesthetic because everybody was dressed up like
5 a martian as well as you obviously expect masks but
6 people had heavy duty masks on, they were double
7 gowned they also had plastic aprons on and they were
8 wearing visors, so it was just humiliating and very
9 upsetting.

10 Q. So the course of interferon, the trial, it was an
11 18-month course?

12 A. It was.

13 Q. You had to inject yourself three times a week.

14 A. Yes.

15 Q. What can you recall about the side effects of that
16 trial?

17 A. Awful, awful. You just felt like you had flu
18 constantly, aching, swollen joints, difficulty getting
19 up and downstairs, difficulty walking. I had no
20 option because I had a young baby, a young child, and
21 also a severely handicapped child to look after, so
22 I put down a lot of the tiredness to that but it was
23 in excess to that. It was just awful. I struggled
24 really to remain on the trial.

25 But the early stages of it, when I was being

1 tested, it was working; so that was a huge incentive
2 to stay on it because if I could clear the virus,
3 I just hoped that I would completely feel well again
4 and so, therefore, I did complete the 18 months.

5 Q. During that process you described in your statement it
6 took quite a toll on your family life, your ability to
7 look after your children --

8 A. I was very depressed.

9 Q. -- and on your mental health?

10 A. Yes. Because I'd only taken maternity leave. I was
11 going to go back to work. I was unable to go back
12 full time so I went back part-time nights and still
13 managed to do it but it required my parents coming to
14 live with us for a short period of time because taking
15 the interferon and the children, it was just too much
16 and my choice of job had to change.

17 I did coronary care instead of intensive care
18 because that wasn't invasive and, of course, I had to
19 go through the rigmarole of telling my employers
20 again.

21 Q. What was the outcome of the treatment?

22 A. It was successful. After about eight months I think
23 I had completely cleared the virus but the team in
24 Edinburgh thought to make sure I should complete the
25 18 months and I did. I took their advice and

1 I completed the 18 months.

2 Q. You have talked in your statement about how you were
3 treated by others when you informed them of the
4 infection.

5 You give a particular example in relation to
6 seeking dental treatment. What can you tell us about
7 that?

8 A. Once I knew I was hep c positive, as a responsible
9 person and when you fill in a questionnaire, of
10 course, when you attend a dentist you have always got
11 to fill in and you fill it in truthfully. So I had to
12 fill in I was hep c positive and I had more than one
13 occasion where I was refused treatment because they
14 said they didn't have the facilities for treating
15 people with blood-borne viruses and wouldn't take me
16 on as a patient. So I tended to have to go to
17 hospital departments where they were used to dealing
18 with people with blood-borne viruses.

19 Q. But even having your dental care in the hospital, you
20 describe it being very different from how you would
21 have expected it to be in terms, again, of the
22 precautions that were being taken.

23 A. Yes, because again at that period people were being
24 extra safe and so you were treated like a leper,
25 always at the end, always separate instruments, always

1 called the dirty instruments. They would be the
2 instruments that would be saved for people with hep c
3 and AIDS and this would always be made -- drawn to
4 your attention that that was what was happening and,
5 of course, the ancillary staff would always come and
6 have a look at you, the dirty patients at the end of
7 the list, which is soul-destroying.

8 Q. You have told us already about the experience when you
9 gave birth to your third child in Edinburgh. The way
10 you put it in your witness statement is you felt like
11 you were being treated like a plague victim?

12 A. Mmm.

13 Q. Now, you have tested negative for a number of years
14 now.

15 A. Yes.

16 Q. But I think it's right you still get this response
17 when you seek medical treatment and I wondered if you
18 could tell us a little about that.

19 A. Yes, unfortunately. I was tested routinely at first
20 at six monthly intervals then 12-monthly intervals and
21 when it got that I was five years down the line still
22 negative, the consultant haematologist told me that
23 the research had shown that that would probably be
24 indefinite and, therefore, I did not need to keep
25 presenting and having being tested because, of course,

1 simple things like applying for a mortgage and things
2 like that always resulted in great difficulty for my
3 husband and I. So very often I was missed off because
4 it would just muddy the waters and we'd have to have
5 AIDS and hepatitis screening and so I just remained
6 off it.

7 So -- sorry, I've forgotten the question now.

8 Q. You described in your witness statement how you
9 continue, even when you've been clear of the virus for
10 many years, to still be treated by some medical
11 professionals as if you still have the virus.

12 A. As if I've still got it, yes, exactly. Recently, and
13 it depends which hospital you go in and what policies
14 and procedures you have, I've recently been in
15 hospital because I had breast cancer and had
16 a mastectomy and a reconstruction, no problem
17 whatsoever with that hospital because everyone is
18 treated the same and, therefore, I was not treated as
19 a dirty patient. I was not shoved at the end of the
20 list and it was hugely relieving. It was very good.

21 But then you can go to another hospital whose
22 policies and procedures are completely different and
23 even if you are negative you are still guilty until
24 proven innocent, so I will be asked to have another
25 test.

1 I don't mind now but I do feel that if I am
2 a risk and I've got numerous negatives in my notes,
3 why aren't they asking everybody who comes through the
4 door, because I'm probably be the only person that day
5 who can show them a line of negative results whereas
6 they have no idea about other people's statuses. That
7 occurred recently when at the age of 60 you're called
8 for, where I live, a routine colonoscopy for screening
9 for bowel cancer and I was routinely asked to go for
10 that and, of course, you've got to go for
11 a pre-procedure consultation.

12 So I went for this with the specialist nurse and
13 was told in no uncertain terms that -- I had been
14 given my time and date and the consultation was just
15 routine -- but she actually changed the date and the
16 time because she said, "Oh, I notice you have been
17 hep c."

18 "Well, yeah, I'm negative now."

19 "Oh well, you'll have to have it done again.
20 You'll have to go at the end of the list and we'll
21 have to use the dirty scope", at which point I'd just
22 had it and I just said, "Why is this happening? Is
23 everybody on the list", there were six people on the
24 list, "are they all being tested for hep c?"

25 "No."

1 "Well, why am I being tested for hep c?" At
2 that stage I'd been negative for 23 years and I must
3 have had at least 23 tests saying I'm negative for
4 hep c. I'm negative for HIV. Why am I having it
5 done?

6 In the end, just -- I capitulated and I had it
7 done and yet again there was another negative. No
8 apology, nothing and ended up didn't have to have the
9 dirty scope. So whoopee.

10 Q. What in general terms has been the impact of, first of
11 all, the infection itself and then the treatment on
12 your family life and your social life?

13 A. I think over the course of the years I had had periods
14 of depression which required treatment and so,
15 therefore, I can't say what I would have been like had
16 I not been depressed, but the treatment for depression
17 wasn't particularly pleasant nor was having
18 a depression pleasant, and that on top of having
19 hepatitis and the treatment interferon, obviously,
20 impacted on my ability to pursue my career and I think
21 in the end I more or less gave up on my career.

22 During the interferon, I went back to work just
23 part-time so I finished my -- because you had to go
24 back for a certain length of time for the maternity
25 leave or you had to pay the money back, all the rest

1 of it, so I managed to complete that.

2 But because I was still in the middle at that
3 point of interferon I could not return to work
4 full-time and therefore enrolled and was accepted to
5 do -- with the University of London to do an
6 extra-mural law course and I got all the material and
7 started but I had to disband it because I had this
8 huge brain fog, tiredness, and I just couldn't do it,
9 so I gave that up as well. Never given anything up in
10 my life, and it started a chain of events where
11 I started not believing in myself, just if -- I just
12 thought that things were unattainable and so
13 I wouldn't pursue things anymore, so a complete change
14 in personality. I'd been very confident and would
15 give lectures and go in front of a lecture theatre of
16 maybe 150 people, wouldn't be able to do that now.
17 Completely changed.

18 Q. You had had a particular concern and worry because one
19 of your children also has von Willebrand disease, same
20 genotype?

21 A. Yes.

22 Q. You have been worried that they could be given
23 cryoprecipitate and be infected themselves?

24 A. Yes.

25 Q. And to the extent that you put yourself on

1 a particular medical trial to try and address that.

2 A. Yes.

3 Q. What was that?

4 A. Well, he was diagnosed when he was quite small, he was
5 about two, and by this stage I had had the hepatitis
6 and I was quite adamant that -- I knew I had had non-A
7 non-B, I didn't know at that time I had C, but I was
8 adamant that he was not having it and I was not
9 risking it.

10 And so I went to a children's hospital where
11 they were doing some research and I said if he -- he
12 has it quite mild like I did -- but if he, for
13 instance, were to have an operation is there any other
14 treatment and they said, yes, you could have DDAVP,
15 which was IV and how would I realise that that would
16 work in his genotype and they said, "Well, it's
17 exactly the same genotype that you have, so if you
18 have the trial we could almost 100 per cent be
19 confident that it would work for him".

20 And so I put myself forward for the trial, and
21 was admitted and had a series of infusions with lots
22 of blood tests and it did work and so, subsequently,
23 when he was small and he went to school, he always had
24 a card and so the school would know that utterly and
25 absolutely we refused for him to have blood products

1 because we knew that the DDAVP would work.

2 Subsequently, I had that myself and I've had
3 numerous operations just under DDAVP and an operation
4 recently where I had nothing whatsoever and nothing
5 happened.

6 Q. You have told us about how you had to tell employers,
7 medical professionals and the impact that had on what
8 had been your work ambitions. You I think had
9 support, obviously, from your immediate family and
10 close friends but you felt you couldn't tell your
11 extended family?

12 A. No.

13 Q. And that was because of the fear of stigma?

14 A. Well, also the complete ignorance really of the -- if
15 there was ignorance with medical profession, which
16 I had found quite a lot of, it wasn't unusual to
17 expect that the general population would be equally
18 ignorant and people start extrapolating and obviously
19 try to protect themselves and their children and
20 I didn't want people keeping me at arm's length
21 because people start thinking you can get it from
22 hugging, kissing, shaking hands, touching the same
23 light switch.

24 I've seen nurses pushing meals into people with
25 hepatitis C with a window pole because they thought

1 they would get it from just handing a tray to people.
2 You think if medical people are doing that what on
3 earth are the general population going to be like? So
4 I just didn't tell people.

5 Q. Then very finally in terms of the questions I wanted
6 to ask you, Mrs A, you made an application to The
7 Skipton Fund and you found it, I think,
8 a straightforward process and you received some
9 assistance in return but you for many years had no
10 knowledge whatsoever that The Skipton Fund existed.
11 Is that right?

12 A. No, it was brought to my knowledge by the consultant
13 haematologist who asked me why I hadn't heard of it
14 and sort of put my name forward and filled some forms
15 in for me.

16 Q. That was some time in the 2000s?

17 A. It was, yes.

18 MS RICHARDS: Thank you. Those are the questions I have
19 for you Mrs A.

20 Sir?

21 SIR BRIAN LANGSTAFF: I have none. It remains for me to
22 thank you very much indeed, Mrs A, for coming to give
23 your evidence and to your supporter for supporting
24 you.

25 A. Thank you.

1 SIR BRIAN LANGSTAFF: It will be convenient I think to
2 take a short break.

3 MS RICHARDS: Yes.

4 SIR BRIAN LANGSTAFF: Shall we say 20 minutes. That
5 should give people long enough to get a cup of tea or
6 just to stretch their legs. Then we will have our
7 third and final witness of the day.

8 MS RICHARDS: Thank you, sir.

9 **(2.59 pm)**

10 **(A short break).**

11 **(3.23 pm)**

12 SIR BRIAN LANGSTAFF: Ms Richards, I understand the next
13 witness would like to be known as Lesley.

14 MS RICHARDS: That's right, sir.

15 SIR BRIAN LANGSTAFF: Would Lesley like to come forward to
16 give evidence.

17 **LESLEY BROWNLESS, affirmed**

18 **Questioned by MS RICHARDS**

19 MS RICHARDS: Lesley, you've got von Willebrand disease.

20 A. I have, yes.

21 Q. And you have described that very vividly in your
22 statement. It means your blood clots but the blood
23 doesn't stick to the wound. Von Willebrand factor is
24 a bit like the glue that helps the clot form a plug
25 over a wound, similar to having mild haemophilia?

1 A. Yes.

2 Q. And you've got mild von Willebrand disease?

3 A. Yes, I have.

4 Q. And that was diagnosed when you were a child?

5 A. Yes.

6 Q. You have had blood products whilst under the care of
7 the Newcastle Victoria Royal Infirmary in the earlier
8 '70s?

9 A. Yes.

10 Q. Then Leeds St James University Hospital from 1975
11 onwards?

12 A. That's correct.

13 Q. When generally would any kind of blood product
14 treatment be given to you and for what reason?

15 A. Early doors, it was mainly when I had perhaps a nose
16 bleed that was quite heavy or if there was some kind
17 of minor surgery, a tooth extraction. It was all sort
18 of given in case just to protect me as a cover.

19 However, later they did start to give me DDAVP
20 but that stopped working and I have had surgery since
21 without because they thought the DDAVP was working and
22 without any problems at all. So I think that kind of
23 shows the mildness of the von Willebrand's disease.

24 Q. If we can look at an extract from your records.

25 Paul, it's 1111002.

1 That should come up on the screen in front of
2 you, Lesley. If we can turn it round so it's
3 landscape and could we go to the second page. I'm
4 sorry, there is only one page.

5 So we can see from this, Lesley, we've got --
6 picking it up from 1982, we see references there to
7 cryoprecipitate.

8 A. Yes.

9 Q. And then 1986 Leeds Factor VIII (BPL)?

10 A. Yes.

11 Q. 1986 Leeds Factorate. That's the Armour product?

12 A. Yes.

13 Q. You don't think this is a complete record, do you?

14 A. No, there's things not on there that I know I've had
15 in the past.

16 Q. You recall getting the cryoprecipitate but you recall
17 it being different from the factor products you
18 subsequently had?

19 A. Yes.

20 Q. What was the difference from your perspective?

21 A. I always seem to remember the cryo was very cold and
22 it was administered via a drip. In fact, many times
23 if I'd had nose bleeds and I had to go into hospital
24 just for some treatment, the nose bleed may well have
25 stopped by the time I got there but they still carried

1 on and gave me the treatment because normally a phone
2 call in advance they would thaw it out, so it wasn't
3 as cold when we got there.

4 There was often a second bag as well that went
5 in which was to, I don't know, stop it feeling so cold
6 or something to that effect they used to say, so that
7 was how I remember cryoprecipitate.

8 At some point in 1985, I believe, and I do think
9 it's somewhere in my records but it's not on here,
10 I attended Leeds A&E department with what was probably
11 a stiff neck or a pulled muscle, it was quite painful.
12 It didn't seem to want to go. So they treated it as
13 an internal bleed which is something I didn't really
14 suffer from, and the product they brought to give me
15 was in a very large syringe and the lady -- like
16 I say, it was in 1985 so I'd only just started hearing
17 about HIV at that point and when the lady went to give
18 me it, I said to her, quite naively, "I hope there's
19 no AIDS in that", and she says, "No, no, it's all
20 heat-treated now", and it was totally different. It
21 was quite warm when it went in and within I would say
22 maybe 20 minutes of that being administered, I came
23 out in blisters all over and they kept me in, admitted
24 me that night, assured me that it was a one-off, it
25 wouldn't happen again and I had to return the

1 following evening and they gave me some more and it
2 happened again, although not as bad as it had the
3 night previous and they just said all it means is from
4 now on we have to give you a more purified version.
5 I didn't know what that meant but that's what they
6 said.

7 From -- probably from that day on I have got an
8 itch that I've always described as not a skin itch as
9 such but it's coming from inside of me and from that
10 day on within a few months I was started on
11 antihistamines which I take to this day and I've taken
12 all those years and I do believe that's where it came
13 from.

14 Q. So we'll talk about your diagnosis in a while but you
15 think that the infection that you got with hepatitis C
16 was in consequence of the factor products that were
17 administered to you on that hospital visit in 1985?

18 A. Yes.

19 Q. You think you've got some haematology records.

20 A. I have got haematology records, yes.

21 Q. You are going to check them, aren't you, and see
22 whether you can come up with a specific date for us?

23 A. Yes.

24 Q. Your Mum did a statement which you have exhibited to
25 your witness statement. I don't need to bring it up

1 on screen, but she says in that -- her name is
2 Dorothy -- she says in that that whilst you were
3 a child, she was never given any advice on any
4 potential risks involved in receiving any kind of
5 blood or factor product treatment.

6 When you turned 18, when you became an adult, do
7 you recall whether any advice or warnings were given
8 to you on any of the occasions when you received
9 factor products?

10 A. Never.

11 Q. Now you were diagnosed with hepatitis C when?

12 A. I've always thought it was 1995. Going back over some
13 more records that's possibly '94, that was the first
14 time I got told. I was never brought in by the
15 haemophilia centre or anything to, you know, even
16 though I was on the radar they never contacted me. In
17 fact, I had been visiting the clinic and nobody had
18 told me anything about hepatitis C. I'd never heard
19 of it and it was only through bulletins I used to get
20 from The Haemophilia Society that sort of had
21 something on the front saying that I think it might
22 have been 90 or 95 per cent of people treated with
23 blood products will have probably got hepatitis C, and
24 it was on that information that I contacted my
25 haemophilia centre and asked could I go in and see

1 them.

2 Q. And you saw a consultant, a consultant haematologist?

3 A. Yes.

4 Q. Who told you that you were hepatitis C positive.

5 A. Yes.

6 Q. What information were you given and what impression
7 were you given of the seriousness of the condition?

8 A. He was really flippant. It was just like, "Yes, it's
9 positive", you know, and that was more or less it and,
10 of course, I was quite concerned "but isn't this bad"
11 and you know that kind of attitude and he just says,
12 "All of my patients have got it", and it was a case
13 of, "Just go away and get on with your life. You
14 know, we'll monitor your blood and, you know, we'll
15 keep a check on it", but it was nothing to worry
16 about. That was the impression I was given.

17 Q. You've said in your statement you were made to feel
18 a nuisance for bothering them.

19 A. Eventually, yes, eventually I was because there was
20 very little information about there and I was given
21 none by them and the information that I found myself
22 was quite scary. You know, it was full of statistics
23 of 20 per cent will go on to get this and 20 per cent
24 will die. So it was quite scary really and I suppose
25 at that time I had three young children, so it was

1 even more frightening because I'm thinking if I die
2 what's going to happen to them. You know, it was
3 really worrying.

4 So I did what I could to find out what I could
5 and, of course, I went back and I'm saying -- and
6 bearing in mind I had been quite poorly for a number
7 of years and I was then becoming aware that the
8 problems I'd been having were the same problems that
9 other people with this were having, so I went back to
10 him and I would say, "Well, I've got this, I've got
11 that". I was I felt -- you know, he made me feel that
12 I was being a nuisance.

13 He said to me, "Do you want to go on treatment?"
14 Well, I'd seen some scary stuff about so I said, "Do
15 I need it?"

16 "No, no."

17 "I don't really want to."

18 "Okay then", he said, "we'll give you a liver
19 biopsy", and I was sent home to think about it.
20 I went back and I said, "I don't want a liver biopsy,
21 you know, because I know it can be dangerous for
22 haemophiliacs". That's what I'd read. He says,
23 "Well, do you want to go on treatment?" I says, "Do
24 I need it?" He says, "Well, no, but, you know, it
25 appears that you are not going to be happy until we

1 give you something".

2 It was at that point that I lost all confidence
3 in him as a haematologist and for the next few years
4 I didn't attend very often. In fact, I had the
5 haemophilia nurses ringing and saying you need to come
6 in, you really need to come in, but it did put me off
7 going because I had no faith and from then on when
8 I did go in I'd just tell him I was fine.

9 Q. You described it as a dark time in your life?

10 A. It was a very dark time, very.

11 Q. Why was that?

12 A. Because I had the three children, small. I wasn't
13 with their father any longer. They were my
14 responsibility, you know. I was there to bring them
15 up and give them a good life and that didn't appear to
16 be what was going to happen. It was not knowing, you
17 know, and I'm one of these people, I need to get
18 things straight in my head and I cannot settle until
19 I do but the information just wasn't out there for me.

20 Q. You've said in your statement you feel you should have
21 been given more information, you should be kept
22 informed, you should have been offered counselling to
23 help you deal with what you felt was a bombshell?

24 A. Absolutely.

25 Q. And that you weren't offered any help or assistance at

1 all?

2 A. No, no. I think counselling could have made a big
3 difference to sort of making you realise you're not
4 just alone. I ended up, because I didn't know anybody
5 else, you know, I wasn't a regular at the haemophilia
6 centre, so I didn't know other people in the same
7 situation. I ended up having a pen pal in Malta who
8 had hep c. I didn't know where she got it from but
9 that was my only sort of contact at that time.

10 Q. You did go and see your GP but your GP said you
11 effectively knew more about it than they did?

12 A. He did, yes. They said that on several occasions.

13 Q. Now, you obviously were aware you were being tested
14 for hepatitis C because you'd actually initiated that
15 process.

16 A. Yes.

17 Q. If we could just look in your records, please, at
18 1111006, please, Paul, we can see here documents which
19 show or appear to show your understanding is testing
20 for HIV.

21 A. Yes.

22 Q. Were you aware that you were being tested for HIV at
23 any time?

24 A. Never, no.

25 Q. Were you told that you had been tested and were

1 negative?

2 A. No -- not at this point anyway.

3 Q. How was it that you eventually found out that you had
4 been tested for HIV and that you were HIV negative?

5 A. This was 1985 I see that they did tests, but in 2008
6 when I was about to start treatment, I went in to see
7 my consultant and he asked me my HIV status and I said
8 I've no idea. So he flicked through my records and he
9 said, "Oh yes, negative". That was the first time
10 I was ever aware that I'd been tested.

11 Q. Then if we look, please, Paul, at 1111005, you will
12 see there vCJD data. The handwriting is yours; is
13 that right?

14 A. It is, yes.

15 Q. If we look across the top, we can see there:

16 "At risk? Yes. Patient notified? No.
17 Assessed date 21 February 2005."

18 So were you told at any point that you had been
19 assessed at risk of vCJD?

20 A. I never got hold anything with regard to tests or any
21 data like that but I did get a letter through the post
22 from the haemophilia centre, sort of what everybody
23 else I think got was quite a lengthy letter explaining
24 that we're all classed as at risk because we've had
25 blood products. But, you know, you don't know how at

1 risk, you don't know if you have had that batch number
2 or not so, again, there was another worrying
3 consequence, you know, and just prior to that I had
4 had -- my daughter had -- they'd asked my daughter --
5 asked me if I'd allow them to give my daughter a blood
6 transfusion I'd refused and they told me, they tried
7 to assure me that blood was -- it's all safe now, and
8 I had said, "But you don't know what's round the
9 corner and unless my daughter is on death's door
10 I won't allow you to give her a blood transfusion",
11 and not long after I received the letter about the
12 variant CJD, so I was quite happy and my daughter was
13 never on death's door and her blood recovered, you
14 know, on its own.

15 So that's why, you know, I always think there's
16 always possibly something round the corner.

17 Q. Can you tell us about the physical effects, first of
18 all, of having hepatitis C.

19 A. As I said earlier, I had the effects before I knew
20 I had it and I didn't know what it was. So visiting
21 your GP, again, you feel like they think you're
22 a hypochondriac because you go in there with no
23 reasons for these. The pain, the fatigue, as other
24 people have said it's debilitating, and the joint
25 pain, the mental -- the sort of brain fog. For me,

1 I always describe it as like I'm running on batteries
2 and they go dead. Even to move your mouth to talk is
3 an effort when you hit that sort of point. So it was
4 more about pain, joint pain, fatigue, not wanting to
5 do anything you know and, of course, depression comes
6 in as well which I think if you're depressed on top of
7 the physical symptoms it does make it worse as well.

8 Q. You've said in your statement you described the mental
9 and physical effects of the infection as devastating,
10 spent almost 30 years of your life on antidepressants
11 and painkillers.

12 A. Yes.

13 Q. Not being able to get up in the morning, not being
14 able to go to work, not being able to provide for your
15 family. You have had debilitating fatigue and pain.

16 A. Yes.

17 Q. What impact did it have on your family life generally?

18 A. Well, for me, it was more me because I felt guilty
19 because I couldn't give the children what I thought
20 they should have.

21 To the children it was probably normal because
22 it's all they never knew. You know, I had this when
23 they were born but mentally it affects you because you
24 know what you were about.

25 I mean, I didn't want to have to have benefits.

1 I wanted to be self-sufficient and provide for my
2 children. That was very important to me. I had
3 a good career which was gone, you know. So it
4 impacted on me more so. It impacted on my mother
5 quite a lot because she had to pick up the slack and
6 look after the children a lot. She had to go
7 part-time to be able to do that.

8 So, you know, massively from my point of view.

9 Q. You'd had a promising career as an entertainer,
10 singing?

11 A. Yes, yes, I was a professional singer.

12 Q. And you had to give that up to the pain and the
13 fatigue and the depression?

14 A. Yes.

15 Q. You had a desire to study law?

16 A. Yes, I did, I thought I always wanted to. People did
17 tell me that I had a flair for it and it's something
18 I wanted to do and I thought once I get the children
19 into full-time school that would be something I would
20 have liked to have followed but it never came.

21 Q. That had an inevitable impact, your inability to work,
22 on finances and on what you were able to do for your
23 children.

24 A. Yes.

25 Q. You've had a number of other health consequences

1 associated with the hepatitis C, I think. Fibro
2 myalgia.

3 What can you tell us about that?

4 A. Yes, I was actually diagnosed with fibro -- I think it
5 was after the hepatitis C. Yes, it was after I was
6 diagnosed with that, which again is another
7 debilitating illness that I believe it is
8 knowledgeable that it is connected and many people
9 with hepatitis C do suffer from that. So, you know,
10 whether or not I would have had it anyway I don't know
11 but I do see there's a big connection and, again,
12 that -- there's a lot of, like, overlapping symptoms
13 of hepatitis C, fibro myalgia, so it's hard to define
14 which one is which although I do believe the fibro is
15 caused by the hepatitis C.

16 Q. You have also had cancer and pre-cancerous cells
17 found.

18 A. Yes.

19 Q. You have at least a suspicion, I think, that those may
20 have been associated with the infection?

21 A. There's evidence out there to show that people with
22 hep c have a higher chance of developing cancer, any
23 type of cancer. Obviously, liver cancer's more, you
24 know, notable but, yes, I do believe that.

25 Q. The form of cancer that you had was thyroid cancer?

1 A. Yes.

2 Q. You eventually went through a year of treatment in
3 2008-2009?

4 A. Yes.

5 Q. What was the treatment like?

6 A. Not very pleasant. It's like you know every Monday
7 night I would inject, knowing that I was going to, you
8 know, within a couple of hours I was going to be full
9 of flu or that's how it felt. You couldn't make any
10 plans ever during that treatment, not plans that you
11 thought -- you know, you knew you were going to be
12 able to stick to. It wasn't very nice at all. It
13 wasn't pleasant for the children.

14 But it was at that point that I told the
15 children because they were a little bit older by then,
16 but prior to that it had been hidden from them.
17 I didn't want them to be involved in anybody saying
18 anything because we did have -- there was an episode
19 with a neighbour of mine that knew the children had
20 bleeding disorders so -- knew I had, so presumed I'd
21 got HIV and decided to shout it out to the street one
22 day in anger, which was quite awful.

23 So it was a way of protecting the children.
24 I didn't tell them until, you know, they were old
25 enough and just prior to me going on treatment. But

1 it was a horrible, horrible time. Looking back now,
2 I went on treatment with a promise that "if I cured",
3 as they say, I would be okay and that never happened.

4 Q. Did you clear the virus with the treatment or do you
5 not know?

6 A. I do know but I don't think I cleared it. That's the
7 word they choose to use, but I think I would like to
8 say the virus is undetectable with today's tests. In
9 the future, you know, when they get finer tests they
10 may be able to detect again, but I don't think it's
11 cleared, I don't think it's gone.

12 Q. Your symptoms themselves, as I understand your
13 statement, haven't gone?

14 A. No, no.

15 Q. So your statement says in terms:
16 "I felt worse than before I started the
17 treatment and still do to this day."

18 A. Yes.

19 Q. The infection and the treatment and all the
20 consequences you have described also took its toll on
21 your relationships.

22 A. Yes, yes.

23 Q. You'd recently married I think in 2007?

24 A. Yes.

25 Q. And with a childhood sweetheart who came over from

1 Canada who you married?

2 A. Yes.

3 Q. Then you began treatment a few months later and what
4 happened?

5 A. Well, he came over to England earlier than we'd
6 planned because I was going to start treatment and
7 I just think the person that he thought I was, that
8 I wasn't that person on treatment and things just went
9 pear shaped quite quickly, and I suppose we thought,
10 well, this is a big mistake what we've done. Without
11 the treatment, I don't think it would have been like
12 that because I'm quite a laid-back person, and so he
13 returned to Canada and I never saw him again.

14 With hindsight, I'm quite happy about that,
15 but ...

16 Q. You had from the treatment mood swings, your hair fell
17 out, unbearable pain, your skin and nails and teeth
18 were all affected. You had problems sleeping?

19 A. Yes. I did consider stopping treatment at some point
20 because my hair was falling out and I just --
21 everything felt so sore and just didn't feel right and
22 I did have to reduce the treatment a couple of times
23 due to I think it was the white blood cells dropping
24 too low or something and I did consider -- but my
25 haemophilia nurse talked me into continuing and I did.

1 I did it for the year. It wasn't nice.

2 Q. Were you ever offered any counselling?

3 A. No, never.

4 Q. Do you think that would have been helpful?

5 A. Absolutely. At the time it would. I don't think it

6 would now because, you know, everything's already

7 deeply embedded, you know, and it was at the time that

8 I needed it. It wouldn't change anything now. It

9 wouldn't change how I felt then if that makes sense.

10 Q. Can I ask you about the financial assistance that you

11 sought from The Skipton Fund and Caxton. So you got

12 an initial Skipton Fund payment and that was used for

13 paying off debts, basic --

14 A. I actually took my children on holiday with it for the

15 first time abroad, yes.

16 Q. But you said it was more about the realisation that

17 that would probably be it, you wouldn't be able to

18 afford any other holidays?

19 A. Yes, it wouldn't be something I could continue.

20 Q. Then the Caxton Foundation. Sometime 2011 or after

21 2011, you were allowed some help from the Caxton

22 Foundation towards some furniture and repairs?

23 A. Yes.

24 Q. And some debt clearance?

25 A. Yes. Well, they actually asked me if they could come

1 out to my house and visit me, which at first I was
2 a bit reluctant because I thought they are coming to
3 spy on me to see what I've got and what I haven't got,
4 because you sort of the develop this type of mistrust.
5 But they came out and they were really quite good and
6 they came with a bit of a checklist that they weren't
7 just going to ask me what it was I needed. They were
8 going to say, well, you can you have this, you can
9 have that and, initially, they very, very good.

10 At that time I'd run up a little bit of credit
11 card debt putting my twins through college because the
12 2010 review we were sort of hoping that there might be
13 some changes in payments and I'm thinking, well, I'll
14 get them through college. There may be something
15 then. I will be able to pay it off. So I'd run up
16 a little bit -- it wasn't much, so I asked them if
17 they would help me with that. They agreed that they
18 would, and I had to give them the details, and then
19 they said to me, "What we want you to do, we want you
20 to contact these two credit card companies and we want
21 you to ask them to reduce the amount you owe them",
22 and I says, "I'm not doing that". I said, "I've never
23 had bad credit in my life and I don't intend to start
24 now. I've never missed a payment", and they said,
25 "Well, you know, that's the only way we would do it,

1 if you can try and get a reduced amount".

2 So they agreed to do it for me and contact them
3 and I think it was probably almost a year later they
4 were still trying to do it, by which time I'd run up
5 more because I were having to pay that off the money
6 I was due to live on and sort of spend more. So when
7 the time finally arrived that they did pay it, they
8 paid the original amount, but I was obviously still
9 had more to pay back so I was back in the same
10 situation. I also found that they were paying on this
11 system of vouchers. They were ace, £10 vouchers, and
12 so I needed a washing machine so I got 30 vouches to
13 go to Currys with and, you know, you have got to stand
14 there and count these vouchers out.

15 Q. How did that make you feel?

16 A. Just so embarrassed.

17 Q. You cried afterwards you've said?

18 A. Oh God, yes.

19 Q. Because you felt it was degrading?

20 A. It was very degrading. Then I needed a bit of repair
21 work done in the house and you've got to get quotes,
22 obviously, from different tradesmen. But when those
23 tradesmen come to do the work, you've got to say --
24 they have got to be aware that you're not going to pay
25 them on the day, they've got to wait for a cheque once

1 they'd given you an invoice. So when the cheque
2 comes, it's got "Caxton Foundation" on it; so it's not
3 hard to find out what is wrong with me. I found that
4 embarrassing to the point where I did take it up with
5 them and, eventually, they agreed that if you could
6 get somebody to pay for it for you, they would
7 reimburse it but only after they had agreed it.

8 Q. One of the problems you have described is the
9 difficulties of the application process itself and all
10 the documents you had to get and the quotes and all
11 the rest of it is something you were having to do when
12 you have the brain fog and the fatigue that you
13 described.

14 A. Absolutely. I mean, once applied for what they call
15 a clothing grant for me and the children and you've
16 got to get two quotes for everything. So it would be,
17 if you can imagine, six pairs of socks for that child,
18 six for that, two quotes for them, two quotes for
19 them ... every single item two quotes and then they'll
20 only give you a set amount anyway. So it doesn't
21 matter what those quotes are, they will give you -- it
22 was £250 I believe per person. They will give you it
23 then, no matter what it came to, what you asked for.
24 Even if you asked for less, they would still give you
25 the 250 probably, then you have to give all the

1 receipts. So you have to shop for it all.

2 Now, if they allowed you in money in advance you
3 could have bought it online. A lot of people were
4 poorly and it's difficult to go out there and shop for
5 these things, you know, when you're not feeling up to
6 it.

7 So the whole system it was horrendous, you know
8 and I believe many people just didn't apply because of
9 it and that's how it became for me in the end.

10 Q. You once with I think with some other in a similar
11 position to yourself --

12 A. Yes.

13 Q. -- went to Alliance House in London, where a number of
14 the trusts and schemes were based, at the invitation
15 of Mr Harvey?

16 A. Yes.

17 Q. How were you made to feel on that occasion?

18 A. We had a meeting at some point with Mr Harvey in
19 Coventry and he had said we were welcome to drop in at
20 any time.

21 I believe at this point Mr Harvey was on sick
22 leave and there was a new -- somebody else taking
23 over, and we called in, we were down at other
24 meetings, and we called in because I'd never seen what
25 it looked like and some of the members had and when we

1 got in, they -- it was because somebody had sort of
2 like opened a door and guided us along. They were
3 astounded that we were there and they just all stopped
4 and looked at us as if we were -- you know, "What you
5 doing here?"

6 It transpired later that they were going to call
7 the police, that we'd sort of like bombarded their
8 offices and I mean one of us was, not me, but one of
9 them was in a wheelchair. We were older people, you
10 know. We'd been invited by Mr Harvey to do that and
11 it did get really quite nasty with the threat of
12 solicitors and things.

13 Q. You'd said in your statement you were mortified that
14 they would stoop to these levels to the very people
15 they were paid to help?

16 A. Absolutely.

17 Q. Lesley, in 2001 you wrote a letter to the then Prime
18 Minister, Mr Blair --

19 A. I did.

20 Q. -- which sought to summarise your situation and the
21 effect of the hepatitis C and everything else upon
22 you.

23 A. Yes.

24 Q. Do you want me to read it out or would you like to
25 read it?

1 A. I'm happy for you to.

2 Q. You want me to, okay. Could we have it up on screen
3 please. It is 1111007:

4 "Dear Mr Blair, I am a 39-year old mother of
5 three children and I have hepatitis C. When I was
6 diagnosed with hepatitis C in 1994, I was absolutely
7 horrified. What was this disease? What will happen
8 to me? Will I get ill? Will I die? Who will look
9 after my children? They were just some of the
10 questions flying around in my head, and the worst
11 thing was I had no-one to give me answers, no-one to
12 talk to that knew very much about it. Counselling
13 would have been welcomed with open arms at this point
14 in time. My consultant told me the news and I was
15 just expected to go away and get on with my life.

16 "Over the next few years I read as much as
17 I could to find on the subject, spoke to as many
18 people as I could who had the slightest bit of
19 information and discovered the ailments I had suffered
20 over the years were actually symptoms of the
21 hepatitis C, the following being some of which
22 I suffer on a regular basis; severe fatigue, total
23 lack of energy, even an effort to talk, nausea, joint
24 pains, depression, itching all over body all day every
25 day, mood swings, problems concentrating, loss of

1 appetite, sore throat, swollen glands, general
2 feelings of ill health, and other things I would
3 rather not mention.

4 "On top of all these symptoms are various other
5 factors that have had a major impact on my and my
6 children's lives. I am unable to work which is
7 a great financial loss to the whole family. We don't
8 get to go on holiday, have treats and the little
9 extras that most people take for granted and above all
10 that my dignity has been taken away from me as I would
11 want nothing more than to be able to hold down a job
12 and provide for my family the way I had planned.
13 I cannot plan ahead as I never know from one day to
14 the next how I'm going to feel. Consequently, my
15 social life is pretty non-existent.

16 "My children say to me when I'm ill in bed, 'Why
17 can't you be like a normal Mum? Why do you have to be
18 in bed so much?' That breaks my heart. I was
19 a single Mum as I split up with my partner due to
20 stress and pressure we were under due to the
21 hepatitis C. At this point I was faced with another
22 set of problems. Would anyone want me? If so, do
23 I tell them straight away or do I wait? Would they
24 be frightened off? And the sad truth was some people
25 were. So not only was I suffering all the stress and

1 anxiety and worrying about the future, but I had to
2 face it alone.

3 "This is just a brief account of the effects the
4 hepatitis C virus has had on my life. It would take
5 hours to explain the impact it has had on me and my
6 family also. I hope you can find it in you to listen
7 to what we, the haemophilia community, are saying and
8 compensate us accordingly for the pain and suffering
9 we've had to endure through no fault of our own. And
10 secondly to allow us all the use of recombinant factor
11 so that we can be spared the pain and worry of any
12 other virus that is lurking around the corner. And
13 last but not least let us have a public inquiry to
14 find out why this was allowed to happen in the first
15 place. Then perhaps lessons will be learned to avoid
16 this happening again. I would appreciate it if you
17 could reply to me giving your views. I look forward
18 to hearing from you in the very near future."

19 Did you ever had a reply, Lesley?

20 A. No.

21 Q. Is there anything else you would like to say?

22 A. Yes. I've written a little bit but it's because of
23 this being so short notice I needed to write it down
24 if that's okay. But, first of all, I'd just like to
25 say that I personally welcome this Inquiry with open

1 arms and I intend to engage with it thoroughly
2 whenever possible.

3 One of the biggest impacts on me over the last
4 25 years, aside from my health, is the fact that
5 I haven't been able to give my children the life that
6 I thought they deserved and not being able to work and
7 provide for them and give them some of the nicer
8 things in life that they would have had had this not
9 happened to me. Not being able to spend quality time
10 with them, playing with them when they were younger
11 due to the constant pain and fatigue and to this day
12 it haunts me.

13 I have three children and three grandchildren.
14 All but one have inherited the von Willebrand's
15 disease from me because we don't know -- it didn't
16 come from anywhere previously -- and it terrifies me
17 that maybe there's more deadly viruses out there that
18 may come along in the future and affect them.

19 It's for this reason that I personally have
20 campaigned for years along with many others to get
21 where we are today and my legacy to my children and my
22 grandchildren will be to finally get justice and the
23 truth and, most importantly, that lessons are learned
24 so this is never allowed to happen again.

25 Q. Thank you, Lesley. I am just going to turn my back

1 and ask Ms Gibbs, who as you know represents you, and
2 ask if there's anything to add.

3 (Pause)

4 There's just one matter Ms Gibbs raised. We
5 looked previously at the HIV tests and you confirmed
6 you were unaware you were being tested?

7 A. Yes.

8 Q. You've said in your statement that you think that that
9 was possibly being used for research, that that sample
10 was stored and used for research because you were
11 unaware of any other purpose for which it would be
12 done.

13 A. Absolutely, yes.

14 Q. Thank you.

15 SIR BRIAN LANGSTAFF: Thank you very much indeed, Lesley,
16 and, as you say, this was at short notice; so you are
17 deserving of particular thanks for coming and giving
18 us the benefit of your evidence.

19 A. Okay, thank you.

20 SIR BRIAN LANGSTAFF: That concludes the business for
21 today. I'm told that there is some tea available, but
22 just on this floor, should anyone wish to have it as
23 they leave. What do we have tomorrow?

24 MS RICHARDS: We have three witnesses tomorrow: Matthew
25 Johnson, Jacqueline Britton and Joan Edgington.

1 SIR BRIAN LANGSTAFF: Thank you very much. It will be
2 10.00 tomorrow. So that anyone who is making plans
3 for next week may be alerted in advance, next week we
4 plan to start in the morning at 10.30. It may give
5 people a little more time to get here in the morning.
6 It may help with travel arrangements.

7 **(4.02 pm)**

8 **(Adjourned until 10.00 am the following day)**

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