

Thursday, 2 May 2019

1
2 (10.03 am)
3 **SIR BRIAN LANGSTAFF:** Good morning.
4 **MS RICHARDS:** Good morning, sir.
5 **SIR BRIAN LANGSTAFF:** The first witness this morning,
6 Clair Walton, wishes to be known as Clair, I think.
7 **MS RICHARDS:** That's right, sir.
8 **SIR BRIAN LANGSTAFF:** Mrs Walton -- Clair, I'm sorry.
9 **CLAIR WALTON, affirmed**
10 **Questioned by MS RICHARDS**
11 **MS RICHARDS:** Clair, I'm going to ask you, first of all,
12 about your husband Bryan and what happened to him and
13 what happened to you, and then I'm going to ask you
14 about the dealings that both you and Bryan had with
15 the Macfarlane Trust.
16 So you are the widow of Bryan Walton?
17 **A. Yes.**
18 Q. Bryan was treated with Factor VIII products over
19 a number of years?
20 **A. Yes.**
21 Q. He was infected as a result of that treatment with HIV
22 and with hepatitis C?
23 **A. Yes.**
24 Q. He died in 1993 of AIDS-related illnesses?
25 **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

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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

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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?

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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**

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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:

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- 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**

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- 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**

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- 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

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- 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?

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- 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

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- 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.**

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- 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**

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- 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**

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- 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

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- 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

18

- 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

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- 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

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- 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.**

23

- 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**

22

- 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**

24

- 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**

25

- 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.**

27

- 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?

26

- 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**

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- 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**

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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

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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

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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,

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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 his 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

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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

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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

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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

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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 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 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 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

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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

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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

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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

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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

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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.**

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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?

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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**

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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

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- 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**

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- 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**

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- 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.**

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- 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**

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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?

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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.**

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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**

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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**

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- 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.**

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- 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

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- 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**

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- 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**

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- 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

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- 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

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- 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

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- 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 ..."

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- 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?

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- 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**

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- 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

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- 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 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 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 **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 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 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 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

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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,**

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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

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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."

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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?

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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**

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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

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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".**

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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 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 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 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

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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

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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

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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

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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 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 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 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

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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**

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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

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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 knowledgeable 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**

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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 **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 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 **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 The next witness could be known by a number but
2 from what Clair was saying I wouldn't want to call her
3 anything like 1823A or witness 104. We know that she
4 is anonymous. I will have more to say about that at
5 2.20 but we shall know for our purposes we will call
6 her Mrs A, shall we?

7 **MS RICHARDS:** Yes, sir.

8 **SIR BRIAN LANGSTAFF:** Very well. Mrs A at 2.20.

9 **(1.16 pm)**

10 **(Luncheon Adjournment)**

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