

Wednesday, 24 July 2019

(10.04 am)

SIR BRIAN LANGSTAFF: Good morning. Our first witnesses this morning are Colin and Janet, are they?

MS RICHARDS: Yes, sir.

SIR BRIAN LANGSTAFF: Colin and Janet, please.

JANET SMITH, sworn

COLIN JOHN SMITH, sworn

Questioned by MS RICHARDS

MS RICHARDS: Janet and Colin, you are here to talk about your late son, Colin.

JANET: Yes.

SIR BRIAN LANGSTAFF: We've got a photo of Colin we're going to display on the screen. Paul, it's 1523005.

I understand this is one of your favourite photos of Colin.

JANET: It is.

MS RICHARDS: We'll keep that up other than when we have documents to display.

Colin was born in 1982.

JANET: Yes.

MS RICHARDS: He was the youngest of your four sons.

JANET: Yes, he was.

MS RICHARDS: When he was about four months old he was diagnosed with haemophilia A. How did that come

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bottom where it says:

"Drugs nil, never given VIII, concentrate or cryo."

So at that time, when Colin was seen by Professor Bloom, he was identified as a child who'd never been given any form of treatment for his haemophilia.

JANET: That's right, yes.

SIR BRIAN LANGSTAFF: May I just ask, if we go back to the top of the page, the underlining under "not treated" is original, is it?

MS RICHARDS: We only have photocopies and it is in the photocopy. I don't know whether, Colin, if you know because you looked at your son's records at the time. Is that underlining that has been added subsequently, do you know, or is that the original?

COLIN SNR: No, I think that's the original.

SIR BRIAN LANGSTAFF: Thank you.

MS RICHARDS: That was 21 July. The nursing records show that Colin was given Factor VIII concentrate for the first time by a doctor the very next day.

JANET: Okay.

MS RICHARDS: 22 July 1983. Then we're going to look at one further document. It's 1523003.

We'll see it's a letter from Professor Bloom

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about, Janet?

JANET: It was through my sister, actually. [Redacted]

I was changing his nappy and she saw a tiny bruise on his knee and she said that's a haemophiliac bruise.

She knew straight away and we got him tested and that's how we found out that he had severe haemophilia.

MS RICHARDS: His care was transferred, his haemophilia care, from the Royal Gwent Hospital which was your more local hospital to the Heath Hospital in Cardiff under the care of Professor Bloom.

JANET: Yes.

MS RICHARDS: We're going to look a handful of notes from Colin's medical records which I know you've seen.

Paul, could we have up on screen, please, 1523002.

We can see this is dated 21 July 1983; so Colin would have been about a year old at this time?

COLIN SNR: Yes.

JANET: Yes.

MS RICHARDS: We can see the consultant is identified as Professor Bloom and the first line of the clinical notes says this:

"Known haemophiliac -- not treated."

Then, Paul, if we go down towards the bottom of the page, please, we can see there just before the

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dated 3 August 1983. I'm just going to read the first paragraph. It was addressed to your GP and it says this:

"I saw Colin in the clinic again this week.

I understand that he turned up in the paediatric ward about a week ago having fallen down and hit the back of his head. He received an intravenous injection of one bottle of 250 units of Factor VIII concentrate and made an uneventful recovery without any evidence of intercranial bleeding. The concentrate which we used was prepared from British blood from the Lister Institute. However, all these materials carry the risk of hepatitis, particularly non-A non-B, but this is something that haemophiliacs have to accept."

Were you told, either of you, by Professor Bloom or any of the other treating doctors or clinicians at the time that there was a risk to Colin of developing non-A non-B hepatitis?

JANET: No, absolutely not.

MS RICHARDS: We're going to look at another document I know you've seen shortly before coming in this morning.

Paul, it's 1523007, please.

This is a document dated 24 June 1983, so it's roughly a month before that entry that we looked at.

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1 **JANET:** Yes.

2 **MS RICHARDS:** And roughly a month before Colin received

3 his first treatment. If we just look at first,

4 please, Paul, at the second page so we can see who

5 this is from.

6 It's from Professor Bloom in his capacity as

7 Chairman of the Haemophilia Centre Directors

8 Organisation and Dr Rizza, who was secretary to the

9 same organisation.

10 **JANET:** Yes.

11 **MS RICHARDS:** If we go back to the first page please,

12 Paul, we can see that the letter is headed:

13 "Acquired Immuno Deficiency Syndrome", in other

14 words, AIDS.

15 **JANET:** AIDS.

16 **MS RICHARDS:** And it says this:

17 "A meeting of reference centre directors was

18 held on May 13, 1983, to discuss this problem in

19 haemophilia, its implications and our recommendations.

20 So far one possible case has been reported to our

21 organisation. This patient conforms to the

22 definition ..."

23 **SIR BRIAN LANGSTAFF:** Published.

24 **MS RICHARDS:** "... published", Thank you, sir, "by the CDC

25 in Atlanta Georgia but cannot be considered as

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1 between NHS products or American products?

2 **JANET:** It was never spoken about. We just believed the

3 doctor. You know, they were treating Colin and it

4 sounds terrible but he was like a god to us,

5 Prof Bloom, because he was looking after my son. So

6 why would I ask any questions about? We thought he

7 was getting the best treatment possible.

8 **MS RICHARDS:** The August 1983 letter to your GP that we

9 looked at referred to British products having been

10 used to treat Colin on that first occasion but we're

11 going to look at one further document.

12 Paul, it's 1523006.

13 These are treatment records for Colin and we can

14 see that a month after that first treatment that we've

15 discussed on 22 August 1983 Colin was treated with

16 Kryobulin, a commercial product. He was treated again

17 with Kryobulin the following month on

18 19 September 1983. We then see a treatment record for

19 the following year, Elstree, that's the British

20 product, and then we see possibly 12 June 1984, it's

21 not clear, what looks like Armour, another commercial

22 product, and then Elstree products.

23 **JANET:** Yes.

24 **MS RICHARDS:** Can you recall any discussion with you at

25 all about using these commercial products instead of

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1 a definite case. We are not aware of any other

2 definite patients amongst the UK haemophilia

3 population. At the above-mentioned meeting on May 13

4 the following general recommendations were agreed:

5 "(1) for mildly affected patients with

6 haemophilia A or von Willebrand's disease and minor

7 lesions treatment with DDAVP should be considered

8 because of the increased risk of transmitting

9 hepatitis by means of large pool concentrates in such

10 patients. This is in any case the usual practice of

11 many directors."

12 Then this:

13 "For treatment of children and mildly affected

14 patients or patients unexposed to imported

15 concentrates many directors already reserve supplies

16 of NHS concentrates (cryoprecipitate or freeze dried)

17 and it would be circumspect to continue this policy."

18 Was anything from that, any reference to any

19 possible risk of AIDS communicated to you as Colin's

20 parents?

21 **JANET:** No, nothing at all. Nothing.

22 **MS RICHARDS:** Were you told anything about any risks

23 associated with the use of the Factor VIII product?

24 **JANET:** No, nothing at all.

25 **MS RICHARDS:** Were you told anything about differences

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1 NHS products?

2 **JANET:** No, not at all.

3 **COLIN SNR:** As far as we were aware it was all the same

4 product.

5 **MS RICHARDS:** You have both expressed the views in your

6 witness statements that Colin was regarded by

7 Professor Bloom as a previously untreated patient,

8 which as a matter of fact he was --

9 **JANET:** Yeah.

10 **MS RICHARDS:** -- in July 1983, and that he was

11 deliberately treated with Factor VIII for the purpose

12 of research; is that right?

13 **JANET:** Yes.

14 **COLIN SNR:** Yes.

15 **MS RICHARDS:** You have described him, Colin, in your

16 statement as an easy target. What did you mean by

17 that?

18 **COLIN SNR:** I believe he was, yeah. He was just unlucky

19 enough to be diagnosed with haemophilia at the same

20 time as these trials were starting.

21 **MS RICHARDS:** You have also referred, Colin, in your

22 statement to your recollection that blood samples

23 would very frequently be taken from Colin.

24 **COLIN SNR:** Yes, almost every time we went to the centre

25 they'd take blood. They never explained why. They

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1 just said checking his blood count.
 2 **MS RICHARDS:** You said this in your statement, Colin:
 3 "There was a letter in Colin's medical records
 4 stating that the hospital were unable to send any more
 5 blood samples as the family have withdrawn the
 6 patient."
 7 You have assumed that was a letter sent to
 8 pharmaceutical companies and you have a recollection
 9 of seeing it in 1989.
 10 **COLIN SNR:** Yes.
 11 **MS RICHARDS:** But when you have looked at Colin's records
 12 more recently you cannot find that letter.
 13 **COLIN SNR:** Yeah, I did see it as I was walking between
 14 the wards. They gave us the records to carry, so
 15 being nosey I did have a look. That was just after
 16 we'd decided that we would take Colin from the
 17 hospital.
 18 **MS RICHARDS:** Paul, we can have the photo back now, thank
 19 you.
 20 You have also described in your statement, both
 21 of you, the impression that you had that
 22 Professor Bloom was very keen for Colin to transfer to
 23 his care; is that right?
 24 **JANET:** Oh yeah, very much so.
 25 **MS RICHARDS:** What gave rise to that impression?

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1 I was very distressed, I don't know why, and then Prof
 2 found out about it and he actually came back down and
 3 took us into a room, but the damage had already been
 4 done. He told us in a corridor.
 5 **MS RICHARDS:** What do you recall about that, Colin?
 6 **COLIN SNR:** Well, we were still coming to terms with the
 7 fact of haemophilia. There was no record of it in the
 8 family. We'd only just learnt about that, then he
 9 says, "HIV. He's one of the unlucky few", which we
 10 assumed there was one or two cases, but as it turns
 11 out there's thousands.
 12 **MS RICHARDS:** Were you given any information either at
 13 that stage or over the following weeks or months about
 14 the nature of the condition?
 15 **JANET:** No.
 16 **MS RICHARDS:** What course it might take?
 17 **JANET:** No. The only thing that really sort of stood out
 18 was Colin being Colin he used to sleep in with his
 19 brother. They had bunk beds but always, you know
 20 what's kid are like, they just get in together and he
 21 had a severe nosebleed and I phoned the hospital and
 22 they just said, "Did Daniel get any blood on him?" and
 23 I said, "No". They said, "Leave Colin, let him bleed,
 24 it doesn't matter. Get Colin, clean him, bring him
 25 down and throw his mattress away. Just burn his

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1 **JANET:** He just said he, you know, they had the proper
 2 unit there, haemophilia unit, and it was the best care
 3 that you could get.
 4 **MS RICHARDS:** Colin continued to receive Factor VIII as
 5 we've seen from those records.
 6 **JANET:** Yes.
 7 **MS RICHARDS:** He also, however, as his records show
 8 received cryoprecipitate on a number of occasions.
 9 **JANET:** Yes, he did.
 10 **MS RICHARDS:** Was there ever any discussion with either of
 11 you about why cryoprecipitate on one occasion, why
 12 Factor VIII on another?
 13 **JANET:** Nothing at all.
 14 **COLIN SNR:** No.
 15 **MS RICHARDS:** How did you learn that Colin had been
 16 infected with HIV?
 17 **JANET:** He was about two/two and a half. He was in
 18 hospital because he had a bad chest and Prof Bloom
 19 came down to see him and then called us out and then
 20 just told us that he's HIV, in the corridor, with
 21 children running around and other parents, and -- but
 22 we still didn't comprehend what that meant to us
 23 because it had never been discussed. Nobody had told
 24 us what HIV was or, you know, we just thought, "Oh
 25 okay", you know, and we just went back into Colin's --

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1 mattress". That's, I suppose, when we realised how
 2 serious this was.
 3 **MS RICHARDS:** You have also described in your statements
 4 how the awareness of how serious it was came not from
 5 the doctors but from seeing adverts on TV.
 6 **JANET:** Oh, those adverts were devastating. They
 7 destroyed a lot of people. You know, we started
 8 getting "AIDS dead" written on the house, not little
 9 letters, 6-foot letters on the side of the house,
 10 crosses in the door, car vandalised, people going
 11 across the street from us, you know, threatening to
 12 take their children out of school if Colin went there.
 13 It was devastating.
 14 **MS RICHARDS:** There is no -- in the medical records that
 15 we have, there's no HIV or HTLV-III (as it would then
 16 have been called) test and there's no record of any
 17 communication to you by Professor Bloom of the
 18 diagnosis.
 19 What's your best estimate of when it was that
 20 you were given this information in the corridor in the
 21 way you've described?
 22 **COLIN SNR:** We assumed he was about two but actually after
 23 Colin passed we asked when he was infected and they
 24 said it could have been his first treatment and that's
 25 all the information we had on that.

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1 **MS RICHARDS:** Your statements suggests that this
 2 conversation took place when he was about two which
 3 would have been 1984 or thereabouts.
 4 **JANET:** Yes.
 5 **MS RICHARDS:** Had you known before that conversation that
 6 Colin was even being tested for HTLV-III.
 7 **JANET:** No. You know, we took Colin to the hospital in
 8 good faith, you know. We trusted that doctor. We
 9 trusted people to look after our son and, no, they
 10 were just testing him all the time.
 11 **MS RICHARDS:** How did Colin's infection affect him in the
 12 early years after 1984/1985?
 13 **COLIN SNR:** He wasn't too bad to start with. He'd get the
 14 occasional cold which would linger a little bit longer
 15 than normal but other than that he carried on as
 16 normal. Colin was Colin, he just went round the house
 17 destroying stuff.
 18 **JANET:** The other kids they knew if he cut himself or
 19 anything they just classed him as having special
 20 blood, not because of the haemophilia, nothing else,
 21 and you know they'd just come to us and say, "Mum,
 22 Colin's got special blood", and they knew not to touch
 23 him or -- we never had to -- they were only kids
 24 themselves. I didn't want to put that pressure on
 25 them of knowing Colin was HIV.

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1 1988, had his health been deteriorating?
 2 **JANET:** Yes. Yes, he lost a lot of weight. Kept getting
 3 bad chest but, you know, we took him to the hospital
 4 with bad chest and I said to Prof that, you know, he
 5 was complaining of chest pains and he just looked at
 6 me, smiled and said, "He's got a good imagination that
 7 kid". That's what he told me, and he had pneumonia
 8 twice but we were never, ever told that. We only saw
 9 that when it was in his records.
 10 **MS RICHARDS:** You have also seen in his records, I think,
 11 a reference to suspected meningitis which was also not
 12 told to you.
 13 **JANET:** Yeah, never told nothing.
 14 **MS RICHARDS:** What was the effect of Colin's health on his
 15 schooling?
 16 **JANET:** He didn't go to school very much --
 17 **COLIN SNR:** No, he missed a lot of school.
 18 **JANET:** -- he missed a lot of school, yeah.
 19 **COLIN SNR:** We couldn't actually get him into school
 20 unless he had a private nurse because parents were
 21 threatening to withdraw their children.
 22 **JANET:** I mean, he loved school. He did love school. He
 23 had such beautiful friends there, you know, and it's
 24 just a shame parents weren't like that, you know, with
 25 the abuse that we had. But he loved school but he

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1 **MS RICHARDS:** In 1988 or thereabouts Colin started to
 2 receive treatment with AZT.
 3 **JANET:** Yes.
 4 **MS RICHARDS:** What can you recall being told about AZT by
 5 Professor Bloom?
 6 **JANET:** Wonder drug, that's what Prof -- he told me it was
 7 a wonder drug and he wouldn't be able to start it
 8 because they need to send away for it, but it could
 9 save his life -- and it didn't, did it?
 10 You know, I can remember going to a meeting and
 11 somebody just pointed a finger at me and said, "Get
 12 him off it, you're killing him", and I think they were
 13 right.
 14 **MS RICHARDS:** Did you raise those concerns with
 15 Professor Bloom?
 16 **JANET:** No.
 17 **MS RICHARDS:** He told you that this was the right
 18 treatment.
 19 **JANET:** He told me it would save his life. It was
 20 a wonder drug is what he told me.
 21 **MS RICHARDS:** You have said in your statements you trusted
 22 what Professor Bloom said to you.
 23 **JANET:** Of course I did. Of course I did, he's looking
 24 after my boy.
 25 **MS RICHARDS:** By the time that Colin started on AZT in

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1 became too ill to go really. I mean, sometimes he'd
 2 just say, "I think I want to go school today", and
 3 we'd put him in a wheelchair, wrap him up and we'd him
 4 literally to the door and then he'd say, "I want to go
 5 home now".
 6 **MS RICHARDS:** Now, the time came when Colin had to spend
 7 more time in hospital.
 8 **JANET:** Yes.
 9 **MS RICHARDS:** He would suffer frequent chest infections.
 10 **JANET:** Yes.
 11 **MS RICHARDS:** Colin, I think you used to take him to
 12 hospital. You drove him to hospital.
 13 **COLIN SNR:** Yes.
 14 **MS RICHARDS:** Sometimes if you were running late you would
 15 play a game with Colin. What was that?
 16 **COLIN SNR:** Well, we played lots of games. His favourite
 17 was counting different coloured cars. His best hobby,
 18 he loved driving so we'd sit in the car park and drive
 19 him round on my lap. He'd do the steering; I'd do the
 20 pedals.
 21 We got stopped one night by the police going to
 22 the hospital and they gave us an escort and my car
 23 blew up on the way home because they went faster than
 24 I did. But he just loved -- he loved life. He often
 25 went to hospital just to make sure it was still there.

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1 That's how trusting he was. He was ill. He'd want to
 2 see the doctors. He'd walk in and see the doctors on
 3 the ward and say, "Okay, you can take me home now".
 4 He didn't want treatment. He just wanted to see them.
 5 **MS RICHARDS:** You have described in your statements what
 6 a brave boy he was.
 7 **JANET:** Oh, he was.
 8 **MS RICHARDS:** Never asked what was wrong.
 9 **JANET:** No.
 10 **MS RICHARDS:** He never complained.
 11 **JANET:** No. Never.
 12 **MS RICHARDS:** Never asked if he was going to be okay.
 13 **JANET:** No.
 14 **MS RICHARDS:** But you think he knew ultimately that he was
 15 going to die.
 16 **JANET:** He started to sort of -- I mean, he loved drawing.
 17 He adored drawing but he started to draw like crosses,
 18 headstones. He'd only use black and things like that
 19 and I can remember because my Mum died not long before
 20 him and we were going to the cemetery and I was crying
 21 and he just looked at me and said, "Mummy, why are you
 22 crying? You're selfish". He said, "You don't cry".
 23 He said, "You know where she is", and for a six year
 24 old to say that, well, just gobsmacked me.
 25 **MS RICHARDS:** You have recounted in your statement that

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1 **JANET:** Oh, we did, yes.
 2 **MS RICHARDS:** What can you recall about that, Colin?
 3 **COLIN SNR:** Well, I made a mistake, I had to tell the
 4 family, [redacted] told a friend, next we know
 5 everybody knew. So I got up one morning and there was
 6 "AIDS dead" written across the side of the house in
 7 good six foot letters, so I'm painting that out.
 8 The following day there was "AIDS dead"
 9 scratched into the front door with a big cross. It
 10 was dark at that time I remember and I was painting
 11 the door in the dark and the boys come out and asked
 12 what I was doing, so I just said, "Your Mum didn't
 13 like the colour", and they accepted that.
 14 Then "AIDS dead" scratched on the car. Constant
 15 phone calls day and night, he should be put down, put
 16 on an island, shouldn't be allowed to sleep with his
 17 brothers. It just went on and on. We stuck it as
 18 long as we could but before I done something silly if
 19 I found somebody, we decided to move, which is what we
 20 did.
 21 **MS RICHARDS:** You have also described how you lost
 22 friends, parents didn't want their children playing.
 23 **COLIN SNR:** No.
 24 **JANET:** No, and do you know I think, you know, we had that
 25 all the time but I think the worst one was Colin's

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1 after a row with his brother he said, "You're going to
 2 miss me when I'm gone" --
 3 **JANET:** Yeah, he did.
 4 **MS RICHARDS:** -- and "You can have all my toys".
 5 **JANET:** "You can have my toys", yeah, he did.
 6 **MS RICHARDS:** As Colin spent more time in hospital you
 7 didn't want to leave him there alone so one of you
 8 would be there and you said in your statement that
 9 that obviously had an impact upon your ability to be
 10 there for your other three boys.
 11 **JANET:** It did.
 12 **MS RICHARDS:** They spent a lot of time with other family
 13 members at this stage.
 14 **COLIN SNR:** Family and friends, yeah, day-to-day. Didn't
 15 know where they were.
 16 **JANET:** They lost really, you know, when Colin, because we
 17 wouldn't leave him, they lost their mummy and daddy
 18 too, the other kids, because we weren't there.
 19 **MS RICHARDS:** You tried to keep Colin's infection private.
 20 **JANET:** Yes.
 21 **MS RICHARDS:** But because of what was in the news about
 22 haemophilia and AIDS and what was known locally people
 23 put two and two together.
 24 **JANET:** Yeah.
 25 **MS RICHARDS:** You suffered a lot of abuse.

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1 godmother. She had a little girl and she used to come
 2 to our house and then she didn't come anymore because
 3 she didn't want her daughter playing with Colin and
 4 that was his godmother.
 5 **MS RICHARDS:** You had a member of your family, Colin, who
 6 insisted on separate cutlery.
 7 **COLIN SNR:** Yeah, she turned up one day with a knife and
 8 fork and a cup and plate and said, "These are Colin's,
 9 special", not to touch them, and I don't think I've
 10 spoken to her since actually.
 11 **MS RICHARDS:** You also had people not wanting their
 12 children to go to the same school as Colin and his
 13 brothers.
 14 **JANET:** Oh, they threatened to take -- if Colin went to
 15 that school they threatened to take them out but the
 16 teachers amazingly said, "No, you carry on, because
 17 he's coming to this school". They were very, very
 18 good.
 19 **MS RICHARDS:** You have explained in your statement how you
 20 were known locally as the AIDS family.
 21 **JANET:** AIDS family, yeah, for a long time.
 22 **MS RICHARDS:** Your other boys were bullied at school. You
 23 didn't know at the time because they wanted to protect
 24 you but they were called things like AIDS kids.
 25 **JANET:** Yeah.

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1 **COLIN SNR:** We didn't find that out until they were
2 adults. They just told us one day.
3 **JANET:** They had a lot of abuse.
4 **MS RICHARDS:** What was the effect on your employment,
5 Colin?
6 **COLIN SNR:** I lost my job because the boss was scared of
7 people finding out and losing customers. So within
8 a week I got another job. I thought I'd take a night
9 shift job. Nobody around, nobody would know me, but
10 the day I was going to start he called me into the
11 office and said he couldn't start me, so from that
12 point on I was basically unemployable. I went to the
13 Job Centre. They wouldn't let me sign on. They just
14 paid me my benefits, and that was it until Colin died.
15 I informed them that Colin had died. Within
16 just over a week I'd had a letter saying get a job, so
17 that was the thought of them as well, you know.
18 **MS RICHARDS:** There came a point when Colin was very ill,
19 he'd been in hospital and you decided you wanted to
20 take him home. Can you tell us about that, Janet.
21 **JANET:** It was 19 December and Prof wanted him to stay in
22 hospital and we said, "No, we're taking him home".
23 Well, it was just before that and then we gave Prof
24 19 December we're taking him out whatever, and Prof
25 went mad because he said that he's got to die in

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1 **MS RICHARDS:** I am going to, with your agreement, just
2 read a few paragraphs from your son Daniel's witness
3 statement where Daniel talks about Colin --
4 **JANET:** Yeah.
5 **MS RICHARDS:** -- and his understanding as a brother close
6 in age to Colin of how Colin felt at the time. Daniel
7 said this:
8 "Colin knew he was dying. I slept in the Heath
9 Hospital with him during the last year of his life.
10 He spent the whole time there. He had a room which
11 was decorated with cards from friends and toys.
12 I remember playing with Lego and we got into an
13 argument. I said to him, 'I will break your Lego',
14 and he said, 'Do not do that, you will miss me when
15 I'm gone'. He lost a tremendous amount of weight and
16 had to be wrapped up in sheet blankets. He spent his
17 time from the age of five to six at home. If he was
18 having a good day when he was five or six he would go
19 to school in his wheelchair as he loved school."
20 **JANET:** Yeah, he did.
21 **MS RICHARDS:** "Other children loved him in school, which
22 I also attended. They knew he was very poorly but did
23 not know about the AIDS. He picked up infections very
24 regularly and was admitted to hospital around the age
25 of six.

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1 hospital. That was the first time we sort of realised
2 how ill he was. He has to die in hospital because
3 there's no undertakers that will take an AIDS patient.
4 That's what he told us.
5 We said, "Well, whatever, but he's coming out on
6 the 19th", and that morning Prof came down with
7 a Christmas tree for his room and I just said, "You
8 can stick that", and we just picked him up, undone his
9 drips, and took him home.
10 **MS RICHARDS:** Until that conversation had you been told
11 that Colin was effectively dying at this stage?
12 **JANET:** No. No.
13 **MS RICHARDS:** So that --
14 **JANET:** It came to us about I think Colin was about five,
15 wasn't he, and he said he's full-blown AIDS and still
16 we didn't realise because it was never explained to
17 us. Prof never sat down and talked to us about it or
18 what was going to happen or anything like that. We
19 were left to our own devices really because it was
20 never sort of -- it was just a matter of fact thing.
21 **MS RICHARDS:** So you learned essentially for the first
22 time that your 7-year old son was dying when the
23 Professor told you that you couldn't take him home
24 because he had to die in hospital?
25 **JANET:** Yes.

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1 "My grandmother passed away six months before
2 Colin. He mentioned that he was not scared of death.
3 He said he knew he was going to see her and she passed
4 away to be there for him and did not want to suffer
5 any more pain. He was very weak and could not move.
6 He had to be given a potty at the age of seven. He
7 was permanently on the drip. He was in a lot of pain
8 even when he was sitting down and at that time he was
9 very frail. As a child, I did not know what HIV was.
10 I was too young. I thought it was a name for his
11 special blood. A week before the Christmas my parents
12 demanded that Colin came home because they knew this
13 would be his last Christmas. My parents bought him
14 everything he wanted that Christmas."
15 **JANET:** Yes, a bike.
16 **MS RICHARDS:** "I was confused. I did not know how he was
17 going to die and did not understand it. I felt fear
18 as Colin and I were always together and my older
19 brothers were close. I was scared and worried about
20 who I was going to play with or sleep with. We had
21 just lost our grandmother. I was fully aware what
22 death meant. I knew I was never going to see him
23 again. Many emotions were running through my mind but
24 we had a truly fantastic Christmas together."
25 **JANET:** Yes.

24

1 **MS RICHARDS:** You spent that Christmas giving everything
2 that you could to Colin.
3 **JANET:** Yes.
4 **MS RICHARDS:** He died at home on 13 January 1990 aged just
5 seven years old.
6 **JANET:** Yes.
7 **MS RICHARDS:** Paul, could we just have up on screen please
8 1523004.
9 This certifies the causes of Colin's death and
10 if we go towards the bottom of the page, please,
11 Paul -- keep going down please, thank you:
12 "Certified cause of death, disease or condition
13 directly leading to death, PCP pneumonia; other
14 disease or condition leading to that, AIDS due to
15 contaminated Factor VIII infusion; other disease or
16 condition leading to that, haemophilia."
17 You have said in your statement, Janet, that the
18 devastation of having your child on your lap watching
19 the rise and fall of his chest and waiting for it to
20 stop is absolutely heart-breaking.
21 **JANET:** It was.
22 **MS RICHARDS:** You didn't, in fact, have problems with
23 funeral arrangements. You have said there was
24 a brilliant funeral director.
25 **JANET:** It was, yes.

25

1 because protecting each other I suppose so we didn't
2 talk about it with the kids but they missed him as
3 much as we did and we didn't realise that.
4 **MS RICHARDS:** Colin, you used to go to the cemetery.
5 **COLIN SNR:** Yes.
6 **MS RICHARDS:** And sit there and talk to Colin.
7 **COLIN SNR:** Not so much talk, as shout and rant and rave
8 to him for the things he'd done to us, put us through.
9 I knew it wasn't his fault but I always felt better
10 afterwards, so I'd tend to go to the cemetery on my
11 own at that point.
12 **MS RICHARDS:** You have also said in your statement that
13 you felt suicidal at times.
14 **COLIN SNR:** At times, yes.
15 **MS RICHARDS:** Daniel, as the brother who was the closest
16 in age to Colin --
17 **JANET:** Yes.
18 **MS RICHARDS:** -- says in his statement that his world
19 turned completely upside down and he withdrew into
20 himself a lot. He had shared a room with Colin and he
21 kept all Colin's things as a shrine to Colin.
22 **JANET:** It was a shrine, literally. We weren't allowed to
23 touch anything in that bedroom. Daniel had it all set
24 and it was his. He's still got all his cars now and
25 he's got children of his own. They can play with the

27

1 **MS RICHARDS:** The staff from the ward came to the funeral
2 because they had loved Colin.
3 **JANET:** They did, on the ward itself.
4 **MS RICHARDS:** After Colin's death, life fell apart for you
5 both.
6 Janet, can you describe that time.
7 **JANET:** Well, when Colin died, we couldn't talk about it.
8 If I went into the room, Colin would walk out or vice
9 versa. There was just this silence, you know. The
10 kids walking on egg shells and it was horrendous and
11 it all came to a head, really, the first Christmas
12 that we didn't have Colin and I can remember arguing
13 and I picked up a bottle of drink -- I don't drink.
14 I'm literally teetotal. I don't drink -- I picked up
15 a bottle and was going out of the house. I was going
16 to get in the car, drink it and just crash into a wall
17 or ... my other kids were screaming, "Mummy, mummy,
18 don't go, don't go, please", and that brought me back.
19 It brought us back, didn't it --
20 **COLIN SNR:** Yeah.
21 **JANET:** -- because we realised then those kids needed us.
22 **COLIN SNR:** I think we were mourning at different times.
23 If Janet had a good day, I was having a bad day and
24 vice versa.
25 **JANET:** We never talked about it, couldn't talk about it

26

1 cars but only when Daniel's in the room.
2 **MS RICHARDS:** Daniel's told us in his statement that he
3 used to sleep with Colin's clothes so that he could
4 smell him.
5 **JANET:** Yes.
6 **MS RICHARDS:** Daniel said he eventually had counselling
7 and that really helped him.
8 **JANET:** Yes.
9 **MS RICHARDS:** Were you offered counselling, the two of
10 you?
11 **JANET:** Eventually -- not while Colin was ill or anything
12 like that. It was after his death.
13 **COLIN SNR:** It was years later, wasn't it.
14 **MS RICHARDS:** Daniel's also described the effect on one of
15 his other brothers and how that other brother
16 sometimes would disappear, and you'd have to go
17 looking for him and he could be found sobbing on
18 Colin's grave.
19 **JANET:** Yes.
20 **MS RICHARDS:** You have said, Janet, in your statement that
21 in more recent years Daniel still struggled with the
22 absence of Colin in his life.
23 **JANET:** Yes.
24 **MS RICHARDS:** What was the position when Daniel got
25 married?

28

1 **JANET:** Well, he was, you know, excited about getting
 2 married, obviously, but he was so upset because he
 3 wanted -- he would have wanted Colin to be his best
 4 man. So what they done is Laura, his wife to be,
 5 sewed a little something of Colin's in her wedding
 6 dress and Daniel had one of Colin's cars with him
 7 because he felt then he was with him.

8 **MS RICHARDS:** You've both described in your statement that
 9 Colin remains a huge part of your lives every day.

10 **JANET:** Talk about him every day. Not sad, not, you
 11 know -- but pictures everywhere. The grand-kids, you
 12 know, they know who Colin is. They never met him but
 13 they just talk about him. It's just natural. It's
 14 just a natural thing that he comes up sort of every
 15 day, really, in some way or another.

16 And, you know, it's only a few weeks back that
 17 my granddaughter, she's six, she was out in the dining
 18 room and she was quiet. So we said, "Well, where's
 19 [redacted]?" and we went out there and she's just got
 20 her hands. And we said, "What are you doing?" She
 21 said, "I'm just praying to Colin" and then just ran
 22 back out and like it was just a normal thing. "I'm
 23 just praying to Colin", she said, because there's
 24 a picture of him there. That's just -- you know, we
 25 don't force it on them or anything like that. It's

29

1 of people think it's a bit sick that we still take him
 2 a card or a little present, but that's our way of
 3 dealing with things and that'll never stop.

4 I still get -- do you know, people think it's
 5 really strange but I still get like a Mother's Day
 6 card off Daniel off little Colin. I still get that
 7 now and I think if he stopped now, I'd think
 8 something's seriously wrong because it's always been
 9 the same.

10 **MS RICHARDS:** We've got a video to play but before we play
 11 that, is there anything further that either of you
 12 would like to say?

13 **JANET:** Gosh. Well, I'd just like to really say is
 14 I don't know where I would have been without Sue,
 15 Mark, Tainted Blood, all of those because without
 16 their support, you know -- I can just email any one of
 17 them and complain or get upset about something and
 18 there is always, always somebody at the end of Tainted
 19 Blood that will answer you. And we still need that.

20 It might be a long time ago but I'd be lost
 21 without them because that's the only support we get
 22 and that's the only support a lot of us get. And
 23 somebody will always answer you. In seconds somebody
 24 is there for you and that does mean a lot to all of
 25 us. I don't know where we'd be otherwise.

31

1 just the way they are with him.

2 **COLIN SNR:** [Redacted] is actually a female version of
 3 Colin. She does exactly the same things he used to
 4 get up to. That brings back a lot of memories because
 5 she's quite funny.

6 **JANET:** And she loves drawing, you know, and things like
 7 that. She's got a lot of Colin's mannerisms, you
 8 know.

9 **MS RICHARDS:** You've said in your statement, Colin, that
 10 Christmas is difficult because it's Christmas without
 11 Colin and also because it's close to the anniversary
 12 of his death.

13 **JANET:** Yes.

14 **COLIN SNR:** Yes, I hated Christmas because I knew when it
 15 was due because Janet always gets depressed. So, yes,
 16 for the first eight or nine years if I could have
 17 avoided it I would. But you had younger children, so
 18 you had to bite the bullet and pretend everything's
 19 fine.

20 **JANET:** But it's, you know, now -- it's sort of -- you
 21 know, we go over to Daniel's because he only lives
 22 across the road. We watch the grandchildren open
 23 their presents. They all come back to us and we all
 24 go straight up the cemetery. That's the first thing
 25 we do. We all take him a little -- you know. A lot

30

1 **MS RICHARDS:** Colin?

2 **COLIN SNR:** I just -- I've seen a lot of death in my life
 3 when I was in the forces, you know, in the Troubles in
 4 Ireland, violent and other. But that was training.
 5 You could handle that.

6 But there's no training for what was about to be
 7 dropped on us with what happened to Colin. There's no
 8 way a child should have to die the way he did. It
 9 wasn't pleasant. It still affects us now. And it's
 10 not just our son, there's lots of children have had to
 11 go through that. Most of the men campaigning today
 12 were actually children when they were infected. So
 13 that's something else that needs to be taken into
 14 account.

15 I could cope with death but not with the death
 16 of my son. I still have trouble today the fact that
 17 he's in a grave on his own, and the guilt will never
 18 go away.

19 **JANET:** We just need people to recognise that children
 20 were infected as well. We're talking about Treloars;
 21 we're talking about Colin; and Denise; the little boy
 22 Lee, he was ten -- ten. People don't realise just
 23 what this thing has done to people, you know, took
 24 lives, maimed people. You know, they are crippled
 25 with such horrible things, you know, and then when

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1 people come on the Tainted Blood and, you know,
 2 there's more devastation. It's always devastation.
 3 We need justice. We need something done about
 4 this. There's a lot of people who have lost their
 5 lives, children, husbands, and it's just so wrong.
 6 And I get really angry about it because something
 7 needs to be done about this.
 8 And thanks to this, we feel now maybe we're
 9 getting somewhere for the first time in all these
 10 years.
 11 **MS RICHARDS:** I am going to ask Mr Snowden if there's
 12 anything further he wants me to ask before we play the
 13 video. No.
 14 Paul, could we play the video, please.
 15 (Video played)
 16 Thank you for your evidence. Sir.
 17 **SIR BRIAN LANGSTAFF:** What you might have expected with
 18 a seriously ill child was sympathy and help. What you
 19 described in brutal terms is that what you got was
 20 rejection, vilification, and abuse to the extent that
 21 you ultimately could not talk about it to each other.
 22 It takes a very special kind of resilience to be
 23 able now to talk to everyone about what happened to
 24 you, what happened to Colin, and to tell us in the
 25 most moving of ways how you have managed to keep Colin

33

1 only I woke up and I was on a drip.
 2 **Q.** You had haemorrhaged very significantly.
 3 **A.** Haemorrhaged, yes.
 4 **Q.** Lost a lot of blood.
 5 **A.** Lots and lots, yeah.
 6 **Q.** And the next thing you remember is waking up with
 7 a blood bag hanging next to you?
 8 **A.** Yes.
 9 **Q.** It's your understanding that you had about eight units
 10 of blood at that point in time.
 11 **A.** I had five and they told me I couldn't go home just
 12 yet, I needed another three.
 13 **Q.** You were in hospital for quite a long time.
 14 **A.** Six weeks, yes.
 15 **Q.** And it obviously took some time to recover from that
 16 surgery and the further attention you needed. But
 17 after you were discharged from hospital, what was your
 18 health like?
 19 **A.** Well, you know, the op, it took me a long time to get
 20 over because I had a baby 18 months old and two other
 21 children. But as time progressed, yes, I did have
 22 lots of problems. I lost my teeth but I didn't know
 23 it was to do with what I had because I didn't know
 24 I had it. My hair, I had lots and lots of migraines,
 25 flu-like symptoms, and ...

35

1 alive for you. All I can do is say thank you.
 2 We will take a slightly longer break after that.
 3 11.30.
 4 **MS RICHARDS:** Thank you, sir.
 5 (10.50 am)
 6 (A short break)
 7 (11.34 am)
 8 **SIR BRIAN LANGSTAFF:** What does our next witness wish to
 9 be called?
 10 **MS FRASER BUTLIN:** Elaine.
 11 **SIR BRIAN LANGSTAFF:** Elaine, please.
 12 **ELAINE HUXLEY, sworn**
 13 **Questioned by MS FRASER BUTLIN**
 14 **Q.** Elaine, you underwent a total abdominal hysterectomy
 15 in 1976.
 16 **A.** Yes.
 17 **Q.** Can you tell us what happened.
 18 **A.** I had in the morning, the morning after the operation,
 19 I woke up about 5/6 o'clock in the morning and felt
 20 something running from ... and I told the lady in the
 21 next bed and as I was telling her I saw it was coming
 22 through the counterpane, bright red blood. So we all
 23 pressing our buzzers and the nurse came in, and she
 24 run back out. By the time the doctor came in it was
 25 running off the bed. I don't remember any more then

34

1 **Q.** You had lots of other health problems but it was never
 2 understood what was going on for you?
 3 **A.** No.
 4 **Q.** During this time, you worked as an NHS support worker?
 5 **A.** Yes.
 6 **Q.** You then became a blood donor?
 7 **A.** Yes.
 8 **Q.** Why was that? What motivated you to become a donor?
 9 **A.** I've always wanted to be a blood donor. I went to
 10 give blood before I had my hysterectomy but they told
 11 me I couldn't because my blood levels, iron levels,
 12 were low, so when I was able to then I was quite happy
 13 to give back what I'd received.
 14 **Q.** And you were a blood donor for about six years?
 15 **A.** Yes, nearly six years, yes.
 16 **Q.** How often did you give blood?
 17 **A.** Twice a year.
 18 **Q.** You have said in your statement you wanted to do that
 19 to give something back, having had blood yourself?
 20 **A.** Yes.
 21 **Q.** Then in March 1992 you received a letter from the
 22 Welsh National Blood Transfusion Service.
 23 Can we have that on the screen, Paul. It's
 24 2354004 and the first page.
 25 If we look at the very first section of the

36

letter, we can see that you are told that they tested your blood after your donation and have referred the sample for additional tests.

"In the light of these we now find that at some time in the past you have had an episode of viral jaundice which you would not necessarily have been aware of. There is a slight risk that the disease could be transmitted to patients receiving your blood which means we will be unable to use your blood for transfusion purposes. It is, therefore, with much regret that we have had to remove your name from the donor panel and must ask you not to give blood for transfusion purposes in the future. You yourself need not be concerned since it implies that you are probably just a healthy carrier, although it would be advisable for you to discuss the results with your own family doctor."

How did you feel when you first received this letter?

- A. I thought there was something seriously wrong, you know, and I went then to see the doctor and when he told me I had hepatitis C I just -- I just didn't know how serious it was. I just carried on with my life and I didn't have a clue.

- Q. Can you tell us a little bit more about what the GP

37

transfusion service commenced routine testing. If we look at points 3 and 4 it says:

"The disease is endemic in the community, with an antibody incidence among normal donors of about 1 in 1,000. This new ability to identify recent or past infection, with a fairly rapid case identification rate through the Blood Transfusion Service must not be confused with the emergence of an epidemic, which it is most categorically not."

Then if we look at point 8 under the heading of "Liver disease", the information to the GP was that clinical progression of the disease is impossible to predict. It gives general guidance that 50 per cent of those who have tested positive have reverted to normal liver function within six months and, over the page, 50 per cent retain liver function abnormalities beyond six months. One third of these, 17 per cent of the total, have definable hepatic inflammation liver biopsy, of which 10 to 15 per cent, 2 per cent of the total, progress to chronic active hepatitis or cirrhosis.

If we carry on down through the document:

"It is felt by some hepatologists that very few cases of serious liver disease due to hepatitis C occur in the community so for most people this is an

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told you at that point.

- A. He just, if I can remember rightly, he just said he would be putting me under the care of Dr Yap at the hospital, the liver specialist, and I was under his care every six months, I believe.

- Q. From your medical records there's a letter that was sent to your GP from the National Blood Transfusion Service. It's page 2 of the document we were looking at. We can see there on 19 March, so just a week later, the letter to the GP says that:

"This patient of yours recently attended one of our blood donation sessions and virological testing of her blood showed her to be positive for antibody to hepatitis C."

So you went to the GP the letter from the transfusion service had said you may simply be a carrier but by the time you got to the GP, you were told you were hepatitis C positive.

- A. Mmm.

- Q. Also in your records, and we can see it referred to in this letter, there was an information leaflet that was provided to the GP.

If we can have a look that, Paul, it's 2354005 and it's the second page is where it starts.

We can see there that it notes that the

38

incidental finding unlikely to cause serious disease or symptoms of any kind."

Over the page, the final recommendation is for clinical monitoring by intermittent assessment of liver function tests, et cetera, with referral to a gastroenterologist if deemed appropriate. Were you told anything by the GP about these sorts of figures of what the prognosis for your hepatitis C might be?

- A. No.

- Q. You said you were shocked when you were told that it was hepatitis C but that you just carried on with life.

- A. Yes.

- Q. Did you have any understanding at all of what it meant?

- A. No.

- Q. At that point when you were diagnosed with hepatitis C, you had been a blood donor for a number of years. What were your feelings about that at the time?

- A. I can't remember really but I just carried on with my life and, you know ...

- Q. You had blood tests every six months after your diagnosis?

- A. Yes.

40

1 Q. Until about 1995, and then you got very worried in
2 1995 about your hepatitis C?
3 A. Yes.
4 Q. What can you tell us about that?
5 A. Because it was coming on the media; it was coming on
6 the news.
7 Q. What did you see?
8 A. I saw that there was treatments out there and the next
9 time I saw Dr Yap, I mentioned that I'd seen
10 treatments available and I would like to give it a go
11 and he told me --
12 Q. Before we get to the treatment aspect, you had to go
13 back to your GP for a referral, didn't you?
14 A. Yes.
15 Q. What did you tell your GP about your concerns?
16 A. That I wanted to go further and get treatment.
17 Q. Can we have document T354004, please, page 3.
18 It's a letter from a GP trainee and the last two
19 paragraphs say:
20 "She has recently watched a Panorama programme
21 which has seemed to put considerable fear in her mind
22 with regard to the hepatitis C infection. She has
23 been to see Dr Napier who I believe is involved with
24 the Blood Transfusion Service who has told her she
25 should contact her GP and insist that she should see

41

1 A. Okay.
2 Q. If we have a look at T354004 and page 4, this is the
3 letter that was written after your referral back into
4 the hospital:
5 "Thank you very much for asking me to see
6 Mrs Huxley who was stated hepatitis C positive in 1991
7 by the Blood Transfusion Service. The test which was
8 used there was almost certainly first generation and
9 inaccurate and she has had no confirmatory tests done
10 since then."
11 Then the last paragraph:
12 "I've repeated the hepatitis C test and have
13 also asked for liver function tests. I will review
14 her in three weeks' time but I think the more
15 sophisticated tests of today may well prove to be
16 negative."
17 Do you remember any conversations in 1995 at the
18 hospital about that?
19 A. I don't, no. I don't remember that, no, that letter.
20 Q. So, as far as you were concerned, you were hepatitis C
21 positive and no-one was doing anything about it?
22 A. Yes.
23 Q. Those tests came back positive and from then until
24 about 2003 you simply attended for blood tests every
25 six months?

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1 a liver expert."
2 Just pausing there, do you remember watching
3 that Panorama programme?
4 A. Yes, I do, yeah.
5 Q. What was it that made you so concerned?
6 A. It gave a bit more in detail about hepatitis C that
7 I didn't know and I realised that I've got it, I know,
8 I need to do something about it.
9 Q. And then the last comments from the GP trainee:
10 "She attended with the story and it is rather
11 difficult for me to further manage her with these
12 being her opening remarks and I would be very grateful
13 if you could see her."
14 You were then referred, and what were you told
15 at that appointment?
16 A. That he was going to keep an eye on me every six
17 months. I would go and see him every six months and
18 have liver function tests.
19 Q. But you weren't particularly happy about that and you
20 wanted to know a bit more. Do you remember what
21 happened when you saw Dr Yap?
22 A. No, I don't. No, I can't.
23 Q. Don't worry. So in 1994 you went to see Dr Smith and
24 he said at that point that the test may have been
25 wrong.

42

1 A. Yes.
2 Q. How did you come to receive treatment for your
3 hepatitis C?
4 A. Okay. I went for my normal six-monthly check-up and
5 I'd seen on the media that there was treatment out
6 there. So I asked Dr Yap if I could have the
7 treatment and he told me that it was being given to
8 only the chosen few because it was so expensive. So
9 I went home and I think the next time I saw him then,
10 another six months down the line, he said was I still
11 keen for the treatment and I started the treatment.
12 Q. So 2006 you asked for the treatment but it couldn't be
13 given. 2007 you started it?
14 A. Yes.
15 Q. That was with pegylated interferon and ribavirin?
16 A. Mmm.
17 Q. And that obviously entailed injecting yourself?
18 A. Mmm.
19 Q. How did you feel about having to do that?
20 A. Working in the hospital, in one of the injection sites
21 I had MRSA so that was another problem. I had a big,
22 what do you call it, abscess which I had to have cut
23 out and, yeah, it was very hard.
24 Q. When you were first told you would need to inject
25 yourself, what did you think of that?

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1 A. I was okay with injections, yeah. They showed me on
2 the ward what to do and I just, you know, carried on.
3 Q. Can you tell us about the side effects of the
4 treatment.
5 A. Same, really bad migraines, my hair went very, very
6 thin, and tired, tired all the time. I had, I don't
7 know how many verbal warnings I had in work for going
8 home sick. Yeah, I couldn't carry on my shift in
9 work, you know, because I was vomiting and ... yeah.
10 Q. You said in your statement you were plagued with aches
11 and pains and felt miserable.
12 A. Yes.
13 Q. You cleared the virus?
14 A. Yes.
15 Q. But you have remained worried about it. Do you have
16 any follow up in relation to your liver?
17 A. No, I haven't, no.
18 Q. You've gone back to your GP a couple of times, haven't
19 you, since clearing the virus?
20 A. Yes.
21 Q. What have you asked them about your liver?
22 A. I've asked them for a liver function test to make
23 sure -- because I have heard that it can come back.
24 It's always in the back of your mind, you know, will
25 it come back.

45

1 get worked up because CPR training you have to do
2 mouth to mouth on the dummy and I asked my ward
3 manager do I really have to go because I can't do
4 mouth to mouth and she said, "Yeah, you have to go
5 because it's law", so I would go to training but then
6 I'd be in the queue waiting to do CPR knowing that
7 I couldn't do it and I'd have to say in front of
8 everybody, you know, I can't put my mouth on the dummy
9 because I've got hepatitis C.
10 Q. You also had difficulties treating certain patients or
11 being involved with certain patients?
12 A. Any patient with infection I couldn't treat. Not
13 because of them but because of myself, because my
14 immune system was so low.
15 Q. When you were having the treatment?
16 A. Yeah.
17 Q. So day-to-day it was the CPR training that was
18 difficult but during your own treatment you had
19 difficulties with who you could actually work with?
20 A. Yes.
21 Q. Were you able to tell anyone beyond your ward manager
22 that you had hepatitis C?
23 A. No, only my close circle of friends which was about
24 six of us.
25 Q. What made you hesitate to tell anyone else?

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1 Q. About five years ago you were diagnosed with a skin
2 condition?
3 A. Yes.
4 Q. Can you tell us what that is?
5 A. When it first appeared on my leg I thought it was ring
6 worm. So I went to the doctor and he said it was
7 actinic keratosis but he would need to take a biopsy.
8 He took a biopsy and it came back then peri -- I can't
9 say it -- porokeratosis which I've got on my arms now
10 and -- upper arms and legs.
11 Q. You are concerned that it might be linked to the
12 hepatitis C?
13 A. It is, yes.
14 Q. Why is that?
15 A. Because I went on Google to find out if there was
16 a cream that would get rid of it and it says on Google
17 that it's 200,000 Americans have got this and it's
18 mainly an American disease, so I fear that was in the
19 blood as well.
20 Q. You spoke a moment ago about your work as an NHS
21 support worker and you've said in your statement that
22 having hepatitis C has been very difficult at work.
23 A. Yes.
24 Q. Can you tell us why.
25 A. In work, we have to do CPR training and I would really

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1 A. I didn't want to. It's dirty, isn't it.
2 Q. You were worried about people's reaction?
3 A. You know, when you go to give your blood, for your
4 normal blood, you have to tell the nurse because
5 I don't want her thinking that I've done terrible
6 things in my life because I haven't. I haven't been
7 promiscuous, nothing.
8 Q. You are worried that that's how you will be perceived
9 if you tell them?
10 A. Oh, yeah.
11 Q. You've tried to obtain your medical records to try and
12 understand a bit more of what was happening?
13 A. Yeah.
14 Q. What have you been able to get hold of?
15 A. The surgery are very good but the hospital I went back
16 down to see them and I said all my notes are not here,
17 the part that is important isn't here and they said
18 it's been destroyed, so ...
19 Q. So what notes did you receive and what notes didn't
20 you receive?
21 A. I received my notes from the hospital just from my,
22 only the operation on, not the blood transfusion,
23 nothing about the blood transfusion. But the doctors
24 yeah, it's down at the doctor's surgery.
25 Q. So your GP had everything but the hospital was just

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1 missing the records dealing with your transfusion?
 2 A. Yeah.
 3 Q. You've received payments from the Skipton Fund?
 4 A. Yes.
 5 Q. How did you find the process of applying? What was
 6 that like?
 7 A. It was easy, yeah, it was fine, yeah.
 8 Q. How did you know about it?
 9 A. I think I had a letter from the Blood Council or
 10 something to do with that, yeah.
 11 Q. Can you tell us a little bit about the impact that the
 12 infections had on you mentally in light of the fact
 13 that you went on to give blood as a donor yourself.
 14 A. I don't understand that part now, sorry.
 15 Q. After you had had your own transfusion, you were
 16 a blood donor for a few years before you were
 17 diagnosed?
 18 A. Yeah.
 19 Q. We talked earlier about the effect of knowing that,
 20 that's it's had on you.
 21 A. Yeah, that did concern me a lot.
 22 Q. Can you tell us a bit more about that.
 23 A. It concerned me because my blood could have gone to
 24 babies, children, you know, that haven't had a chance
 25 in life.

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1 alongside the medical profession for over 40 years
 2 enjoying caring for others. However, I want to say
 3 how very sad and low I feel when I remember donating
 4 my blood for almost six years thinking I was doing
 5 good but unknowingly to me at that time I was in fact
 6 infecting other innocent people with hepatitis C. I'm
 7 so very, very sorry from the bottom of my heart and
 8 I hope these people can be traced from my donor card
 9 which I've kept all these years and get the treatment
 10 they so deserve.
 11 Sir Brian, Inquiry team, can I just thank you
 12 all for the hard work you are doing and standing with
 13 us all. Thank you.
 14 **MS FRASER BUTLIN:** I am just going to turn and ask
 15 Mr Williams if there's anything else he would like me
 16 to ask. No, there's nothing.
 17 Sir?
 18 **SIR BRIAN LANGSTAFF:** It's not your fault, Elaine, that
 19 you gave blood which might have been contaminated, so
 20 please don't think that it is. What I say won't stop
 21 you thinking it but I hope it's some reassurance.
 22 It's not easy, is it, to talk about what
 23 happened to you. If there's anything that you want to
 24 add when you have a chance to think and think you
 25 might have said more, perhaps, about some things,

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1 Q. And you thought you were doing good and you're worried
 2 now about what happened?
 3 A. Yeah, that they've got hepatitis C and they don't know
 4 they've got it.
 5 Q. What would you like to know has happened?
 6 A. I would like for my blood to be traced because I've
 7 still got my blood donor card and try and find these
 8 people, you know. They must know from the numbers on
 9 the blood transfusion.
 10 Q. And you want to be reassured that that's happened and
 11 that the tracing has been done?
 12 A. Yeah.
 13 Q. Because has anyone ever said to you that tracing has
 14 happened? Have you ever been told?
 15 A. No.
 16 Q. Those are the questions I have for you.
 17 A. Thank you.
 18 Q. Is there anything else you would like to say? I think
 19 you had something you wanted to.
 20 A. I did but ...
 21 Q. Please do.
 22 A. Okay, thank you.
 23 I cannot believe I am here today giving
 24 testimony against my Government for knowingly
 25 infecting me with dirty blood. I have worked

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1 please feel free to let your solicitors know and they
 2 can pass it on to the Inquiry. But can I just thank
 3 you for coming and saying what you have particularly
 4 when it hasn't been particularly easy for you.
 5 A. No. Thank you very much.
 6 **SIR BRIAN LANGSTAFF:** We will take a break now until 1.15.
 7 (11.58 am)
 8 (Luncheon Adjournment)
 9 (1.19 pm)
 10 **SIR BRIAN LANGSTAFF:** Now, our next witness wishes to be
 11 anonymous, so let me tell you what that means. This
 12 is the first witness who is giving evidence
 13 anonymously here in Cardiff. Those of you who have
 14 been following proceedings elsewhere and live
 15 streaming will have seen other witnesses give their
 16 evidence anonymously elsewhere.
 17 In each case I make a legal order the full terms
 18 of which I read out before the witness gives evidence.
 19 That is because breach of it is actually a very
 20 serious matter. It is a contempt of court, it will be
 21 treated in that way and so the order is one which,
 22 like orders of the court, is there to be obeyed. It
 23 has exactly that effect.
 24 The purpose is to protect someone from other
 25 people discovering who he or she is. For that reason,

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each of the witnesses who wishes anonymity and for whom anonymity is granted will be known by a letter and because we have exhausted the alphabet first time round there will be two letters, the first of which for the next alphabet begins with A and we will have reached AE in the case of the next witness, so that's how he in his case will be known.

What this means is that there won't be any live streaming of the image of the witness. In some cases for reasons, again, of protecting others and his or her anonymity, there won't be any transmission of the recording either.

It follows that I must ask you to be very careful if you are taking photographs in and around this building you've seen when you come into the hall there's a notice there saying no photography no filming within this room, but if you are taking photographs outside, which you may well be, please just take care that you don't inadvertently catch Mr AE in one of those photographs because that would tend to show anyone who gets the photograph that he was here, and it's better that people don't know that.

You, however, are privileged by being here because you will see the witness unless the witness wishes and some witnesses might -- we haven't yet had

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one but it is open to witnesses to keep themselves away from your gaze in any case anyway, but that's not the case with Mr AE, so the order I make reads like this: the name and address of witness W2422 (that's Mr AE to you and me) the name of his wife and the name of any other member of the witness's family and any other identifying information, such as the witness's image or a description of their appearance, cannot be disclosed or published in any form unless express permission is given by me or by the solicitor to the Inquiry acting on my behalf. Witness W2422 must be referred to only as "Mr AE".

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

That is the order. With that introduction, let us have Mr AE, please.

MR AE, sworn

Questioned by MS RICHARDS

Q. Mr AE, you have severe haemophilia A.

A. Yeah.

Q. And that was diagnosed at birth.

A. Yeah.

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Q. As a child you were constantly in and out of hospital with bleeds.

A. Yeah.

Q. You used to receive cryoprecipitate a lot. What can you recall about the process of receiving cryoprecipitate?

A. I had an inhibitor against the facts, against cryo and the Factor VIII and everything; so I was always hospitalised constantly. I spent half my life in hospital really and the cryo was in the early days, you know, like the '70s, the late '70s and the -- it got a bit better then, you know.

Q. Because of the inhibitor that you mentioned you would have to be given larger doses and spend longer periods of time receiving the treatment and, as you said, lots of time in hospital often with bed rest as well.

A. Yeah.

Q. You missed a lot of school.

A. Loads.

Q. You said in your statement and again just now you feel like you spent half your childhood in hospital.

A. Yeah.

Q. From about 1977 you were under the care of Professor Bloom.

A. Yeah, well, from an early age. He was Dr Bloom when

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I first ...

Q. You started to receive Factor VIII --

A. Yeah.

Q. -- on a very frequent basis. Can you recall whether Professor Bloom or anybody else at the hospital gave you any information or advice or warnings about any risk of infection?

A. Nothing at all.

Q. What, if anything, were you told about the Factor VIII?

A. It's a wonder drug, you know, but I still couldn't -- because I had the inhibitor I still couldn't go on home treatment so I had to go in, so a few of us who had inhibitors were always in together, you know.

Q. You talked about Professor Bloom in your statement as the doctor who called all the shots at the Haemophilia Centre.

A. Yes.

Q. So his word was what everybody went by?

A. Yes.

Q. You've described the early 1980s as actually a rather happy period for you --

A. Mmm, fine.

Q. -- because you were starting to tolerate the products more and the inhibitor issue became less of a problem.

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1 A. Yes, yes.
 2 Q. What, if anything, can you recall about the type of
 3 Factor VIII products you received?
 4 A. I had so many, I don't really know. There's so many
 5 different types.
 6 Q. Was there ever any discussion with you about the
 7 differences between different products --
 8 A. No.
 9 Q. -- NHS or American products?
 10 A. No, didn't question it.
 11 Q. There came a time in the 1980s when you were told by
 12 Professor Bloom that you had been infected with what
 13 we now know as HIV. What can you recall about that
 14 conversation?
 15 A. I just come back from a family holiday in Spain and
 16 I was in on A7. I was in a four-bedder and he come up
 17 with his entourage. I'd come in on a Saturday into
 18 hospital, Sunday getting better. I was supposed to be
 19 going home on the Monday and he came up with the
 20 entourage and he told all them to go, and he pulled
 21 the curtain round and he said, "I got something to
 22 tell you, you got the AIDS virus". Devastated me.
 23 Q. Your response was, "What does that mean?"
 24 A. What does that mean, yeah, and he told me not to say
 25 nothing to nobody. I said, "I'm going to phone my

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1 A. Nothing whatsoever, just no counselling, nothing,
 2 even -- he just didn't want to see us. I wanted to
 3 see him, like have a moment with him. He would say he
 4 wasn't available, you know, and it was just nobody,
 5 just on my own, and my mother, you know.
 6 Q. Did you know that you had, in fact, were being tested
 7 for HIV HTLV-III?
 8 A. No.
 9 Q. You've described in your witness statement that your
 10 reaction was one of complete shock.
 11 A. Well, it was just before he told me. About a week
 12 before I went on holiday, I saw a documentary on the
 13 gays in America all dying of this disease and the next
 14 thing I'm a happy 19-year old and all of a sudden
 15 I got this disease. You can't write it, you know.
 16 Q. I am just going to look at one document, Mr AE.
 17 Paul, it is 2242002, please.
 18 If you can turn it round. This is an extract
 19 from the National Haemophilia Database and we've got
 20 there date first positive 15 July 1984.
 21 When you wrote your statement, you were
 22 concerned that that might have meant that doctors knew
 23 from 1984 --
 24 A. Yeah.
 25 Q. -- but you weren't told until 1985?

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1 mother now."
 2 "No, I'd rather you not because we don't know
 3 what we're going to do yet", more or less, you know,
 4 and just devastated, and he just said to me, he was
 5 going to answer no questions but that day I had an
 6 answer off him in the end, you know, about life
 7 expectancy, yes.
 8 Q. What was the answer he gave you in relation to life
 9 expectancy?
 10 A. Don't know how long I had it, but he said
 11 18 months/two years.
 12 Q. You in your statement thought that that was 1987?
 13 A. Yeah, but it wasn't. I know it wasn't.
 14 Q. When now do you think --
 15 A. '85.
 16 Q. Without mentioning any names, that's in part because
 17 you know of other people who were given the diagnosis
 18 you know it was the same time as you.
 19 A. Same time, yeah.
 20 Q. And they know that it was 1985 and that's how you've
 21 traced it to 1985.
 22 A. Yes.
 23 Q. Were you given any information at that stage other
 24 than the shortened life expectancy about treatment or
 25 how to manage the condition or --

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1 A. Yeah.
 2 Q. In fact, I think as you now know it's not clear when
 3 you were first tested and whether that represents
 4 a sample that was stored and later tested or whether
 5 it represents the date of a test.
 6 A. Yeah.
 7 Q. But, in any event, you simply hadn't been told at any
 8 point that you were going to be tested at all.
 9 A. No, nothing at all.
 10 Q. You ignored Professor Bloom's advice and did call your
 11 mother.
 12 A. Yes.
 13 Q. She came to the hospital. But apart from a very small
 14 number of family members, you kept your diagnosis
 15 secret.
 16 A. Yes.
 17 Q. Why was that?
 18 A. The stigma was terrible, absolutely terrible. Not
 19 only that, it was a disease, you felt dirty, you know.
 20 It was just -- the adverts on telly were just --
 21 degrades you, like, you know.
 22 Q. You've said in your statement that the effect of the
 23 diagnosis on you, a 19-year old young man, was you
 24 felt very alone.
 25 A. Terrible, yes.

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1 Q. You felt that people, if they knew of your diagnosis,
2 would assume you'd contracted it through sex or drugs?
3 A. Being gay or whatever, yeah.
4 Q. You had difficulty sleeping because you thought you
5 were going to die.
6 A. Didn't sleep for days on end.
7 Q. You felt worthless?
8 A. Yeah.
9 Q. And, your words, you went off the rails.
10 A. Right off the rails. Selfdestruct button was pushed,
11 you know.
12 Q. I am going to ask you about a couple of incidents.
13 One was when you were walking home, we won't mention
14 any names or place names but you were walking home and
15 you had an encounter with a police officer.
16 A. Police officer, yeah.
17 Q. What can you remember about that?
18 A. Well, the police were told, apparently, and I was
19 classed as like a lethal weapon, they classed me as,
20 and I was in -- I won't say the place but I was
21 walking through a town centre and I was eating a curry
22 and chips in a tray on the way home about 2.30 in the
23 morning, and I was going down to get a taxi and he
24 said, "No, you go that way". I said, "No, I want to
25 get a taxi". I could hear him. He was behind me and

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1 they worked on me all night then to keep me alive, you
2 know.
3 Q. You became addicted to the drugs that were prescribed
4 to you.
5 A. Yeah.
6 Q. The drug you have mentioned palfium, which was
7 painkiller?
8 A. Very strong painkiller, yeah.
9 Q. And to diazepam and temazepam?
10 A. And Heminevrin.
11 Q. You've described yourself in your statement as someone
12 who went from a happy young man to a --
13 A. Completely -- yeah, completely crazy.
14 Q. What can you tell us about that time in your life?
15 A. Just frightened to die. That was the main thing,
16 taking all those drugs, frightened to die because
17 I had been in hospital and watching these people die
18 of this dreadful disease, especially good friends, you
19 know, you just don't want to go through that. Call it
20 gutless, I don't know, but I felt gutless because
21 I just didn't want to die that way because they were
22 so brave, you know, they knew they were dying, like,
23 and I've seen grown men go to nothing, good friends,
24 and it broke my heart, so I just drowned it out
25 with -- as long as I was absolutely out of it that's

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1 antagonised me all the way, you know, "We know all
2 about people like you", and all that, and so I just
3 attacked him.
4 Q. And the reference to people like you was to a person
5 who was infected with HIV?
6 A. Yeah, "We don't want people like you in the town",
7 yeah.
8 Q. You felt suicidal on a number of occasions.
9 A. Oh, big time.
10 Q. There's one occasion you described to me about
11 standing on --
12 A. On a motorway bridge, yeah.
13 Q. -- a motorway bridge. Are you able to tell us about
14 that?
15 A. Yeah. It was Sunday night and it come to the lowest
16 point in my life really. Stood on a motorway bridge
17 waiting for a lorry to come but one didn't come, you
18 know. So I thought imagine I survived the accident,
19 that's what was worrying me, surviving the accident on
20 top of what I got. So by now I've been describing big
21 amounts of Heminevrin and a drug called palfium. So
22 I went home and took the whole bottle of Heminevrin
23 about 2.00 in the morning. Didn't want to get found,
24 I just went asleep on my bed, and my mother heard
25 a thump and she come in and I was blue in the face and

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1 when I was happy.
2 So I went to my GP and he prescribed me 90
3 palfium a week, Heminevrin, whatever I wanted, for two
4 years. Then I went in there one day and he just said,
5 "No more", and I just -- that's when I got admitted
6 then to a -- well, call it a mental institute.
7 Q. You have said in your statement that taking these
8 drugs that you had been prescribed made you feel
9 nothing, made you forget that you had been
10 contaminated with the HIV virus and had a death
11 sentence hanging over your head.
12 A. Yeah.
13 Q. It was your way of blocking it all.
14 A. Frightened of dying, yeah, frightened, because it was
15 like drawing straws really because he'd be gone, he'd
16 be found he'd got full blown AIDS this week, you know,
17 "You got a couple of months to go", and then there'd
18 be another one and in like six months' time, then
19 there's be another one in three months' time.
20 I thought, "I'm going to be the next, surely". That's
21 the only way to drown it out. There was no
22 counselling, nothing.
23 Q. You were admitted to a mental health unit.
24 A. Yeah.
25 Q. And you have described in your statement the physical

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1 symptoms you were experiencing at the time, cramps,
 2 sweating, still wanting to die.
 3 A. Yes.
 4 Q. And that was the first of two occasions you were
 5 admitted.
 6 A. Yeah.
 7 Q. What happened in between the two admissions? How were
 8 things in that time?
 9 A. Like I got in and they put me on a drug called
 10 methadone and I sort of come off that nearly but as
 11 soon as I -- I was all right in there,
 12 institutionalised, you know, but as soon as I come
 13 back out, oh, hear again somebody in the hospital had
 14 gone again, you know, or you go in to the unit and but
 15 you'd be in all the time and just back on it again
 16 then.
 17 Q. You have put it this way in your statement after that
 18 first admission and then going out again and taking
 19 drugs again you said, "Mentally I'd lost it".
 20 A. Yeah, completely.
 21 Q. And you were admitted to the mental health unit again.
 22 A. Yeah.
 23 Q. Just going to look at one document. It's a letter
 24 from a psychiatric doctor.
 25 2422005, please, Paul.

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1 supply of these in order to treat his spontaneous
 2 bleeds."
 3 Then the next paragraph please, Paul:
 4 "He has found that taking opiate drugs has
 5 helped him to forget his problems ..."
 6 Then it talks about the problems that had
 7 brought and you being in receipt of treatment. Then
 8 it says this:
 9 "I have now started to prescribe methadone for
 10 him on a regular basis and shall in due course notify
 11 him to the Home Office as a registered addict. He is
 12 of course not in quite the same class as the other
 13 addicts that attend the drug clinic as he could in all
 14 honesty be described as a therapeutic addict."
 15 It's that phrase "therapeutic addict" that has
 16 stayed with you and is important to you.
 17 A. Yeah.
 18 Q. Because you have said in your statement you had never
 19 prior to your diagnosis had the mindset of
 20 a recreational drug user.
 21 A. No, I just used to like a drink with the boys, you
 22 know. I never ...
 23 Q. It was the diagnosis that --
 24 A. Yeah.
 25 Q. -- in your words, made you feel worthless?

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1 We can see it's a letter from -- go down to the
 2 bottom of the page please, Paul, to start with, just
 3 right down to the bottom.
 4 So it's a letter from a Dr Thomas, a senior
 5 registrar in psychiatry. It's dated 6 May 1987 and
 6 we'll look at the second paragraph. It explains you:
 7 "... suffered with severe haemophilia all his
 8 life. This has necessitated his receiving many
 9 transfusions of Factor VIII. Through no fault of his
 10 own, as with some other haemophiliacs, this resulted
 11 in him catching the AIDS virus. As I am sure you can
 12 appreciate as a result of this he has become very
 13 depressed and I was asked to see him approximately
 14 a year ago when I prescribed some antidepressant
 15 medication for him. He did make a reasonable recovery
 16 on this but continues to worry about his condition
 17 although at present he does seem to be physically well
 18 and shows no sign of the AIDS disease itself at
 19 present. He is, however aware of the very real
 20 possibility of him developing the condition at any
 21 time, and over the last six months particularly has
 22 had great difficulty in coming to terms with this. As
 23 a result of his worry, he has taken to drinking in
 24 order to try to relax, and also has started to use his
 25 opiate drugs and, of course, he has a legitimate

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1 A. Well -- and frightened, petrified.
 2 Q. You have said also in your statement that you believe
 3 if you had had counselling at an early stage that
 4 might have made a difference; is that right?
 5 A. Yeah.
 6 Q. Were you ever during this time in the 1980s or 1990s
 7 offered counselling?
 8 A. Never.
 9 Q. You learnt in the early 1990s, again the precise date
 10 is not clear, that you had also been infected with
 11 hepatitis C.
 12 A. Yes.
 13 Q. How did you learn of that diagnosis?
 14 A. I got told in the centre and I was told really that it
 15 wouldn't be a worry really to me because the AIDS was
 16 the thing to worry about. That's what I got told.
 17 Q. Can you recall whether you were given much information
 18 about the hepatitis C diagnosis at that time?
 19 A. No, to tell the truth I wasn't really interested
 20 because I was just worried about dying with this AIDS,
 21 you know, so I just didn't really -- nothing could be
 22 as bad as AIDS in that time. I just thought --
 23 I didn't realise what it was.
 24 Q. You met your wife in the early 1990s?
 25 A. Yeah.

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1 Q. -- and with her help you stopped drinking?
 2 A. Yeah.
 3 Q. You stopped relying on drugs and you broke your
 4 addiction.
 5 A. Yes.
 6 Q. You also credit Dr Dasani with making a big difference
 7 to your life.
 8 A. I wouldn't be here, if it wasn't for him, no.
 9 Q. You think you wouldn't be alive without his help?
 10 A. Not for him.
 11 Q. You have talked about the way he treated you made you
 12 feel human?
 13 A. Human again, yeah, because up on the ward when you had
 14 this virus you was like outside your cubicle would be
 15 a trolley, red bags, masks, like somebody waiting to
 16 go on the Apollo XI, you know, like spacemen, dreadful
 17 it was. So how can they treat you like that when you
 18 walk into the hospital but it's only then they treat
 19 you -- they put these -- and Dasani used to come and
 20 just take your bloods, no masks.
 21 Q. May I ask you about the physical effects of the HIV
 22 and hepatitis C. We will come on to the treatment
 23 that you received for both in a moment but in terms of
 24 the physical effects, you have identified in your
 25 statement that you felt very tired and lethargic, you

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1 A. Yeah.
 2 Q. Your joints have been damaged, in addition to the
 3 problems of the haemophilia, the HIV treatment has
 4 made it harder for you to walk. There was one drug
 5 that caused you to have regular nightmares?
 6 A. Yeah, indinavir, a drug called indinavir. You just
 7 live that, the nightmare, you lived it, you know.
 8 Q. Some of the treatments made you violently sick.
 9 A. Yes.
 10 Q. You still get very tired. Even on your current
 11 medication regime, you feel very tired, chronically
 12 fatigued?
 13 A. Yeah.
 14 Q. You also developed OCD, obsessive compulsive disorder.
 15 A. Terrible.
 16 Q. What can you tell us about that?
 17 A. Well, I met [redacted] --
 18 Q. Sorry. (Pause)
 19 We're fine to start again. So without
 20 mentioning your wife's name --
 21 A. Right.
 22 Q. -- I had asked you about the obsessive compulsive
 23 disorder.
 24 A. I met my wife and she had two children and I didn't
 25 realise -- like, I sat and thought and I thought,

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1 couldn't say whether that's one or other or both of
 2 the infections.
 3 A. I don't know what it is. I'm not the same person at
 4 all, especially after the last lot of interferon and
 5 ribavirin, you know. Just completely exhausted all
 6 the time.
 7 Q. You had pneumonia in the early 1990s?
 8 A. Yeah, I didn't know that.
 9 Q. You didn't --
 10 MRS AE: No, they didn't tell him.
 11 A. Didn't tell me.
 12 MS RICHARDS: That was something you found out later from
 13 medical records.
 14 A. I think they thought I worried too, perhaps, I don't
 15 know, they didn't tell me that. Because every little
 16 cold I thought this is it, this is the start of it,
 17 you know.
 18 Q. You received a variety of different treatments for HIV
 19 over the years and that's had a number of different
 20 side effects.
 21 A. The early days when they were horrible drugs, yeah.
 22 Q. Your teeth had been damaged?
 23 A. Yeah.
 24 Q. You have lost a number of teeth or had to have them
 25 removed?

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1 "Well, I do be fetching this into the house, this
 2 hep C, HIV". So if I had a little nip on my finger,
 3 I'd go and bleach every door handle in the house,
 4 bleach it. The toilet seat, bleach it every time. It
 5 used to go ballistic, didn't it?
 6 MRS AE: Yes.
 7 A. And completely, you know, really go over and over
 8 bleaching everything.
 9 MS RICHARDS: And is that something which still affects
 10 you?
 11 A. Yes. Sometimes, yes.
 12 Q. I want to ask you about the treatment for hepatitis C.
 13 You had some difficulty accessing that to start with.
 14 Why was that?
 15 A. Because I weren't in the Cardiff area but, yet again,
 16 in Cardiff that's where I received my death sentence,
 17 more or less. But they wouldn't give it because it
 18 cost too much. So I had to go -- I had to write to
 19 the Health Board and they accepted me then.
 20 Q. You had two courses of treatment.
 21 A. Yes. One in the Haemophilia Centre with Dr Dasani and
 22 that didn't work, and the last lot worked.
 23 Q. So the first course of treatment involved interferon?
 24 A. Mmm.
 25 Q. Was that just interferon?

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- 1 A. I can't remember. Interferon and something else.
 2 Q. Ribavirin, perhaps?
 3 A. Yes.
 4 Q. And what side effects did you experience from that
 5 treatment?
 6 A. Hair loss, depression, horrible -- just horrible
 7 thoughts, you know. Just really -- it's terrible.
 8 I couldn't sleep for nights on end. Not yourself at
 9 all, you know.
 10 Q. And you've also described you became very impatient,
 11 your mood changed?
 12 A. Yes, terrible. Since -- I'm the same now. Since the
 13 last lot, it's completely changed me to who I was.
 14 Q. That first course of treatment didn't succeed?
 15 A. No, I was only on it for about three months, so he
 16 took me off it because it didn't work.
 17 Q. But you had a second course of treatment a few years
 18 ago?
 19 A. Yes.
 20 Q. And that did succeed in clearing the virus?
 21 A. It did succeed, yes.
 22 Q. Did you experience side effects in relation to that
 23 second course of treatment?
 24 A. Oh, yes. Big time, yes.
 25 Q. The same kind of side effects?

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- 1 Q. -- that you had cirrhosis and might need a transplant?
 2 A. Yes.
 3 Q. But, in fact, a scan about two years later revealed
 4 that your liver was not cirrhotic?
 5 A. Yes, fine, yes. But when he just said I don't know
 6 but all my bloods were always okay; so why he said
 7 that to me, I don't know.
 8 Q. Do you receive any follow up and checks on the state
 9 of your liver?
 10 A. Yes.
 11 Q. And how often do you receive those?
 12 A. Every eight months, something like that, you know.
 13 Q. Did you ever receive, as far as you can recall, any
 14 notification about being at risk of variant CJD?
 15 A. Yes.
 16 Q. What can you recall of that?
 17 A. Just a letter coming round to all the haemophiliacs,
 18 I think, and I had been exposed to it, yes.
 19 Q. And what was the effect of that additional piece of
 20 information?
 21 A. What else? What's next, you know. Just the -- you
 22 just don't know what's coming next from it, you know.
 23 Q. You've described in your statement an experience a few
 24 years ago in one hospital with the reaction of
 25 a nurse.

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- 1 A. Oh worse, worse, I think, yes.
 2 Q. Although the hepatitis C virus has cleared, do you
 3 continue to experience the kind of fatigue and other
 4 side effects?
 5 A. Yes, yes.
 6 Q. Now, in around 2006 you were told, following a scan,
 7 that your liver was cirrhotic.
 8 A. Yes. Well, they done a -- I forgot everything. I was
 9 getting on with my life, you know, and I went down the
 10 hospital for a Ram fibroscan and they needed to take
 11 it was ten readings or something but they only could
 12 do six. And I went in to see the consultant after and
 13 he said, "The readings are very high, so I expect your
 14 liver's severely damaged". I thought, well, how can
 15 that be, you know?
 16 He said -- so I was in a terrible worry, a hell
 17 of a mess. So we had a meeting, didn't we, with him.
 18 We had a meeting with him and it was like, you know,
 19 we'll try the fibroscan again but they couldn't get
 20 a full reading again and he was saying, "Not all is
 21 lost. You can go on the transplant list". Two years
 22 that was and then they found out my liver was okay.
 23 So I lived with it again, you know.
 24 Q. For two years you lived with the additional fear --
 25 A. Yes.

74

- 1 A. Yes.
 2 Q. What can you tell us about that?
 3 A. I went in for a knee replacement in Llandough about
 4 eight years/nine years, perhaps it might be ten years,
 5 and I goes in. I was in the ward the night before and
 6 in the morning she comes across the bed in a cubicle.
 7 I thought I don't mind that. Next thing, the barrier
 8 nursing goes up and the trolley with the bags. It's
 9 like going back to the AIDS days now, you know.
 10 And then across right from my room there's
 11 a toilet and she put out the ward on it and she come
 12 and she said that toilet's for you, it's out the ward
 13 and nobody else will use it. Then one of the
 14 haemophilia nurses came in and ripped it all down and
 15 said, you know, this is wrong.
 16 Q. You've explained in your statement that that made you
 17 feel inhuman?
 18 A. Yes, I still do. It's still the stigma's still there.
 19 That's why, you know, I don't want people to find out
 20 now. It's still there.
 21 Q. You've not been able to work?
 22 A. No.
 23 Q. You've spent much of your time in and out of
 24 hospitals.

In terms of financial assistance from the trusts

76

1 and schemes, you've received a single payment from The
2 Skipton Fund.
3 **A.** Yes.
4 **Q.** You receive monthly payments from it was the
5 Macfarlane Trust now the Welsh Infected Blood Support
6 Scheme. You said in your statement they don't amount
7 to very much.
8 **A.** It's like begging all the time, isn't it. You know,
9 it's A begging bowl really.
10 **Q.** You've said you felt like a beggar often on the phone
11 to people?
12 **A.** Yes.
13 **Q.** And it's made you feel worthless, the process of the
14 applications?
15 **A.** Yes.
16 **Q.** Mr AE, those are the questions I have for you. Is
17 there anything that you would like to add?
18 **A.** No, I'd just like to thank my wife, my mother and
19 everybody who put up with me, you know, in them bad
20 days.
21 **MRS AE:** He's not bad. He's lovely. He is so lovely, and
22 he had to put up with all this.
23 **MS RICHARDS:** I am just going to ask Mr Williams if
24 there's anything further.
25 No. There are no further questions from him.

77

1 **A.** Oh, yes.
2 **Q.** There it is. Can you tell us first how you met.
3 **A.** Yes. We met -- he was teaching in Cardiff, in the
4 local school, and I was training as a physio in the
5 Cardiff Royal Infirmary and it was the school near the
6 Cardiff Royal Infirmary and I met him at a party, and
7 he took me to the zoo on our first date.
8 **Q.** What was he like as a person?
9 **A.** He was very energetic and lively and lived life to the
10 full in no uncertain terms. He enjoyed sport,
11 especially water sports, swimming, canoeing, sailing.
12 He became a sailing instructor and he enjoyed
13 entertaining. We had lots of parties, barbecues. He
14 liked dancing and singing, not particularly well but
15 he enjoyed all that sort of thing, yes. He was very
16 sociable.
17 **Q.** Christopher had mild haemophilia A?
18 **A.** As I understand it, yes.
19 **Q.** As far as you are aware, how often did he have bleeds
20 as a child and young person?
21 **A.** Quite often. I'm not sure. Of course, I didn't know
22 him then but I know he did have a number of problems
23 and had to be treated when he was a child.
24 **Q.** Your understanding from Christopher's family is that
25 although he bled frequently it was more because he was

79

1 Sir.
2 **SIR BRIAN LANGSTAFF:** Can I thank you very much for coming
3 to give your evidence. I think everyone can now
4 understand why you wished to be anonymous with
5 everything you have been through, and how difficult it
6 may have been for you even to sit where you are and
7 tell us what you have. But it's important and thank
8 you.
9 **A.** Okay. Thank you.
10 **SIR BRIAN LANGSTAFF:** We will take a break now until 2.20.
11 **MS RICHARDS:** Thank you, sir.
12 (1.53 pm)
13 (A short break)
14 (2.27 pm)
15 **SIR BRIAN LANGSTAFF:** How would our next witness wish to
16 be known?
17 **MS FRASER BUTLIN:** Judith, sir.
18 **SIR BRIAN LANGSTAFF:** Judith, please.
19 **JUDITH THOMAS, sworn**
20 **Questioned by MS FRASER BUTLIN**
21 **Q.** Judith, you are here to talk about your late husband,
22 Christopher.
23 **A.** I am.
24 **Q.** You've provided us with a photograph of him to be on
25 the screen during your evidence.

78

1 doing an awful lot rather than because he had
2 a particularly severe condition?
3 **A.** Yes. He didn't suffer from spontaneous bleeding. It
4 was more, you know, if he'd fallen out of a tree or
5 something as a child, you know, or doing things that
6 young lads do.
7 **Q.** At the age of 21, Christopher underwent a through hip
8 amputation of his right leg?
9 **A.** He did.
10 **Q.** Can you tell us what you know about that.
11 **A.** Well, I did not meet him until after that, after he'd
12 had his amputation of his leg but I do -- it saved his
13 life, basically, as far as I know, and he had it in
14 Cardiff Royal Infirmary and I think he was under
15 Professor Bloom at the time.
16 **Q.** He'd had gangrene after a non-union of a fractured
17 femur?
18 **A.** That's as I understand it, yes.
19 **Q.** As you understand it. So what were Christopher's
20 views of Professor Bloom because of that treatment?
21 **A.** Well, he was held in very high esteem by Christopher's
22 parents and family obviously, because basically he
23 saved his life with that operation because it was
24 a very risky operation on a haemophiliac.
25 **Q.** As you said, you met Christopher after his amputation?

80

1 A. Yes.

2 Q. And despite his amputation, he became a teacher and

3 taught a lot extra curricula activities as well.

4 A. He did. He'd started his training I think before he

5 had the amputation in Carmarthen. He was in the

6 teacher's training college there and -- but then he

7 lost a year when he was -- he was in hospital for

8 I think about nine months when he had the amputation

9 so he had to -- when he recovered, he went back to

10 college but then he had to go back a year later if you

11 know what I mean.

12 But he went on to qualify as a teacher and

13 taught in various -- well, that's how I first met him

14 in the school that he ...

15 Q. He did outdoor pursuits with the children at the

16 school?

17 A. Yes, he used to take them camping and canoeing and

18 fishing and, you know, all sorts of other outdoor

19 pursuits, you know.

20 Q. You bought a terraced house together and Christopher

21 converted it into flats?

22 A. We did, we did. When we were first married we, yes,

23 we bought a terraced house in Cardiff and we converted

24 it into flats so that we could let the flat and pay

25 the mortgage and he did a lot of the work himself. As

81

1 I mean, after the amputation, of course, he -- after

2 the amputation, they were afraid, well, with the

3 haemophilia that he wouldn't be able to wear an

4 artificial leg, he wouldn't be able to withstand

5 wearing an artificial leg, so he -- so he was on

6 crutches for a long time which built up his upper body

7 strength so he was quite -- you know, he was very

8 strong really considering his disabilities.

9 Q. In terms of Christopher's haemophilia, where was he

10 treated?

11 A. Well, originally he was treated in Cardiff, in Cardiff

12 Royal Infirmary, and Professor Bloom, and then when we

13 moved up to the Llyn Peninsula he was treated in

14 Bangor, in the University Hospital in Bangor.

15 Q. Generally, when he had a bleed he would go to hospital

16 for the treatment or to your GP's.

17 A. Well, yes. He'd have -- originally, he used to go to

18 hospital. He used to have cryoprecipitate I think

19 originally and he'd have to be hospitalised sometimes

20 for a couple of days but latterly when he went on to

21 the Factor VIII, he went -- he would go to Bangor and

22 they would give him a couple of days' supply and then

23 he'd bring that back and the local GP surgery would

24 administer the Factor VIII for him. It was pre-home

25 treatment, you know.

83

1 I say, it was a bit Heath Robinson, some of it, but

2 I think it's still up today actually. He put some

3 stairs going up to the outside for an access, because

4 we had the upstairs flat and he put in a flight of

5 stairs going up to the back window and it's still up

6 today I think, amazingly.

7 But you know he used to use things like

8 sledgehammers and things, which wasn't really

9 advisable in his condition, you know.

10 Q. 1973/1974 you bought a derelict cottage and again

11 Christopher did a huge amount of work on that cottage.

12 A. He did. After we'd had our children, he wanted

13 basically a bigger garden. He also was a very proud

14 Welshman and he wanted his children to be brought up

15 Welsh-speaking and we looked for cottages and we found

16 one on the Llyn Peninsula, which is beautiful and

17 that's where I'm living today still.

18 Q. But in terms of the work on the cottage, he did the

19 fencing, the cementing, tiling the roof, absolutely

20 everything?

21 A. Oh he did, yes, put in the windows, and he was on the

22 roof doing the slates.

23 Q. So despite his haemophilia and despite the amputation,

24 Christopher was an incredibly active physical man?

25 A. Very much so yes, and he was really quite big built.

82

1 Q. In 1983, Christopher took early retirement. Why was

2 that? What triggered the early retirement?

3 A. Well, he was having a lot of problems and bleeds into

4 his ankle. Of course, he only had the one, didn't he,

5 and that was becoming problematic, yes.

6 Q. You mentioned earlier he had also had a bad bout of

7 flu. Can you tell us about that.

8 A. Well, yes. I only sort of thought about this

9 afterwards because he hadn't been diagnosed by then

10 but he did have a bad bout of flu and he was in bed,

11 which was unheard of with flu. You know, he didn't

12 usually get things like that to be honest but he did

13 have a particularly bad dose of flu in I think that

14 was '83, yes.

15 Q. In February 1984, Christopher was advised to have an

16 HIV test. Why was that? What led to that?

17 A. Well, I'm not quite sure what. I think -- I mean, he

18 was well-read and he read about it in the papers. He

19 was aware of the AIDS relationship and haemophilia,

20 you know, it was in the papers and things like that.

21 But even before that, maybe he'd read about it and

22 I think he -- I can't recall him ever having a letter

23 to invite him for a HIV test but I think he must have

24 discussed it with Tom Korn, the consultant

25 haematologist in Bangor and been advised to have it or

84

1 asked to have it. I don't know.
 2 Q. There was a wait for two weeks for the results.
 3 A. Yes.
 4 Q. How did you both feel while you were waiting?
 5 A. Very anxious but -- and we were well aware of the
 6 implications really. So it was quite a worrying time.
 7 Well, it had been worrying when he thought about it,
 8 you know, when we realised of the possibility of it,
 9 really.
 10 So then we went to see Dr Korn. We both went to
 11 get the result together and we were told in very
 12 professional circumstances in Dr Korn's office and
 13 he -- yes, and he told Christopher that he was
 14 positive. Of course, we were devastated but -- yes,
 15 and he did give us advice about, you know, how to cope
 16 with the condition and we knew how it was transmitted
 17 and you know and so -- well, it's devastating, isn't
 18 it. I thought he was going to die, I was going to die
 19 and the kids probably would die as well, you know.
 20 But we didn't -- you don't ...
 21 But then when you're in that situation, you just
 22 have to deal with it, don't you, and just have to sort
 23 of take it a day at a time, really.
 24 Q. When Christopher was told he was positive you were at
 25 the appointment, you immediately asked to be tested as

85

1 Q. It records a clinic appointment with Professor Bloom
 2 and an orthopaedic surgeon discussing possible ankle
 3 fusion but it makes no reference at all to his HIV or
 4 HTLV-III as it was then diagnosis and you find that
 5 strange that there's nothing in here about it.
 6 A. Yes, yes.
 7 Q. You've obtained Christopher's medical records and it's
 8 right, isn't it, there's no clinical notes or letters
 9 recording the first positive test or of him and you
 10 being told of his diagnosis?
 11 A. Not that I'm aware of. I haven't had any of those
 12 communications, no.
 13 Q. You've gone through the records and your solicitors
 14 have gone through the records and there doesn't seem
 15 to be anything.
 16 A. There doesn't seem to be any, no.
 17 Q. When Christopher was told about his diagnosis how did
 18 he react?
 19 A. Well, he was distraught, obviously, and -- well, yes.
 20 But then, you know, we just had to deal with it and we
 21 had a dishwasher to make sure that the dishes were
 22 clean and we bought new towels and made sure that the
 23 kids didn't -- we were very concerned about the
 24 cross-contamination really and using toothbrushes and
 25 razors and things like that and, of course, telling

87

1 well.
 2 A. I did.
 3 Q. Was that something you'd discussed before the
 4 appointment?
 5 A. I don't know really. I just thought I want to be
 6 tested now.
 7 Q. You then had to wait for your own results?
 8 A. Yes, we had to wait another two weeks. So that was
 9 a very worrying two weeks to have and then,
 10 fortunately, we went back that I was negative. So
 11 I was very fortunate.
 12 Q. Can we have document 2407005, please, Paul.
 13 It's a letter from 24 February 1984 from
 14 Professor Bloom to Dr Korn. Christopher had been
 15 going down to Cardiff sometimes to deal with his ankle
 16 problems as well as being seen in Bangor?
 17 A. I think so, yes. Possibly, yes.
 18 Q. I think your daughter was clearer that she remembered
 19 that her Dad was going down to Cardiff for certain
 20 treatment and in Bangor for others.
 21 A. Yes.
 22 Q. We've got this letter in February 1984, 24 February,
 23 which you think was after Christopher's diagnosis of
 24 being HIV positive.
 25 A. Yes.

86

1 the children about it was worrying. You know, that
 2 wasn't an easy thing to do. But he was very good at
 3 that. He did that himself, really, and I just let him
 4 tell them in a way that was best for him, really.
 5 Q. What did he tell them? What did he say? Do you
 6 remember?
 7 A. Well, I don't think he made it too alarmist, you know.
 8 He did tell them that he had a condition with his
 9 blood and we must be very careful so that we don't
 10 cross-contaminate anything, no.
 11 Q. I think your children's recollection is being told not
 12 to tell anyone else about it or to keep it within the
 13 family.
 14 A. Well, yes, they were told not to discuss it with
 15 everybody, no. Yes.
 16 Q. Could we have document 2407006, please.
 17 It's another letter from Professor Bloom to
 18 Dr Korn in June 1985; so a little bit of time after
 19 his diagnosis. It records that:
 20 "Christopher had called in to see our social
 21 worker who confirmed what you have already told me
 22 that Christopher is very psychologically perturbed
 23 over his HTLV-III positivity."
 24 A. Yes.
 25 Q. Is that your recollection of Christopher's mental

88

1 well-being?

2 A. Absolutely, yes.

3 Q. Did he receive any counselling or psychological

4 support at that point?

5 A. I think he did go and see one of the social workers in

6 Cardiff Royal Infirmary. Yes, I think he did have

7 some counselling but it was in Cardiff and we were up

8 in the Llein Peninsula so it was a bit of a long way

9 to go.

10 Q. How long would the journey take?

11 A. Four hours -- well, five in those days probably.

12 Q. Can you tell us how Christopher was physically at that

13 point in time, in those early years?

14 A. Well, at the beginning, physically he was okay, you

15 know. He was able to do what he enjoyed doing and he

16 was able to carry on really for a couple of years,

17 maybe two years, two or three years, yes.

18 Q. About 1987 Christopher was started on treatment for

19 his HIV.

20 A. Yes.

21 Q. What can you tell us about that?

22 A. He was put on the AZT, azathioprine, and I can't

23 remember exactly what his symptoms were at that time

24 but he was beginning to get symptoms probably at that

25 time. What year did you say?

89

1 the stigma and lack of knowledge, really, about the

2 condition, and I was working as a physio as well so it

3 was, you know, quite an anxious time, really. But,

4 yes, but eventually I did finish work, yes.

5 Q. You have mentioned working as a physio. What was your

6 particular concern about your job if people found out

7 that Christopher had HIV?

8 A. Well, the fact that I was negative, people don't

9 understand necessarily all the implications do they

10 and so ... and they just didn't understand about the

11 condition, I suppose. It's not something that you

12 discuss, really, unless you have to, you know.

13 Obviously, if you're going for some sort of medical

14 treatment and things or dental treatment, then you

15 would mention it then.

16 Q. You had some support through the Birchgrove Group?

17 A. The Birchgrove Group, yes.

18 Q. Can you tell us about that.

19 A. Well, Mary Dykes, the social worker, set up the

20 Birchgrove Group and right at the beginning when he

21 was first diagnosed really and we did -- but we lived

22 in North Wales then so we did come down and go to

23 a couple of those meetings, which were very helpful.

24 You didn't feel so much alone, if you know what

25 I mean, you know, and you could talk freely with

91

1 Q. 1987.

2 A. Oh yes. That was just before -- so he'd lost a lot of

3 weight, he'd lost some weight by then anyway, quite

4 a considerable amount of weight, and he was tired,

5 yes. And he used to experience a lot of diarrhoea and

6 stomach problems and all sorts of -- he'd had a few --

7 sinusitis and things like that.

8 Q. As Christopher began to decline, and to start to

9 become unwell, what impact did that have on you and

10 the children?

11 A. Well, basically, at the beginning I did -- I think

12 I used to work -- I did some extra work because of

13 course he'd taken early retirement, so we were a bit

14 financially -- we didn't have as much. So I did extra

15 work and so the children had to do lots more at home,

16 helping out with, you know, cooking and gardening and

17 all the things that need doing, which they might have

18 had to do anyway, I don't know.

19 Q. At that stage as Christopher became -- started to

20 become unwell, did you tell many people about his

21 diagnosis?

22 A. Well, to be honest, his medical condition -- I mean,

23 with medical confidentiality it wasn't up to me to

24 tell people really and it wasn't something you shared

25 with everybody for the reasons we've heard before with

90

1 people because they were all in the same -- similar

2 situations to yourself and understood what was going

3 on, you know.

4 Q. You have said in your statement you also attended some

5 meetings that the Haemophilia Society organised which

6 you found very helpful.

7 A. Oh, yes, we went to a woman's weekend up in

8 Newcastle-upon-Tyne and I went to my sister-in-law and

9 that was -- I found it extremely helpful, very

10 supportive.

11 Q. From about 1988 Christopher's condition really started

12 to deteriorate.

13 A. Yes.

14 Q. He had problems with eating and weight loss.

15 A. Yes.

16 Q. What other difficulties did he have about that time?

17 A. Well, I'm just ...

18 Q. 1988.

19 A. Yes, he lost a lot of weight, he was very weak and,

20 yes, he had problems. He had diarrhoea and all sorts

21 of sinusitis, all sorts of infections like that.

22 Q. I think by then he also had some neurological

23 difficulties?

24 A. Well, that was probably just about when that -- yes,

25 he did have neurological symptoms like tingling in his

92

1 fingers and he couldn't write. He used to write
2 letters to my daughter who was in college and he found
3 he couldn't write properly, you know, and then of
4 course it had effects he couldn't wear his leg because
5 of the -- because it was uncomfortable and his good
6 leg had become weaker as well and with the ankle
7 problem, you know, so there was problems.

8 So he started using a wheelchair more often. He
9 did used to use a wheelchair occasionally before. He
10 always had a wheelchair, you know, access to
11 a wheelchair then.

12 Q. But around this time he really became much more
13 dependent the wheelchair --

14 A. Yes.

15 Q. -- and unable to use his artificial leg.

16 A. Yes, yes, or his crutches really because of his hands,
17 you know, because of the tingling in his fingers and
18 hands.

19 Q. Christopher gave up driving at about the same time.

20 A. Yes.

21 Q. And he could no longer really get to the beach himself
22 or go sailing?

23 A. No, no. Yes, his social life was compromised and,
24 well, just life in general was compromised really by
25 his condition.

93

1 and he used to have quite alarming hallucinations and
2 that sort of thing, which were very alarming actually.

3 Q. That really distressed both him and you when he had
4 these hallucinations.

5 A. Absolutely and -- well, and the children as well, you
6 know.

7 Q. In July he was hospitalised. He came home for
8 a little bit of time and then he was hospitalised
9 again.

10 A. Yes.

11 Q. At that point I think you were staying with him as
12 much as you could?

13 A. Yes. He was very ill by this time and he was rushed
14 into hospital. He had some sort of blockage. I think
15 he had some sort of major urinary infection or
16 something, and anyway he was rushed into hospital that
17 time. His temperature was 105 and something. So he
18 stayed in hospital and I was able to stay with him in
19 hospital and my sister's in law, his sisters used to
20 come and help and my daughter and my son as well. We
21 all helped to nurse him and to -- and I had
22 magnificent support from all the family and friends as
23 well, mega support from friends.

24 Q. Christopher wanted to come home for his final few
25 weeks.

95

1 Q. What was the effect of that inability to go to the
2 beach and inability to go sailing and drive on his
3 emotional well-being, on his mental well-being?

4 A. Well, he became quite depressed and angry. I think
5 the anger was more at the beginning. I think towards
6 the end it was more of a depression, you know, yes.

7 Q. At around about this time, you went on to sick leave
8 from your job.

9 A. Yes.

10 Q. And then ultimately gave up work to care for
11 Christopher?

12 A. Yes, I did.

13 Q. And about by July 1990 Christopher was really very
14 unwell?

15 A. Oh, yes.

16 Q. Can you tell us what was happening then.

17 A. Well, he used to have to go into hospital for blood --
18 he had -- I think it was the AZT that possibly made
19 him anaemic or it could have been the HIV, I'm not
20 quite sure, but I think anaemia is a symptom of the
21 AZT treatment sometimes. So he'd have to go into
22 hospital for blood transfusions, occasionally. So he
23 went in a couple of times for that and --

24 Q. He was having high temperatures.

25 A. Oh, yes. Yes, he used to have very high temperatures

94

1 A. Yes.

2 Q. What was the reaction of the hospital staff about
3 that?

4 A. They weren't keen, really, but then he was quite
5 determined to come home and so Dr Korn had said that
6 he could come home if he had 24-hour nursing care.
7 Well, so -- but he was quite happy with the
8 arrangement we made. I've got a superb friend who was
9 nursing at the time and she -- well, I think it was
10 between the social workers and whatever, but she
11 arranged for some of her colleagues to come and to do
12 a night each, you know, and then I used to look after
13 him in the day with the help of district nurses coming
14 in as well.

15 You see, the thing is we lived right out in the
16 sticks, basically, but we had excellent care from, you
17 know, the local surgery, brilliant. You couldn't have
18 wished for anything better and also from the
19 haematology unit in Bangor. They were fantastic.

20 Q. Because of the input and help from your friend who was
21 a nurse --

22 A. Yes.

23 Q. -- you were able to bring Christopher home --

24 A. We were.

25 Q. -- for the last couple of weeks.

96

- 1 A. Yes, I think he was home for about two weeks, two or
2 three weeks before he died, yes.
- 3 Q. Christopher died in September 1990 --
- 4 A. He did, yes.
- 5 Q. -- at the age of 46.
- 6 A. Yes.
- 7 Q. Can you tell us a little bit of the impact of
8 Christopher's illness and death and what that impact
9 has been on you.
- 10 A. Well, I'm just trying to think. It's devastating,
11 isn't it, and then ... yes, well, I wasn't working,
12 was I, and so then I had to sort of go back to work
13 for an income and -- but again I had tremendous
14 support from family and friends, brilliant.
- 15 Q. What was the impact on your children?
- 16 A. Well, they went back to college. I mean, they were
17 devastated as well and, of course, they didn't have
18 their father to help them with applying for colleges
19 and all that sort of thing, you know, and with their
20 education and advice and things like that.
- 21 Q. Your daughter who is sat next to you has said in her
22 statement she struggled particularly after having her
23 own child to deal with her own grief.
- 24 A. Absolutely, yes, yes. Well, he's missed out on my
25 fantastic grandchildren. I've got five.

97

- 1 they didn't, why they didn't basically.
- 2 Q. In terms of the formalities after Christopher's death,
3 can you tell us what was recorded on his initial death
4 certificate.
- 5 A. Well, I think it was septicaemia. Yes, I think it was
6 just septicaemia.
- 7 Q. And then what happened?
- 8 A. Well, then because it was septicaemia we had to have
9 an inquest and so I had a policeman visit me and ask
10 me lots of questions and then I had to go to the
11 inquest, to the court, and answer the questions again.
12 But they were mostly about his medication and how it
13 was administered and his nursing care. I think it was
14 because he died at home but they hadn't -- I'm not
15 sure whether they put HIV on the original death
16 certificate or not.
- 17 Q. You think that initially it was just septicaemia --
- 18 A. I think so, yes.
- 19 Q. -- but after the inquest what do you know was
20 recorded?
- 21 A. Yes, after the inquest they had septicaemia as
22 a result of HIV infection, yes.
- 23 Q. You have mentioned just earlier that the financial
24 impact on you was significant, of having to stop work?
- 25 A. Absolutely, yes.

99

- 1 Q. Your son in his statement has said a lot of the time
2 he tries not to think about what has happened or to
3 think about when he was nursing his Dad but when he's
4 on his own he comes to realise what the loss means.
- 5 A. Yes, yes.
- 6 Q. And that it hits the family at times that are
7 unexpected.
- 8 A. I mean, it's 30 years ago, isn't it, it's a long time
9 ago really but it's still, you know, it still hits
10 home occasionally, doesn't it, when you talk about it.
- 11 Q. Earlier we talked about Christopher's relationship
12 with Dr Bloom.
- 13 A. Right.
- 14 Q. How the family viewed him, but since Christopher's
15 death you feel more conflicted in yourself about how
16 to view Professor Bloom.
- 17 Can you tell us a little bit about what your
18 feelings are.
- 19 A. Well, I just -- I just want to know some answers
20 really when Dr Bloom not just -- not Professor Bloom
21 but, you know, the Department of Health and Government
22 ministers, when they -- and pharmaceutical companies
23 when they knew about the blood, the risks with the
24 blood transfusions and things, you know, when they
25 knew about it and if they took immediate action and if

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- 1 Q. Then you had to go back to work shortly after
2 Christopher died because of financial concerns?
- 3 A. Well, yes.
- 4 Q. You received some financial support when Christopher
5 was unwell?
- 6 A. Yes.
- 7 Q. How did you access that?
- 8 A. Well, we had a social worker from Harlech and he was
9 given access to our financial situation and he was
10 brilliant, actually. He got grants for the kids to go
11 to college and he also -- we had some help from
12 Christopher's teachers' union and from the
13 Physiotherapy, the Chartered Physiotherapy Society, so
14 I had a little bit of help from them. And then
15 I think he also, I think he also probably
16 recommended -- you know, we had help from the
17 Macfarlane Trust then as well.
- 18 Q. To pay for that nursing care --
- 19 A. Well, we had the nursing care, yes. That's when we
20 first arranged that, yes, the nursing care, the night
21 care that he had at home.
- 22 Q. Then after Christopher died you received some payments
23 from the Macfarlane Trust?
- 24 A. I did.
- 25 Q. Then more recently from the Welsh Infected Blood

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1 Support Scheme?

2 A. Yes.

3 Q. There was some delay in receiving the first Macfarlane

4 payment. Can you tell us about that?

5 A. Well, I don't know that it was a delay particularly

6 but the fact that I had a widowed mother's pension

7 because my son was under 18 and then my son became --

8 he was 18 after, just after my husband died and so --

9 but I wasn't -- I couldn't have a widow's pension

10 because I was too young and they -- because I was

11 under 45, so they just upped it, actually. It used to

12 be 40 and then I think it was the year before they'd

13 upped it to 45, so I wasn't eligible for that, the

14 widow's pension, so I lost out there.

15 Q. So very shortly after Christopher's death you missed

16 out on the widow's mother's pension.

17 A. Yes, and then, yes, so I was a bit financially

18 compromised then but luckily I'd started doing

19 a little bit of private work and then the

20 Macfarlane Trust -- I think it was in '91, wasn't it,

21 that the Macfarlane Trust issued that payment which

22 came at just the right time actually, to be honest.

23 Q. Since then, you and your daughter have appeared on

24 some media campaign supporting a campaign for the

25 Inquiry and you have been involved in some campaign

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1 work as Welsh speakers.

2 A. Sorry?

3 Q. Particularly as Welsh speakers.

4 A. Well, my daughter has, yes.

5 Q. Those are the questions I have for you. Is there

6 anything you would like to add?

7 A. Yes, just -- I have left it in my handbag. No,

8 I haven't, I've got it here.

9 I'd just like to thank all those people who have

10 campaigned for this Inquiry for over 30 years and

11 I trust that the outcome will prevent such a harrowing

12 tragedy from ever being allowed to happen again and

13 no-one will ever really know how different our lives,

14 all these people's lives, would be if our loved ones

15 had not been infected with contaminated blood. *Diolch*

16 *yn fawr*, thank you.

17 Q. I am just going to ask Mr Williams. No, there's

18 nothing, thank you.

19 SIR BRIAN LANGSTAFF: Can I thank you for that gently

20 affectionate tribute to your husband in a way which

21 I suspect has concealed rather than revealed some on

22 of the heartache that must have come with it. But

23 thank you very much.

24 A. Thank you.

25 SIR BRIAN LANGSTAFF: Now, Ms Fraser Butlin, that

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1 concludes the witness evidence for today. What do we

2 have tomorrow?

3 MS FRASER BUTLIN: We will be hearing from Tony and Monica

4 Summers, Mr AF, Jane Jones, and Ms AG.

5 SIR BRIAN LANGSTAFF: Thank you. We will start that at

6 10.00 tomorrow.

7 (3.07 pm)

8 (Adjourned until 10.00 am the following day)

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(32) friend... - him

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(34) infection - March 1992

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