

Tuesday, 11 June 2019

1

2 (10.31 am)

3

Opening statement by SIR BRIAN LANGSTAFF

4 **SIR BRIAN LANGSTAFF:** It's lovely for me to be here, but
5 why, you may ask, has the Inquiry come to Leeds? The
6 answer is simple. It's a matter of principle. This
7 is a UK-wide Inquiry. Indeed, the first UK-wide
8 statutory public Inquiry to deal with how it came
9 about that so many died, so many were infected and so
10 many more affected by their suffering, because blood
11 and blood products caused infections which were not
12 prevented or not quickly or sufficiently prevented.
13 What has been called by many in a phrase which
14 deserves thinking about rather than simply repeating
15 as the greatest treatment disaster in the history of
16 the NHS.

17 As a result of their infections many suffer from
18 illness or the after-effects of illness and others do
19 not have the money they might have, but for the
20 infection of themselves or of those close to them. It
21 is easier for them to come in person to an Inquiry in
22 Leeds rather than in an Inquiry in London. So the
23 Inquiry puts people first, UK-wide. It tries to make
24 itself more easily accessible to the public it serves,
25 and that you are here in the numbers you are -- there

1 is hardly a spare seat in the room -- with the press
2 interest that you have attracted shows how right that
3 principle has been.

4 You will have noticed that this is not the only
5 city we are visiting, but it is the only city which is
6 not a capital city. I hope you will forgive me for
7 a personal note. My father was a Yorkshire man who
8 was brought up not very far from here and I rather
9 think that he thought the north of England was
10 a separate country and Leeds was its capital but,
11 despite that, my personal feelings did not enter into
12 the choice of city. Rather, it was what a core
13 participant from Hull said to me several months ago
14 when I floated where the Inquiry might sit in the
15 north of England, and he pointed out that Leeds has
16 the advantage of being central to the region. It is
17 not on the west, Manchester. It is not on the east,
18 Hull. It is not a little bit further north Newcastle
19 or Newcastle -- I must get it right -- and it is not
20 south in Birmingham. It is central to those.

21 As I am committed to do, I listened and heard what
22 he was saying, so we are here.

23 I have already mentioned two of the principles
24 this Inquiry lives by: putting people first and
25 listening. Some of you may already have heard me set

1 out those central principles together with others at
2 the preliminary hearings last September in London, but
3 those who did not make it there may not, and all those
4 principles bear repeating. So please forgive me when
5 I just repeat them.

6 They are putting people at the heart of the
7 Inquiry UK-wide the principle I began with this
8 morning: being as quick as reasonable thoroughness
9 permits, paying proper respect to every person's right
10 to be heard, being as open and transparent as it is
11 legally possible to be, being independent of
12 government and frightened of no-one in the conclusion
13 it draws, and listening.

14 Though all of those six are important, four are of
15 particular importance at this stage of the Inquiry and
16 so I will say a little bit more about each.

17 First, I promised that this Inquiry would put
18 people at its heart, and the room you are in, I hope,
19 symbolises that. The witness or witnesses are centre
20 stage. The public in front. Lawyers and me to the
21 side. The Inquiry is not about them. The Inquiry is
22 not about me. It is focused on the evidence which
23 a witness can give. Friends and supporters in the
24 front row and, if a witness wants it, a family member
25 or supporter beside them when they speak. There will

1 be occasions when a husband and wife or family or
2 brothers and sisters give evidence together and that
3 is only right.

4 There are rooms to the side where anyone who needs
5 space during the hearings can find it and the Red
6 Cross are on hand to assist those who find some of the
7 evidence or indeed their own memories difficult.
8 Indeed, one of the witnesses who gave evidence just
9 last week in London has I think gone on social media
10 to give a particular vote of praise to the way in
11 which the Red Cross dealt with him, so feel no shame
12 or no difficulty in accessing the Red Cross if you
13 want to.

14 But putting people first is not just about
15 physical space or making the practical arrangements we
16 make. It is about giving people time. Now, you will
17 know that this Inquiry is here only for two weeks.
18 You may think only indeed for two weeks. It will
19 never be possible to hear orally from everyone who
20 would wish to be heard, but you should know that is so
21 wherever the evidence is taken, just as much, if not
22 more so, than this is in Belfast or Edinburgh or
23 Cardiff or here. Indeed, those of you who do think
24 that Leeds is the capital of the north may notice that
25 we are sitting for two weeks here whereas Belfast and

1 Cardiff have one week each.

2 The reason for the fact that I can't hear everyone
3 is simple. We don't have the luxury of time. People
4 continue to suffer. People continue to die, but those
5 who are not heard orally this week and those at other
6 centres who would like to be heard, but for whom there
7 is no time to speak orally, will be heard, if not
8 orally in sessions now during or at the end of the
9 Inquiry, then on paper. Every written statement will
10 be read. I have read a huge number already. I will
11 read every single one at least once by the time the
12 Inquiry is concluded. Each will be different,
13 inevitably. Each is important, and the evidence of
14 all those who have made or will make statements is of
15 real value, whether or not they give it orally. For
16 those who hesitate, those who may be watching this on
17 line by streaming as I speak, it is never too late to
18 make a statement, because the Inquiry would like as
19 complete a picture as you can help it paint.

20 Second, can I repeat what I said last September
21 about paying respect to a person's right to be heard.
22 Putting people at the heart of the Inquiry must
23 recognise that people have different perspectives to
24 bring to this Inquiry: those wishing to attribute
25 blame, those wishing to escape blame, those who wish

1 neither, but simply to understand why what happened
2 did or to have an explanation for the actions that
3 were taken, those who received blood products, those
4 who were transfused with infected blood, those who
5 were patients, those who were doctors, those who
6 criticise doctors and those who are deeply
7 appreciative of what doctors did for them. Sometimes,
8 the same person will criticise one doctor and be
9 deeply appreciative of another. All are people. All
10 are entitled to be heard, and I would ask all
11 participants to respect that entitlement however
12 unpalatable or difficult they may find some of the
13 ideas or explanations or accusations being expressed.

14 Third, linked with respect for what a person may
15 say, openness demands that the statement of a witness
16 redacted, blacked out, where appropriate, be published
17 when that witness gives oral evidence, and fairness
18 and openness requires that if that witness appears in
19 the statement, read at first blush at any rate, to
20 criticise someone necessary a manner which may be
21 significant, that that person who is criticised has
22 the opportunity to respond.

23 Where it is at all possible we try to arrange that
24 that is something that witness can do by the time the
25 person comes to give evidence. So in most cases -- it

1 is not possible in all, for reasons I shall come to --
2 but in most cases where a doctor, for instance, is
3 subject to criticism by a witness, that doctor will
4 have been told 21 days or more before the evidence is
5 given that that criticism will be made. They will
6 know who is making the criticism, whether or not the
7 witness is anonymous to you or the general public,
8 because they are entitled to know who is accusing.
9 They have a right to respond by then or at any later
10 time if they wish.

11 If they do respond by means of a written
12 statement, that written statement will be published at
13 the same time as the witness who has just given
14 evidence. It is only fair that you should see both
15 sides of the coin at one and the same time. It is
16 paying respect to that person's right to respond to
17 criticism just as it pays respect to the individual's
18 right to make it.

19 Some of the witnesses you will hear this week wish
20 to give evidence without their identities being known
21 to a wider public than those of you here. Now I shall
22 say more about that before each comes to give
23 evidence, but for now may I just ask that you respect
24 their wishes as best you can.

25 The proceedings are live streamed, but the cameras

1 filming in the room will not take any pictures of you
2 and I must ask you please not to take photographs in
3 or immediately outside the building of anyone else
4 without asking their permission, and remember that if
5 you are taking photographs of someone whose permission
6 you do have, there may be somebody else in the
7 background, so please just be careful. We have to
8 respect people's wishes not to be readily identifiable
9 and we don't know necessarily what their wishes are
10 without asking them first. The press won't take any
11 such photographs. Please do the same.

12 I mentioned that sometimes it might not be
13 possible to allow a doctor 21 days or more before
14 a witness comes to give evidence, and part of the
15 reason for that is something which you may have
16 noticed when looking at the programme for the week.
17 It says at the top that it is liable to change at
18 short notice. There is an example this week.
19 Tomorrow one of our witnesses has proven too ill to
20 come to the Inquiry, too ill even for the Inquiry to
21 be able to go to him to take evidence in his home. He
22 would have wished to give evidence, but he can't.

23 It underscores what I have said about the
24 importance of time, which is not our friend, but it
25 does mean that if it is possible, we shall obtain

1 somebody who is a reserve for the witness sessions to
2 give evidence not in his place -- how could you -- but
3 as a witness in those hours or the time that would
4 otherwise have been taken up by the witness who will
5 not be able to be here. I am deeply sorry that he
6 won't be. I am very appreciative of the fact we have
7 a late replacement, but one of the consequences of
8 that, of course, is that any criticism he makes will
9 not have the same opportunity to be answered, and
10 please bear that in mind when you are listening and
11 drawing conclusions about what's being said, because
12 above all this Inquiry must be fair.

13 Finally, and fourth of the four principles
14 I separate out for special attention, I am here to
15 listen. From reading all the witness statements and
16 documents, which I have, I know a lot more than I did
17 last September, and I knew more then than I did when
18 the terms of reference were framed and I knew a lot
19 more then than I knew when I was appointed to lead
20 this Inquiry just over a year ago.

21 I am grateful for the opportunities you have given
22 me to learn and the education that you have provided,
23 but I also know there is much more for me to learn and
24 that the oral evidence heard here in Leeds will be
25 an important part of that.

1 Well, thank you for listening to me. Enough about
2 me. We should now listen to the evidence. Our first
3 witness is John Cornes and once this has been cleared
4 away, because it rather gets in the way of the witness
5 there, we shall hear his evidence. Thank you very
6 much.

7 Now, Ms Richards, I understand that he wants to be
8 known as John?

9 **MS RICHARDS:** Sir, that's right.

10 **SIR BRIAN LANGSTAFF:** John, will you please come forward.

11 **JOHN CORNES, sworn**

12 **Questioned by MS RICHARDS**

13 **Q.** John, if you want to sit down.

14 **A.** Thank you.

15 **SIR BRIAN LANGSTAFF:** May I just say for future reference
16 that whether people stand or sit to take the oath is
17 not important to the binding nature of the oath and
18 whatever people find most comfortable for them in the
19 circumstances we will respect.

20 **A.** Thank you.

21 **MS RICHARDS:** John, you come from a large family. You
22 [redacted] were haemophiliacs.

23 **A.** That's correct.

24 **Q.** And you are here to speak not only about your own
25 experiences but to speak on behalf of a number of

1 members of your family who can no longer be here.

2 **A.** That's correct.

3 **Q.** John, you yourself have haemophilia A, classed as
4 severe. Can you tell us a little about how that
5 impacted upon your life growing up.

6 **A.** We are from a big family of haemophiliacs, [redacted].
7 As a child we were in and out of hospital all the
8 while. In fact, we went to school at the children's
9 hospital. We spent more time there than the normal
10 schools.

11 So the impact, mainly lots of bleeds, usually
12 ankle bleeds or knee bleeds. That was the main causes
13 of going into hospital. It put us -- leads to being
14 in hospital for weeks on end, sometimes up to three
15 months in hospital as a child.

16 **Q.** Can you tell us a little about your parents.

17 **A.** Yes. My father was born in 1912, very Victorian
18 attitude, which was good in strength ways. He brought
19 us all up to be as normal as possible. Just because
20 we had haemophilia it shouldn't stop us doing what we
21 want to do in life.

22 My mother was more of -- she was born in 1934, but
23 she was more of a '60s babe. She'd talk about sex,
24 drugs and rock and roll and everything. She was
25 always in with everything. So completely ...

1 Q. You described her as a big strong woman and she was
2 capable of coming and embarrassing you kids in the
3 street when you were out playing?

4 A. Yes. She'd talk about -- if there was anybody new
5 coming to the house she'd love to talk about -- her
6 favour thing was talking about sex. She'd joke
7 about -- she'd love to embarrass anybody. She was
8 very protective to all of us.

9 She -- I can remember my oldest brother. He got
10 a clip round the ear hole from -- this was going back
11 to the '70s when you could hit the kids round the ear
12 hole. He had a smack round the ear hole from a woman
13 up the road and my mum was a bit like Les Dawson's
14 character, she'd go up and she knocked the living
15 daylight out of this woman, but she was -- because
16 she was very protective of the kids.

17 Q. Now, you as children were under the care of the
18 children's hospital that you described. Then about
19 mid-teens in your case you came under the care of the
20 Queen Elizabeth Hospital?

21 A. That's correct at the age of 15 under the QE.

22 Q. Two of your brothers, Gary and Roy, attended Treloar's
23 school.

24 A. That's correct.

25 Q. You were treated in your own case with both

1 cryoprecipitate and a number of factor concentrates.

2 **A.** Yes, that's correct.

3 **Q.** We have the records of your treatment from 1979
4 onwards but nothing beforehand. Just in terms of your
5 childhood and the period up to 1978-79 what, if
6 anything, can you recall about the kind of treatments
7 you were given?

8 **A.** When we were kids the main -- only treatment was
9 transfusions, so you'd be in bed for days, weeks or
10 whatever with ice cold packs to stop the bleeding. As
11 I said a few minutes ago, the main bleeds were knees
12 and ankles. Then after the blood products -- that
13 particular blood products was cryoprecipitate before
14 Factor VIII.

15 **Q.** If we just have a look at a document on the screen.
16 It should come up in a few moments.

17 Paul, it is 1170002, and if we could go to the
18 fourth page, please, of that document. Thank you.

19 So we can see from the first four entries there,
20 John, for 1979 and 1980 these are records of you
21 receiving a number of factor products: BPL, Lister,
22 Factor VIII. Then we can see you received Cryo for
23 the other dates there.

24 If we skip on, please, Paul, another couple of
25 pages.

1 Just over halfway down the page we can see entries
2 that are cryoprecipitate and then again we can see
3 what look from the batch numbers to be factor
4 concentrates and 1990 you are recorded as receiving
5 8Y.

6 **A.** That's correct.

7 **Q.** Then just over the page, please, Paul. Top of that
8 next payable we don't have the product detail but we
9 have a number of batch numbers: 81, 82, 83 and 84.

10 You were by this time a young man. What, if
11 anything, can you recall about any information, advice
12 or given to you about these treatments?

13 **A.** We weren't given none, no advice on what the
14 treatments -- the possibilities -- how it could affect
15 us and what -- we didn't know anything about viruses
16 or anything like that, so there was nothing to tell
17 us. We didn't ask. They -- you know, like -- we
18 didn't ask them the question. They didn't come
19 forward with the possibilities of how it could affect
20 us in the future.

21 **Q.** What you have said in your statement, John, is:

22 "They were seen as breakthrough treatments which
23 helped my brother and I get back to school and then
24 work to avoid being in bed for weeks."

25 **A.** That's correct.

1 Q. So no advice or warnings about any risks of
2 infection --

3 A. No.

4 Q. -- as far as you were aware?

5 A. None.

6 Q. In consequence of the treatment you received you were
7 infected with hepatitis C.

8 A. That's correct.

9 Q. That's something you learned a number of years later.

10 A. Yes.

11 Q. We will come back to the circumstances in which you
12 learnt that, but if we just lack on screen, please,
13 Paul, at the same document, 117002, second page, we
14 can see in the last part of this letter, point two:

15 "With regard to the approximate date of being
16 infected with hepatitis C, it would be some time in
17 the late 1970s/1980s although a test was not available
18 until the early 1990s."

19 That's as much information you have about when you
20 were infected?

21 A. That's correct.

22 Q. Now I want to ask you first of all, John, about what
23 happened to three of your brothers starting, if we
24 may, with your brother Gary?

25 A. Right. I can remember Gary saying he's got to go to

1 the hospital for so many tests. They are talking
2 about HIV. None of us knew at the time what HIV was.
3 All we kept thinking it was some sort of cancer, which
4 they would be able to cure and I can remember the day
5 he came home. We -- all of us went over to the house
6 and he was sobbing his heart out, and he actually said
7 he thinks -- it looks as if he's going to die. That
8 particular day was quite emotional, because we were
9 all crying, yes. So -- and then -- do you want me to
10 carry on about Roy.

11 **Q.** If we just pause there, in relation to Gary, he had
12 been told he had HIV --

13 **A.** He had been told --

14 **Q.** And hepatitis C, at some stage.

15 **A.** Yes, that's correct.

16 **Q.** He too had been infected through the products he had
17 been given as treatment for his haemophilia.

18 **A.** That was -- we are not sure if that was at Treloar or
19 at the QE. I have never shown if it's the QE and same
20 as, yes, the other brothers.

21 **Q.** And what ultimately happened to Gary?

22 **A.** He infected his wife because she wanted a child and
23 they were told it was 50/50 whether she would be
24 infected or not. Gary died in -- we had a Christmas
25 party early, in the September. I think he ended up

1 about 4 stone and he died in the November, Remembrance
2 Sunday, 1992.

3 **Q.** He left behind his wife.

4 **A.** His wife, Lee and --

5 **Q.** And a son. We will not name his son but his son at
6 that time was very young.

7 **A.** Yes.

8 **Q.** And his death was of an AIDS-related illness?

9 **A.** Yes. He died -- he got AIDS on the certificate
10 besides a number of other things.

11 **Q.** How old was Gary when he died?

12 **A.** He was 26, second youngest brother, so ...

13 **Q.** Now the impact on you of Gary's death was that you
14 had -- you described it in your statement -- you had
15 some kind of breakdown. You went AWOL.

16 **A.** Yes, it was in between Gary and Roy dying. I went
17 AWOL. I ended up wrecking my marriage. I became more
18 of a workaholic. I have always loved work, so
19 I became more of a workaholic and I spent a lot of
20 time -- I'd do anything just to -- I had to get away
21 from the family mentally, so I spent most of my time
22 keeping myself occupied away from the family.

23 **Q.** And you put it this way in your statement, that you
24 didn't give a damn about things. You felt mentally
25 detached.

1 **A.** That's correct.

2 **Q.** And, as you said, you split up at that stage from your
3 wife?

4 **A.** Yes, from his mother, yes.

5 **Q.** Now, you mentioned your brother, Roy. What happened
6 in relation to Roy?

7 **A.** Well, Roy was the bigger picture of -- I have had
8 several brothers die, but Roy was the -- I think --
9 I am not sure if he was 20, 21. He was told about
10 a month later after Gary died -- sorry -- not Gary
11 dying but after Gary was informed he had HIV, that Roy
12 had got HIV.

13 At the time Roy was Jack the lad. He was a good
14 looking lad. He had several girlfriends, several
15 flings. Roy had infected a girl with HIV and she died
16 before Roy died. What happened, the press got hold of
17 it. They came down on the family, not just to Roy,
18 but to my mum's house, to the rest of my brother's
19 houses, to my house and they ripped the family apart
20 mentally.

21 In Birmingham we was known as the scum bags, the
22 AIDS -- and I have only just found out. Ryan is
23 telling me today there was a pub, pub local -- I live
24 in Kings Heath, Birmingham. There is a pub and they
25 don't call it by the name of the pub. They call it

1 AIDSelwell, because it is Hazelwell. In other words,
2 he asked the question -- he was in there. When was
3 it, a couple of years ago. He only told me today
4 about this. This is where all the AIDS family were.
5 They all live round here.

6 As I say, we did have graffiti. The reporters of
7 them days were vile. That's why our family -- it's
8 took a long time for us -- we have stood back and
9 watched other people come forward with their
10 information but we've stood back away from the press,
11 because you think -- the press has changed over the
12 years and there's different morals. They have become
13 more respectable to people's situations.

14 As I said, Roy was used by the tabloid press. We
15 had a couple of weeks of headline news, all the while.
16 Every day we was on the front pages of the papers. It
17 was nothing good. It was all bad. When I say the
18 press, it wasn't the press just in the UK. It was
19 worldwide. Roy did lots of interviews. He tried to
20 bring over his side of the story, but they just seemed
21 to ridicule him at the time, and it did affect not
22 just him. I felt sorry -- you know, I kept trying to
23 put myself into his place and how would you feel, but
24 it was a bad time for all the family, a very bad time.

25 Q. We have got one of the press pieces that you have

1 provided to the Inquiry.

2 Paul, it is 117006, please. No, that's not it.
3 Sorry, 006: it is this. Thank you.

4 So this is in the Independent newspaper,
5 June 1994:

6 "Haemophiliac accused of infecting women with AIDS
7 dies."

8 This records that Roy, just 26 years old, died in
9 1994 of an AIDS-related illness. It refers to:

10 "Two years ago it was revealed that he had slept
11 with several women who later contracted to the
12 disease."

13 It refers to one of them dying. It refers to
14 Roy's own death in the Queen Elizabeth Hospital on
15 27 May and refers to his wife saying:

16 "People made him out to be a monster, but Roy was
17 a kind, caring and lovely man. Our lives were wrecked
18 when these allegations were first made ... if it
19 hadn't been for all the lies and gossip, I am
20 convinced Roy would still be alive today."

21 Can we just leave that up on screen for a moment,
22 please, Paul. You share the views there expressed by
23 Roy's wife. He didn't know about the consequences of
24 his infection.

25 **A.** At the particular time -- because he did infect one

1 girl, who did die probably two years before he died,
2 but there was no -- with the HIV -- remember this is
3 before hep C was in the equation.

4 There was no information coming out from the
5 hospitals, from the government. You know, the
6 government to the hospitals, "You should be advising
7 these haemophiliacs this is what could happen if you
8 sleep with a partner". As I said a few minutes ago,
9 Gary was told because it was all more or less in the
10 same time -- Gary was told about Lee, it could be
11 50/50, but roy didn't -- he wasn't told anything. He
12 wasn't given any info. As I said, he was a young lad.
13 To me he's a young lad.

14 I think his mind started -- when he was told about
15 HIV, his mind started getting -- everything going out
16 of control, because, as I said, the press were on to
17 him and everything else, but prior to him infecting
18 the girl, there was no information coming forward.

19 **Q.** You said in your statement:

20 "Roy especially did not know the impact of how it
21 could be passed on as he was simply never told."

22 You have explained:

23 "The truth is we did not know much about the
24 disease itself, the risks or the dangers."

25 **A.** That is correct.

1 Q. There is a reference in the bottom of this article to
2 Gary's death and then to your other brother Gordon,
3 who is HIV positive, has survived. That was 1994.
4 What happened to Gordon?

5 A. Gordon, he was told about three months after Gary,
6 because Gary was told first, then Roy about a month
7 later and then Gordon about three months after.
8 Gordon actually did not -- after he informed us lot
9 that he had got HIV he started to deny. "Oh,
10 I haven't. I have made a mistake and they have told
11 me wrong" and he hid from it, because he started
12 realising. He was my older brother and he started
13 realising the effects, and we could -- watching Gary
14 die -- I can remember watching him -- watching --
15 looking at Gordon and Roy at Gary's funeral, and then
16 looking at Gordon at Roy's funeral. What's he going
17 through? What mental -- what state is his mind in,
18 because he knows it's going to -- luckily nowadays
19 they've got lots of cures for AIDS, but it was in --
20 it was Christmas time 1994 when Gordon died and yes,
21 it -- he was bad for -- he -- I just felt sorry for
22 him. I don't know if the word sorry is sufficient
23 enough, you know, devastated. We all did, especially
24 my mother.

25 Q. So three of your brothers, Gary, Roy and Gordon, all

1 infected with HIV in consequence of the treatment they
2 received for their haemophilia and all three died as
3 a result of the infections within a space of some
4 three or four years of each other.

5 **A.** Yes, they were all 18 months apart. Gary was in
6 May -- sorry, Gary was November, remembrance Sunday in
7 1992. Roy was in the May 1994. Then Gordon was
8 December 1995. So they all actually died 18 months
9 apart.

10 **Q.** You have described in your statements some of the
11 events that happened around the time of their deaths
12 and at the funerals in terms of press attention and
13 subsequent treatment of the family. What happened?

14 **A.** It was very bad at Gary's funeral, because Roy had
15 been the centre of newspapers' attention. The actual
16 funeral at Gary's, instead of it being a private
17 funeral -- remember we are just an ordinary family.
18 We're not celebrities who are used to what comes with
19 being a celebrity. We are nothing. You know, we are
20 just an ordinary family.

21 We had them hiding in the bushes and there was
22 lots, at least 50 reporters in the bushes. It made
23 us -- it really infuriated us all knowing they are
24 taking pictures. They didn't ask permission or
25 anything and all they wanted was just to get the

1 grieving AIDS family and get Roy, yes.

2 **Q.** When Roy died, you have said it was the same and you
3 have said this in your statement, John:

4 "People came to the cemetery to throw stones and
5 even wrote 'shit' on his grave. I remember there
6 being a comment, 'Hurray. He is dead'."

7 **A.** There was quite -- one of them was in one of the
8 newspapers as well, a comment. They actually put the
9 comment from somebody and I thought how are they
10 allowed to put things like that, but they did.

11 **Q.** Gary's wife, as you say, had contracted HIV herself
12 and she died in 2000.

13 **A.** Yes. She was a great woman, Lee, and she fought to
14 the end. I've got to say the three of them, they
15 didn't want to die. My family are all -- we love
16 joking and laughing and playing people up and they
17 wanted to live. They did live their lives until more
18 or less the end and Lee was the same. She ended up
19 leaving -- so I have got -- it has affected this, not
20 just me, because I have got problems, or one of my
21 brothers who's got the same problem as me.

22 [Redacted]

23 I have got a load of nephews and nieces from the
24 brothers that have died and I have got nephews that
25 haven't got a mother or a father, so it's affected at

1 least 30 of the family. So I am here to represent not
2 just the infected but also the affected. I didn't
3 want to come. I didn't want to really do this, but
4 there is a need. I got up and admired what the
5 Tainted Blood group have been doing and all the people
6 that have been coming forward and I thought "I have
7 got to say my piece", but it is hard, so ...

8 **Q.** What was the impact of losing three of her sons in
9 that short space of time and in such a way on your
10 mum?

11 **A.** Well, my mum was a very -- as I said earlier, she was
12 a bit like the character in Les Dawson. She loved
13 gossip. She was a big woman. I don't mean fat, but
14 a big, strong woman and if the press look at
15 photographs of her before Gary died -- if fact, she
16 ended up about 6 stone. She went frail and you could
17 see the fraught in her face. She ended up having
18 a massive heart attack after Gordon and, yes, she
19 died, but because we always look at the positives.
20 I have always looked at positives in everything.
21 Apparently my sister lived with my mum at the time and
22 she was looking after her. My mum was found on the
23 side, on the bed with the phone. The last person she
24 was speaking to was my aunty, my mum's sister and they
25 were telling dirty jokes on the phone, so she died

1 laughing, but it was a heart attack that killed her,
2 so yes.

3 **Q.** In the years prior to her death you explained it this
4 way contrasting her with how she had been before:

5 "When she lost three of her sons and knew that
6 there might be two more", and we will come on to that,
7 "the shell crumbled. She became thin and gaunt."

8 **A.** Yes. Before she died, as I said, after Gordon she
9 started getting thinner and thinner and gaunt and all
10 the while -- you know, you always say to your kids --
11 I always say "I love you", and when you go you give
12 them a kiss. My mum became even more obsessive with
13 kisses and phoning. If you didn't see her a day, she
14 would be on the phone half a dozen times that day.
15 She would phone up just to hear your voice or
16 whatever. Yes.

17 She became frail and fraught and it is this
18 that's -- I think she would still be alive. She would
19 be about 85 or something like that now -- I think she
20 would be alive if it wasn't for what happened, because
21 she was a strong woman. The tragedy has brought --
22 ripped her heart out.

23 **Q.** And while this was going on in the mid 1990s you,
24 John, found out you had been infected with hepatitis
25 C?

1 **A.** Yes. It was a matter of fact type of letter I had
2 from the QE and not just me. Two other brothers had
3 letters similar. They were later. I can't remember
4 the time span, but they were later when they had their
5 letters. I thought, "Oh, right. Hep C. Well, at
6 least it is not HIV". I don't mean that
7 disrespectfully but, you know, I thought, "I'm going
8 to be okay".

9 Yes, so it took a while before actually anything
10 was actually done from the QE hospital. Do I go on
11 about me having -- I had to have a liver biopsy?

12 **Q.** Absolutely. I was just going to ask you first of all,
13 John, before we talk about that, in terms of the
14 information you were given when you were told your
15 diagnosis, although you don't have a copy of the
16 letter anymore, you recall you were told by letter and
17 you have described it in your statement as being
18 a very matter of fact, detached way of informing you
19 with very little other information provided.

20 **A.** That's correct. There was no letter to ask, "Could
21 you come into the hospital. We need to talk about
22 a virus that you have received". It was just, "As you
23 may be aware, you may have hep C", blah, blah, blah.
24 I can't remember what. I think it might have been
25 another year before I had the actual liver biopsy to

1 prove I had hep C, because in them days they used to
2 put a big needle inside you and pull the liver -- they
3 don't do it like that now. Yes.

4 **Q.** Do you know how the diagnosis of hepatitis C came to
5 be communicated to you in '95 in the first place?

6 **A.** No.

7 **Q.** Were you aware you were being tested?

8 **A.** No. I have no idea, no.

9 **Q.** So you have a recollection some time after that letter
10 you had a biopsy?

11 **A.** That's correct. They said I had got hep C. At the
12 time they -- I don't think they knew, because they
13 didn't say -- I asked "Can it be passed on through
14 sex?"

15 "No." They didn't -- I don't think they had the
16 information they have had in the last 15, 20 years at
17 that particular time of what hep C -- how it can
18 affect you, so ...

19 **Q.** How did the hepatitis C affect you, first of all,
20 physically?

21 **A.** Well, physically, remember, I am a haemophiliac. So
22 I have always had bleeds. It's just part of your life
23 being in pain. You spend half of your life in pain.

24 You know, to me it is normal. I get on with my
25 life. I don't allow it to stop, but the hepatitis, in

1 the early stages there was nothing and it wasn't --
2 the early stages it was nothing. Then I can remember
3 they started putting me on treatments and the first
4 lot of treatments, I had ribavirin and ...

5 **Q.** Interferon?

6 **A.** -- interferon. It didn't work. They waited two years
7 and they put me on -- they were doing this with my two
8 other brothers that's haemophiliacs as well. It
9 didn't work on them at all. They says, "We are not
10 going through it again. It made us bad", and
11 everything, and I thought -- then two years came down
12 the line. They said, "Would you like to try again".
13 I thought, "In for a penny, in for a pound. I am
14 going to do it".

15 It made me so ill. I carried on working.
16 I managed to carry on, because I have always been
17 a workaholic and work is my therapy. I ended up being
18 on 24 -- because I am diabetic as well. I ended up
19 being on 24 tablets a day, as well as insulin and
20 blah, blah, blah, blah. It made me so ill. Also,
21 which I have never really had, it caused depression to
22 the extent I didn't want to be here, so ...

23 **Q.** And you in the course of that second treatment and the
24 effects it had upon you that you have just described,
25 you said in your statement you had something of

1 a breakdown that point.

2 **A.** Yes. Nearly -- just under eight and a half, nine
3 years ago, I ended up -- I kept crying a lot and I can
4 remember feeling like again -- I am not that type --
5 I have always been a positive person and I think
6 everybody probably goes through a shitty spell in
7 their lives. I really felt like just getting the car
8 and smashing it at something, but I ended up being
9 persuaded to go to the doctor's and that particular
10 day, that morning, they actually sent me straight to
11 a psychologist who I ended up going to see for months,
12 a few months, and it all stemmed down from me hiding
13 from what actually happened to our family, because
14 I think all -- there is a lot of people in here that
15 have had problems with their families, tainted blood
16 and everything, and you actually -- you need to hide
17 from it sometimes, because you can't -- you can't
18 allow it to overtake your life, because it's -- it
19 will rip you apart, but luckily it did -- it helped
20 me. I did come out of the -- I am still on depression
21 tablets, on the low ones now, and I get on with my
22 life as much as I can.

23 **Q.** One of the details you recalled to me this morning,
24 John, about issues relating to what happened to your
25 family is your dislike now or inability to drive on

1 motorways. How did that come about?

2 **A.** Yeah, that came about through when would my first
3 brother was dying, Gary, at the time I was in Cannock.
4 I was working in Cannock, which is in Staffordshire,
5 just if people don't know. I had a phone call, "You
6 need to get back, because Gary is going to die in the
7 next few hours". I must have done 120 miles an hour
8 on the motorway. I was going from Cannock and then
9 the next junction is Walsall and the junction after
10 that is Birmingham.

11 As I got to coming up to Walsall I froze. I felt
12 like -- I was like this, shaking inside and had to
13 pull off the motorway and ended up going all the back
14 way around to Birmingham and ever since then I can't
15 do motorways. I have tried to push myself. One
16 day -- it has been a long time ago, but one day --
17 I have done a couple of times where I have gone on one
18 junction and then got off the next junction. It is
19 usually of a Sunday morning when there is no traffic.
20 Yes, that affected me and it still does, just the
21 driving, so ...

22 **Q.** Then can I ask you about the physical effects in terms
23 of your longer term health of the hepatitis C and the
24 treatment you have received for it. Your second
25 course of treatment, did that succeed in clearing the

1 virus?

2 **A.** Yes, it cleared the virus. I was chuffed at the
3 particular time, because it is nice to -- for anybody,
4 it is nice to do something and succeed, you know, to
5 get a result from it and, yes, I was cleared of it,
6 but what it -- what I have got is cirrhosis. My liver
7 is really quite bad, very bad.

8 **Q.** And you have checks is it every three months?

9 **A.** No. It's gone down to every month now. I don't know
10 if you want me to talk about what happened in April
11 this year.

12 **Q.** Please do.

13 **A.** Yes. April 3, I was sitting down. It was 8.45 of
14 an evening. Everybody has probably been through it,
15 you know when you're having a coughing thing and you
16 think, "Oh, I am going to bring up some phlegm or sick
17 or something". I went to the toilet and it came up
18 nearly two pints of blood.

19 My daughter called an ambulance. I was rushed to
20 the QE hospital and then you -- did you end up -- you
21 ended up at the hospital as well. So I was a bit like
22 this and ended up bringing up more blood. Apparently
23 the varices -- I have got varices that keep appearing
24 in my -- that lower part here (*indicated*) from your
25 liver down, and I had to have eight tied up.

1 They kept me in hospital for ten days, but I was
2 off -- for the first time ever I was off work for
3 a month. That killed me being off work. It was
4 like -- because I am not the type to -- I do sit and
5 chill. I might watch something, or I will read a book
6 or whatever, but I do like being active and it has
7 hurt over the last -- I seem to be getting less active
8 and doing things because it is wearing me out, wearing
9 me out, wearing me out, but yes -- and then I went
10 back in. I was in hospital for ten days. Had the
11 month off.

12 I went back -- it has been four weeks now, because
13 I am due to go back next week to the QE. They found
14 another four varices about to burst, so altogether
15 I've had 12 tied up so far. They said they can carry
16 on tying up the varices but one day will come when
17 I have to have a stent put in.

18 Once you have a stent put in apparently it can
19 make you forgetful. There is side effects to anything
20 you have done. I can remember being in hospital.
21 I did cry for the first time in a long time again.
22 I am not a crier, crier but I did cry in the hospital
23 because I thought, "I have got lots to do. I don't
24 want to be here. I want to go out and be doing this
25 and doing that and everything else", but, yes, so

1 that's the way forward for me is more in hospital.

2 One day I could have cancer. They have told me
3 I could have cancer. This is what will happen in the
4 stages. I have asked the question, "Can I have
5 a liver transplant now?"

6 "You can't have a liver transplant until you have
7 got cancer", so it's a bit weird that you have got to
8 get really bad before you can have, you know, those
9 sort of things. There are not enough people donating
10 their livers, so please donate your livers.

11 **Q.** Notwithstanding your various physical health problems
12 that you have described and also your diabetes and you
13 have rheumatoid arthritis which causes you pain, you
14 have carried on working.

15 **A.** Yes.

16 **Q.** You have to go down to part-time with the assistance
17 of a supportive employer?

18 **A.** Yes. I have got a great employer. Every day is like
19 a Friday, because I work Monday, Wednesday and Friday
20 and, you know, like they have been supportive. I have
21 been open and honest with them from the beginning.
22 That's the way you should be. If you have got a boss
23 who is shitty about those sort of things, you
24 shouldn't be working for them.

25 They don't deserve to have good employees.

1 I think I am a good employee so, yes, work is good for
2 everybody.

3 **Q.** Your children would like you to work less, but you are
4 determined to carry on.

5 **A.** Yes. The older ones, [redacted] and [redacted], "why
6 are you doing this? Why are you doing that?" They
7 understand. They know I like work. I have always
8 been like that. I have always liked work. I don't
9 understand people -- although we are all different.
10 I know we are all completely different. I have never
11 understood in my head why people -- yes, you have got
12 a problem but why is it stopping you from working.
13 You know, you should keep yourself occupied. It is
14 a therapy. I have always -- I keep saying that until
15 I die. It is a therapy.

16 **Q.** John, you have told us about your three brothers
17 infected with HIV. There are three of you then
18 infected with hepatitis C. You, one of your brothers
19 who we are not going to name, who survives along with
20 you?

21 **A.** Yes.

22 **Q.** And then your brother Alan.

23 **A.** Yes. He died.

24 **Q.** What happened to Alan?

25 **A.** Alan -- the three of us, Alan, my other brother and

1 me, were cleared of hep C. I think I was the first
2 cleared and Alan and my other brother have probably
3 been the worriers in the family. They -- and the
4 stigma of what happened in the early '90s of -- late
5 '80s, early '90s, of what happened to our family, it
6 stuck. I pushed it to the back where with them it
7 stuck and it was always at the forefront of
8 everything.

9 This was in the March of 2017. Alan, he was with
10 one of his sons just walking to the shop. I don't
11 know exactly -- no. He had been to his daughter's and
12 walking to a shop and he said he felt funny and all of
13 a sudden he collapsed. He had a brain haemorrhage.
14 He lasted -- so if that's the March, he lasted until
15 Remembrance Day, so he also died, so my younger
16 brother died on Remembrance Day and Alan died on
17 Remembrance Day.

18 He didn't -- he managed to pull through. Just
19 everything collapsed on him sort of thing. In the end
20 he died on Remembrance Sunday 2017. He has got
21 several children. It was through -- on his death
22 certificate it doesn't say he died of hep C or
23 whatever or whatever, but that was a main contribution
24 to his death, we are convinced.

25 Q. That's because the stress, the anxiety, the worry he

1 lived with for so many years?

2 **A.** Yes. Definitely.

3 **Q.** I just want to ask you about notifications you
4 received in relation to the risk of vCJD. What can
5 you recall about that?

6 **A.** Yes. That was a letter from the QE again. I don't --
7 it didn't -- that was another letter that didn't come
8 in saying -- sent to us like -- professionally, really
9 you should be saying "Could you come to the hospital?
10 We need to talk about -- we have something we need to
11 talk to you about?" It was just a letter like, "As
12 you may be aware, this chap has died and you have had
13 a transfusion. He has died of CJD", so we are
14 infected with a transfusion. We don't know how it is
15 going to effect us. I mean, I have always been a bit
16 mad. I don't know -- until it happens we don't know.

17 **Q.** In fact, we have got a couple of the letters you
18 received. 1170003, please, Paul. This is a letter of
19 29 January 2001 from University Hospital, Birmingham.
20 As you have said, John, it starts:

21 "As you are probably aware now variant CJD is
22 a progressive and ultimately fatal disorder of the
23 brain."

24 Then it if he just go down to the next
25 paragraph it refers to:

1 "We have recently been informed by the UK
2 bio-products laboratory that some batches of Factor
3 VIII and Factor IX concentrate made by them in 1996
4 and 1997 contained plasma from a blood donor who has
5 recently developed new variant CJD. I am writing to
6 inform you that having checked through our records it
7 would appear that you have received product from one
8 of the implicated batches."

9 The reference is made in the next paragraph to
10 a recognition:

11 " ... this news may generate anxiety, we feel that
12 our patients are entitled to be informed of all of the
13 facts about their treatment."

14 They offer reassurance and provide a document from
15 the Haemophilia Society:

16 "Should you require any further information about
17 the new vCJD then please do not hesitate to contact
18 either myself or one of the nurses at the centre."

19 I think you received another letter to similar
20 effect in 2004 and again you were told you had
21 received one of the relevant batches.

22 **A.** Yes. I was told that. I have just got to say the
23 doctor -- this doctor who is on, if everybody is
24 reading, he is a great doctor. I have got no
25 complaints about the doctors and the nurses at the QE

1 Hospital. They have always been great. It's been
2 a bit like McDonald's. You phone them up and you say,
3 "I have got a bleed", you go up and they give you
4 Factor VIII. I still have Factor VIII, but it is heat
5 treated, sometimes it is quicker than going to
6 McDonald's. Yes, so looking at that ...

7 **Q.** What you said in your statement about it is you are
8 still not sure how this is going to affect you. It
9 has all been very matter of fact "Here is a risk", but
10 you don't have the information available to enable you
11 to process that.

12 **A.** No, not at all.

13 **Q.** Can I just ask you a little more about the impact on
14 your own family life of the events that you have
15 described? You have told us how after your first
16 brother's death, Gary's death, your marriage broke up.

17 **A.** To his mother, yes.

18 **Q.** And then you had the breakdown that you have described
19 when you were on your second course of treatment for
20 the hepatitis C in about 2011. How did that affect
21 your second relationship?

22 **A.** It was the same sort -- I couldn't believe I was going
23 through the same sort of -- it was worse actually,
24 probably, because I didn't know where I was mentally
25 and, as I said, the only thing that kept me going was

1 working.

2 I know that's sad to say that word, but that's
3 exactly what just kept me going. Through my second
4 partner who I have got three children with I needed
5 space. I needed total -- I just needed to be on my
6 own, so it did affect everything. I see my children
7 all the while. I mean, one of my daughters lives with
8 me. I love my children, so ...

9 **Q.** You have told us about the treatment that your family
10 received in consequence of your three brother's
11 infection with HIV. The stigma was such that some of
12 the younger members of the family changed their
13 surnames. We won't mention any names that were
14 changed, but --

15 **A.** Yes. It was [redacted]. He don't mind admitting it,
16 and my oldest daughter [redacted]. He is 39 this year
17 and she is 40 -- 41. She -- my wife -- I have only
18 been married once and we are the best of friends. We
19 see each other lots.

20 At the time -- because of what people were writing
21 on walls and the whole area was known as the AIDS area
22 and blah, blah, blah, [redacted] was -- was she just
23 about -- was she going to the senior school -- going
24 into the seniors and my ex-wife wanted to change their
25 surname, so their surname was changed to protect them

1 from -- because if you mention the name Cornes, it
2 would be like ... yes.

3 **Q.** And you have a nephew -- we will not mention again any
4 names -- but you have a nephew who did likewise and
5 changed their name.

6 **A.** Sorry?

7 **Q.** You have a nephew who also changed their name, without
8 mentioning any names.

9 **A.** Yes.

10 **Q.** You described to me, John, this morning what you and
11 your family went through, it was a little like the
12 treatment that in the aftermath of the Birmingham pub
13 bombings. If you were Irish, you were treated in
14 a certain way --

15 **A.** Yes.

16 **Q.** -- in the area in which you live.

17 **A.** Yes, because when the pub bombings went off in 1974
18 I think it was, I was 17 at the time and I can
19 remember the atmosphere in Birmingham and I felt sorry
20 for them, because I have got lots of Irish friends.
21 If you was Irish, you would be beaten up and that's
22 the way it was in Birmingham at that particular time.
23 There was -- there was a real bad atmosphere in
24 Birmingham, and the only way I can describe what
25 happened to our family was exactly the same. The name

1 Cornes, the AIDS family. That is the closeness I can
2 feel. I can totally understand the way the Irish
3 community were affected by the bombings and it wasn't
4 their fault and it wasn't our fault what happened to
5 us.

6 **Q.** You have managed to keep on working in the way that
7 you have described, but have there been financial
8 impacts upon you, your infection and treatment in
9 terms of ability to obtain insurance and mortgages and
10 the like?

11 **A.** Insurances have always been a taboo subject for any
12 haemophiliac, whether you have got HIV or hep C or
13 whatever. It always has been and some of them -- some
14 companies, insurance companies, don't even know what
15 it is, yeah. I have been lucky with buying properties
16 because I have worked, but now, because I have gone
17 part-time, financially it is -- I have got to find
18 what's the best for me, so I am still working, which
19 I love, and as I said every day -- every day going to
20 work it is like the week-end because I go in on
21 a Monday, I have got Tuesday off, I go in on
22 a Wednesday and I have got Thursday off. I go in on
23 Friday and I have got the week-end off.

24 I don't sit at home on my -- I am out. Because
25 I have had two families, my youngest son, he is 12

1 next month. I take him tennis. I sit there, because
2 I can't stand -- I can't stand up too long, but they
3 all have activities. I have got one daughter who is
4 down in London. She is in her second year of acting.
5 She is a brilliant singer. She sang three times now
6 at the Royal Albert Hall, so I am proud of all my
7 children, because they have all done things. You
8 know, they have pushed themselves and everything else.

9 **Q.** You have made applications to the Skipton and I think
10 now EIBSS. You have not had any problem yourselves
11 with the applications?

12 **A.** No. I didn't even realise I could claim anything. It
13 was the liver specialist at the QE. He actually told
14 me on the day that I had cirrhosis that I could claim.
15 I said "right. What do I do". He actually -- they
16 were great. They brought the forms. He actually
17 signed the forms and said, "blah, blah, blah and you
18 will get this". I thought "hmm". They were really
19 helpful financially that way, yes.

20 **Q.** John, you mentioned the counselling that you had had,
21 but that was when you had your own breakdown and you
22 sought help in 2011 or thereabouts. Were you ever
23 offered at any time throughout the 1990s and any time
24 prior to that any counselling or psychological
25 support?

1 **A.** None.

2 **Q.** Were your brothers or any other members of your family
3 offered that?

4 **A.** No, no. Not to do with them getting the HIV and what
5 not. They have had none. I remember the -- I don't
6 know what they call them -- parts of the government --
7 it was one of the departments in the government. When
8 all the press came out about Roy and what had
9 happened, they actually had to hide him in hotels,
10 because he felt as though you had people with nooses
11 ready to lynch us all.

12 **Q.** John, those are the questions I have for you.

13 **A.** Thank you.

14 **Q.** Is there anything that you would like to add?

15 **A.** I appreciate that we -- I have had. I didn't want to
16 do this as I said earlier. I appreciate -- I wanted
17 to come out not just for me but also for my family and
18 I have got -- I cry when I think of my nephews and my
19 nieces that haven't got dads. Luckily I am still
20 here. I don't know how long I am going to be here for
21 but I will be a bugger to go.

22 So -- but I just appreciate what's going on and
23 years ago I didn't realise -- until I started looking
24 on the Facebook at the Tainted Blood group, I know Sue
25 Threakall really well. Sue had has been a great

1 woman. When you start looking at this particular
2 group that I'm part of, you know you are not on your
3 own, because we -- me and the rest thought we were on
4 our own and we are not. You look and think "Christ,
5 it is not just us. Look at what's happened to them".

6 I think this is a fantastic thing what is
7 happening now. I hope they get a conclusion soon,
8 sooner than later.

9 **Q.** John, I am just going to ask Mr Snowden, who
10 represents you, if there is anything else.

11 No, there is nothing from Mr Snowden.

12 **A.** Thank you very much.

13 **SIR BRIAN LANGSTAFF:** John, I know you didn't want to be
14 here, but thank you very much for coming and all the
15 more thanks because it can't, I suspect, have been at
16 all easy talking to us now in public, given what your
17 family has been through as the AIDS family,
18 particularly in the 1980s and the stigma that you have
19 told us about. So thank you for your bravery.

20 **A.** Thank you very much.

21 **SIR BRIAN LANGSTAFF:** Well, we will take a break now until
22 12.10, when we are due I think to hear from Graham
23 Binks.

24 **MS RICHARDS:** That's right, sir.

25 **SIR BRIAN LANGSTAFF:** 12.10.

1 (11.41 am)

2 (Short break)

3 (12.16 pm)

4 **SIR BRIAN LANGSTAFF:** The next witness, Ms Fraser Butlin,
5 wishes to be known as Graham, does he?

6 **MS FRASER BUTLIN:** That's correct, sir.

7 **SIR BRIAN LANGSTAFF:** Graham, please.

8 **GRAHAM BINKS, sworn**

9 **Questioned by MS FRASER BUTLIN**

10 **Q.** Graham, you are here to give evidence about your late
11 wife, Margaret.

12 **A.** Yes.

13 **Q.** Can you tell us, first of all, how you met?

14 **A.** We met in a primary school. Margaret, who was ten
15 years my senior, was a primary school teacher in Leeds
16 and in an arrangement that was usual then, but not
17 now, I had two terms before I went to university and
18 I finished up at the same primary school for those two
19 terms as an ancillary teacher, so I was 18 and she was
20 28.

21 **Q.** And when did you marry?

22 **A.** We married 15 years -- no. Sorry. We married five
23 years later when I was 23 and Margaret was 33.

24 **Q.** Can you just tell us a little bit about what Margaret
25 was like?

1 **A.** Margaret was an exceptional person, because besides
2 all the things that you'd want from an attractive
3 partner she was one of the most good and kind and
4 gentle people I have ever met, a person of faith, like
5 her brother, who is with his wife in the front row.

6 You will find this difficult to believe, but it is
7 absolutely the truth. In the 15 years when we were
8 together from my 18th birthday until her death I never
9 heard her say a bad word about anyone and I never
10 heard anyone say a bad word about her. Now there
11 aren't many people you can say that around. So she
12 was a truly lovely, gentle person, a devoted wife and
13 mother, wanted to spend time drawing and reading with
14 the children and so on. So I hope I have given you
15 a little bit of the picture there. She was a really
16 extremely good human being.

17 **Q.** And, as you said, she worked as a primary school
18 teacher and then subsequently as a lab technician
19 until she stopped working when she had your first son
20 in 1972?

21 **A.** That's right.

22 **Q.** The plan was for her to return to work part-time once
23 your boys -- your youngest had started school?

24 **A.** Yes. The idea was once he was 5 and started proper
25 school, then she'd return to some part-time

1 employment, probably in primary teaching.

2 **Q.** After Margaret gave birth to your first son in 1972
3 she received various blood transfusions and then
4 became jaundiced.

5 **A.** That's right. She was kept in hospital for three
6 weeks in Hyde Terrace Maternity Unit in Leeds, which
7 is where both my sons were born, and she received
8 a series of blood transfusions. The baby was healthy.
9 He weighed over 7 pounds and both [redacted] weren't
10 discharged until three weeks after delivery.

11 **Q.** Then after the birth of your second son in 1974 she
12 received further blood transfusions and again stayed
13 in hospital for longer than normal.

14 **A.** Yes. We were advised after the birth of the first
15 son -- our GP advised us that if we wanted to have
16 more children, then we should get on with it,
17 basically, and we assumed, probably correctly, that
18 this was because of her age, because she was 36 when
19 we had the first child, and then 37 when we had the
20 second one or when she had the second one I should
21 say, 20 months later. He was a nice healthy 8 pounds
22 baby, but again she received blood transfusions and
23 was not discharged until 12 days after he had been
24 delivered.

25 **Q.** When each of those transfusions -- when each of the

1 transfusions were given to her, was she or were you
2 made aware of any risks involved in having them?

3 **A.** Absolutely not.

4 **Q.** And it was after the arrival of your second son that
5 she became particularly unwell. Can you tell us what
6 happened?

7 **A.** Well, she was never healthy again after the birth of
8 my second son, and she was within -- I can't remember
9 the exact date, but within a month or two she was
10 diagnosed with hepatitis. This diagnosis by the GP
11 was confirmed by a biopsy, a liver biopsy. So at the
12 time it was described not as hepatitis C but as
13 chronic aggressive hepatitis.

14 **Q.** She was hospitalised for six weeks during the summer
15 of 1975.

16 **A.** That's right. By the time my second son was 11 months
17 old she was hospitalised in St James's for
18 approximately six weeks.

19 **Q.** Because of the hepatitis?

20 **A.** Oh, absolutely, yes.

21 **Q.** When your wife found out about the diagnosis, were you
22 told of any risks of transmitting the infection?

23 **A.** No.

24 **Q.** And were you told anything about managing the
25 infection?

1 **A.** Not as far as I'm aware, no.

2 **Q.** After she was discharged from hospital in 1975 what
3 was your wife's health like?

4 **A.** It was a story of progressive deterioration. She
5 became increasingly yellow. The whites of her eyes
6 turned yellow. Her skin turned more and more yellow.
7 She got more and more tired and exhausted, and this
8 continued until May 1979, when she was hospitalised
9 for several weeks, and then on discharge given six
10 months to live.

11 **Q.** What was she told during that hospitalisation? She
12 was told she had six months to live, but what else
13 about her condition was she told?

14 **A.** Well, I can't remember anything specific that she was
15 told. She was told that she was terminally ill with
16 chronic aggressive hepatitis. No-one ever attributed
17 a cause to this. There were no other risk factors
18 that anybody was aware of, and that was it.

19 **Q.** And in those days liver transplants weren't
20 available --

21 **A.** Absolutely, not, no.

22 **Q.** -- and there were no options for you.

23 **A.** I imagine that had liver transplants been available,
24 she might well have been a candidate for one, but
25 this, you know, is before all that was available, yes.

1 Q. Can you tell us a little of how Margaret coped with
2 that news.

3 A. I hope people will forgive me occasionally referring
4 to notes but I realise that I have only got one shot
5 at this and I don't want to go away this afternoon,
6 drive away thinking there are things I wish I'd
7 mentioned and forgot.

8 She never enjoyed good health again and the effect
9 on her was that when the seriousness of her condition
10 became clear, she was frightened, because who wouldn't
11 be, and not least because during her hospitalisation
12 in the liver ward she had seen other patients in
13 a more advanced state than she was, so she saw what
14 was coming, but despite the fact that she knew that
15 she'd never see her children grow up, she was a very
16 brave and resilient person, and we all know that we're
17 mortal, but an end date concentrates the mind and the
18 sensation for both of us and for other members of the
19 family, but not the children, of course, who had no
20 idea, is if you imagine that you are on an aeroplane
21 and you know it's guaranteed to crash. It's slowly
22 descending but you know that the aeroplane is
23 guaranteed to crash. So it's obviously very
24 depressing, and the difference, if you like, is that
25 for the person infected, then the rest of us knew that

1 this was a tunnel we were going into, but we'd come
2 out the other end in whatever shape. Margaret knew
3 she wouldn't, you know. It's a wall at the end of her
4 tunnel -- not in this life anyway.

5 To a certain extent she went into a country of her
6 own, which I can quite understand. I mean, having
7 that kind of effective death sentence, you know, makes
8 you in some respects a slightly different person, so
9 she was frightened, but she was brave. She had faith.
10 She was a resilient person, and we had two little lads
11 to look after, and that's the best medicine anybody
12 can have.

13 So it did restrict -- the fatigue restricted the
14 time and energy she had available for family life. In
15 the later stages she would get up in the morning,
16 spend a little bit of time with them before they went
17 to school, then go to bed for the whole day, spend
18 a little bit of time with them when they came back and
19 so on, and we moved the bed into the front room and so
20 on, but the objective was to protect our sons really
21 and give them as normal a life as possible.

22 **Q.** And at that stage they were about aged 5 and 7?

23 **A.** They were 5 and 7 when she died, yes.

24 **Q.** What was their understanding of the situation before
25 Margaret died?

1 **A.** Their understanding of the situation was limited,
2 because we'd obviously protected them. So they knew
3 that she was unwell. They knew that she was
4 turning -- that their mother was turning yellow and
5 spending increasing amounts of time in bed. Other
6 than that, I don't think they had much awareness.
7 They knew their mother was ill, but they had no idea
8 of the seriousness, of course.

9 **Q.** In January 1980 Margaret haemorrhaged. Can you tell
10 us about that.

11 **A.** Well, she had deteriorated rapidly and fortunately my
12 parents live just down the road, so my sons were able
13 to spend an increasing amount of time when they
14 weren't at school at my parents' house.

15 Margaret preferred -- expressed a preference to
16 die at home. Our GP explained that this would be
17 an extremely messy business, because a great deal of
18 blood was likely to be ejected, but I wanted to abide
19 by her decision and -- sorry -- I didn't care if she
20 dyed the carpet crimson, but when she began to vomit
21 blood whilst the GP was present as it happened, he
22 persuaded her to go into hospital right at the end, if
23 you like, and called an ambulance. One of my abiding
24 memories is of my children waving through the window
25 of my parents' house down the road with no idea that

1 they wouldn't see their mother again.

2 So the decision to go into hospital turned out to
3 be a very good decision, because it effectively bought
4 her a few extra days and the opportunity for her
5 brother, who I see is in the front row, to visit her
6 in hospital, and in between being in a coma she did
7 have periods of great lucidity.

8 I was amazed at the volume of blood that was being
9 pumped in and vomited out. I didn't really believe
10 that anybody could have a lucid interval while they
11 were going through that, but she did.

12 At the end in the last probably 36 hours --
13 incidentally, I lived and slept at the hospital for --
14 from the Saturday she was taken in on through till the
15 early hours of the following Friday when she died.
16 When she -- towards the end of this, her -- the
17 varices in her throat exploded basically and they had
18 to resort to a procedure called a Sengstaken Tube,
19 which involves having a rubber tube pushed up your
20 nostrils and a balloon inflated in your throat to put
21 pressure on the blood vessels to stop the blood coming
22 out. This was sustained by a kind of weight at the
23 other end of the tube.

24 So it's not the way one would wish to die, shall
25 we say, with this balloon wedged down your throat, and

1 that was how she died in the early hours of Friday,
2 25 January.

3 **Q.** 1980?

4 **A.** Yes.

5 **Q.** And she was 43.

6 **A.** She was 43, yes.

7 **Q.** You were 33.

8

9 **A.** Yes.

10 **Q.** And you had to go home to tell your sons that their
11 mum had died.

12 **A.** Yes.

13 **Q.** You have described that as the hardest thing you have
14 ever had to do.

15 **A.** Far and away, far and away the hardest thing I ever
16 had to do. As I say, they -- they knew that their mum
17 was ill but they had no inkling of how serious the
18 illness was.

19 **Q.** But you told them a little white lie when you told
20 them --

21 **A.** Yes, yes.

22 **Q.** What did you tell them?

23 **A.** Well, I told them the truth in the sense that I said
24 their mother had sent a message that she loved them
25 and was sorry she had to leave them but the white lie

1 I told is I said she told us to be like the three
2 musketeers. So I sat one each on my knee and --
3 sorry -- and we swore an oath of one for all and all
4 for one, and sealed it with a small glass of port,
5 even the 5 year old.

6 Can I reassure any worried parents in the room
7 none of us went on to become alcoholics as a result of
8 this, you will be thrilled to hear.

9 The difference was that the 7 year old was able to
10 grasp the finality of death and the 5 year old
11 couldn't. He kept expecting her to turn up. So my
12 sister-in-law and myself would be asked questions
13 like, you know "When am I going to see any mummy", and
14 the answer might be "When you get to heaven", and the
15 question then would be "But how will I find it" and
16 the answer, which I owe to Chris really is "Don't
17 worry. She will find you", so it was hard for them
18 and I have always been honest with them and -- but to
19 this day I have spared them the most gory details
20 about the final couple of days.

21 They were deprived of a loving and responsible
22 mother, a primary school teacher and consequently
23 their educational support was probably less than -- it
24 was certainly less than it would have been and they
25 led a somewhat less comfortable life than their peers

1 but fortunately they both went on to graduate and
2 enjoy extremely successful careers occupying senior
3 positions in their chosen fields.

4 I must say, by the way, they both offered to come
5 up and support me today but I persuaded them that if
6 they were going to take time off work we had a lot
7 more fun things to do together than go through this,
8 so it's not that they don't support me. It is just
9 I didn't want them to be here, basically.

10

11 **Q.** You said a little bit about the effect on your
12 children.

13 **A.** Uh-huh.

14 **Q.** What about for you?

15 **A.** Well, the effect for me was I hadn't expected to find
16 myself a widower at the age of 33. So that was
17 a surprise. You never ever fully recover from the
18 death of a partner and even 30 years -- 39 years on,
19 I'm no stranger to tears. I am hoping to get through
20 this without them, but we'll see but I had two little
21 lads to look after and a responsible job. So I took
22 a week off work and then worked my backside off,
23 basically.

24 I -- I was very lucky, because I advertised for
25 part-time help and engaged a lady, who has been dead

1 for years now, a lady called Jean Chapman. Jean was
2 already a grandmother, lived very close, and she had
3 just lost her husband and been made redundant from
4 Hepworth's, which was one of the clothing firms in
5 Leeds. So she had had a big change in her life and
6 she was a Godsend, because she was one of the few
7 people who was available to work through the family
8 teatime period. So she would collect my sons from
9 school, feed them, did the cleaning and ironing and
10 babysitting and, much more importantly, built a strong
11 and loving relationship with them, which went on for
12 many years after she had ceased to work for us, as it
13 were.

14 I was also very, very lucky because I come from
15 a large extended very humble family in Leeds, a kind
16 of tribe really, and they were very supportive and my
17 parents who, as I say, just lived down the road, were
18 very, very helpful in all sorts of ways. I mean, they
19 used to take my sons on holiday to Spain every year to
20 give me a break. They used to do babysitting and
21 other things. So they were very helpful.

22 **Q.** Financially, it was also very difficult. Can you tell
23 us about that?

24 **A.** Well, financially I think I used the phrase in the
25 statement -- financially, it was devastating. It was

1 a torpedo through the ship. Entirely due to my own
2 stupidity I was 23 when we married. I took out
3 a mortgage. There was no bank of mum and dad and,
4 like an idiot, I naively assumed that the lady I loved
5 and myself were immortal, so neither my wife's life
6 nor our mortgage -- and this was at a time of rising
7 double figure interest rates -- were insured but
8 I assumed that they would, like probably lots of us do
9 when we are that age, that we would live forever. How
10 wrong can you be? So we had extended the house and
11 the mortgage substantially to accommodate our sons
12 obviously, bedrooms and a playroom for them and so on.
13 The expectation had been Margaret would resume
14 part-time employment, as we said earlier, when the
15 youngest son had started school.

16 Instead, I was faced with substantial funeral
17 expenses and having to support three of us until my
18 sons were through university on one income and also to
19 pay for help in the house, which was quite expensive,
20 although, as I say, I was very fortunate to have found
21 the person that I did, but we managed okay. I had
22 a decent job but I became for a time in the early
23 days, which are difficult, an authority on the precise
24 price of everything in Asda as a result of this.

25 Q. Now, you can't say for sure that your wife was

1 infected with hepatitis C from the blood transfusion
2 she received.

3 **A.** No, no.

4 **Q.** We have had her death certificate, which, if we may,
5 we will just put on the screen. It is document
6 0288005, and we can see there that the cause of
7 death -- just the other half -- is set out as
8 bronchopneumonia, hepatic encephalopathy, bleeding
9 oesophageal varices, and chronic active hepatitis.

10 **A.** Yes.

11 **Q.** Margaret had no other factors by which she might have
12 contracted hepatitis?

13 **A.** None whatsoever.

14 **Q.** So really the best thinking is it was the transfusions
15 that caused her to contract the hepatitis?

16 **A.** Well, I am not a medical person. So I have no
17 authority to say that but there was certainly no other
18 risk factors and, as I say, after that 20-month period
19 she went from being perfectly healthy to being what
20 turned out initially chronically and then very quickly
21 terminally ill.

22 **Q.** You have tried to obtain her medical records --

23 **SIR BRIAN LANGSTAFF:** Just a moment.

24 **MS FRASER BUTLIN:** Of course.

25 **SIR BRIAN LANGSTAFF:** Later on you applied, did you, to

1 the MacFarlane Trust and the Skipton Fund?

2 **A.** No.

3 **SIR BRIAN LANGSTAFF:** You didn't?

4 **A.** No.

5 **SIR BRIAN LANGSTAFF:** I see.

6 **MS FRASER BUTLIN:** You have tried to obtain her medical
7 records to try to work out what was known and what was
8 understood at the time. Can you tell us what happened
9 when you applied for her records.

10 **A.** Well, I -- I approached the GP. I am very fortunate
11 we are patients of one of the best group practices in
12 Leeds in Horsforth and they did a very thorough trawl
13 but could find no records. I was advised to approach
14 the Primary Care Support England and their policy
15 states that it's and I confirmed this in a phone call,
16 that it was a waste of time trying to pursue anything
17 with them, because their policy is that after
18 a certain number of years records are no longer
19 available, and I contacted the Leeds Hospital Trust
20 and their -- I contacted them initially just last
21 October and, as I probably said before, when you're
22 going through these experiences you are not analysing
23 it you are just experiencing it.

24 It is like being on a roller coaster. So you
25 don't -- you know, it never occurred to me that there

1 was even a possibility that infected blood played
2 a role in this and, you know, I suppose it surprised
3 everybody in subsequent years.

4 When I approached Leeds Hospital Trust last
5 October, I explained that the reason I was looking for
6 these records was because I was due to give
7 a statement to your colleagues in London to the
8 Inquiry, so they were aware of that. Despite
9 several -- they acknowledged receipt of my application
10 form. Despite several attempts to chase the matter
11 up, and bear in mind they had a clear legal
12 requirement to provide records even for people who are
13 deceased within a certain time limit, then I didn't
14 receive a single e-mail or response.

15 **Q.** You then wrote to them again on 9 May 2019 and we've
16 got a copy of that letter, 0288003.

17 **A.** Yes. Well, I wrote to them again, because by that
18 time I was called to give evidence and that point
19 I received a response in a matter of a few days by
20 special delivery.

21 **Q.** Just before we go to the response, if we just look at
22 the letter you sent, you made this clear in
23 paragraph 2 and 3 that you had made the request but to
24 date no concrete response of any kind has been
25 received. If we go to the second to last paragraph,

1 you have said:

2 "I also understand that my request is one of many.
3 That being said, over six months have elapsed since
4 I made the request and I have yet to receive
5 a tangible response of any kind -- not a single
6 e-mail -- not a single letter."

7 **A.** That's right.

8 **Q.** As you say, on 13 May you received a response by
9 special delivery indicating that no records were
10 available.

11 **A.** That's right. I mean, this is hardly surprising in
12 view of the fact the events we are talking about, the
13 transfusions we are talking about, were over 40 years
14 ago now.

15 **Q.** But the six month delay has caused you some concern
16 that there was not a reply more promptly.

17 **A.** Yes.

18 **Q.** Those are the questions I have for you. Is there
19 anything else you would like to say?

20 **A.** Just that I'd like to make a brief -- with your
21 indulgence -- a brief statement in conclusion.

22 I wish to make clear in my evidence that I am
23 alleging nothing and I am criticising nobody. I have
24 no knowledge of the presence or otherwise of infected
25 blood in the Leeds Hyde Terrace Maternity Unit at the

1 periods in question. Neither do I know whether and,
2 if so, how many other mothers who received post-birth
3 blood transfusions there went on promptly to develop
4 and suffer serious life-changing illness, nor whether
5 any statistical analysis, should it prove possible,
6 would cast light on the matter. I don't know.

7 I am here today because I feel I owed it to my
8 late wife, to my sons and to others who may or may not
9 have been affected in similar circumstances to furnish
10 the Inquiry with such facts as I possess, which may or
11 may not contribute a relevant piece to what I assume
12 is a very large and complicated jigsaw puzzle and
13 I don't envy Sir Brian trying to write his report.

14 I would like to thank the Inquiry and all its
15 staff both for affording me this opportunity and
16 especially for the manner, both professional and
17 humane, in which I have been dealt with throughout and
18 I think, having talked to a few other witnesses, they
19 would echo those sentiments.

20 Finally, nearly 40 years on from the event in
21 question I'd like to put on record my heartfelt
22 admiration and thanks to all the staff of the health
23 service who treated Margaret and myself with such
24 understanding and kindness, namely our GP, the late
25 Dr Lawson, the consultants, doctors and nurses at

1 St James's and not forgetting even the staff in the
2 canteen, who served a very sad man with his breakfast
3 every morning for a week. Thank you.

4 **SIR BRIAN LANGSTAFF:** Thank you very much indeed, Graham.

5 **A.** Thank you. Can I run away now?

6 **SIR BRIAN LANGSTAFF:** It is entirely up to you. You are
7 free to stay, go, as you wish, but thank you very much
8 indeed for what you had to say.

9 **A.** Thank you for the opportunity. Thank you.

10 **SIR BRIAN LANGSTAFF:** I should add -- Graham, I should add
11 one thing. It was this. At the start of when you
12 gave your evidence you were saying that you had some
13 notes because you were scared that you might in this
14 one opportunity you had miss something.

15 Can I make it clear that if you or for that matter
16 anyone who comes to give evidence thinks after the
17 hour or so, however long it is, is over that they have
18 forgotten something when they think about what they
19 have said that night or later on, they are entirely
20 free to write to the Inquiry, and if the Inquiry
21 thinks that it would be worth hearing, as it probably
22 will be, they will ask you to put it into
23 a supplementary statement, which will be read, so it
24 doesn't have to go and stay secret.

25 **A.** No.

1 **SIR BRIAN LANGSTAFF:** So if there is anything else from
2 you -- and this is really addressed through you to
3 everyone else -- don't feel after testimony has been
4 given, that's it. This is an ongoing inquiry. It
5 will last until it finishes, as I say, I hope within
6 a reasonable time, but that's -- I want to hear what
7 people have to say and I recognise that some people
8 may forget some things they would wish to have said.
9 So thank you.

10 **A.** Well, thank you very much: in my case Sarah has done
11 a very good job. So you won't be getting any
12 supplementary information from me I don't think, but
13 thank you.

14 **SIR BRIAN LANGSTAFF:** Well, Ms Fraser Butlin, we will take
15 a break now until 2.05.

16 **MS FRASER BUTLIN:** Thank you, sir.

17 **SIR BRIAN LANGSTAFF:** 2.05.

18 **(12.49 pm)**

19 **(Lunch break)**

20 **(2.10 pm)**

21 **SIR BRIAN LANGSTAFF:** Ms Fraser Butlin, how does our next
22 witness wish to be known?

23 **MS FRASER BUTLIN:** She wishes to be known as Jo-Anne.

24 **SIR BRIAN LANGSTAFF:** Jo-Anne. Could Jo-Anne please come
25 forward.

1 **JO-ANNE COHRS, sworn**

2 **MS FRASER BUTLIN:** Jo-Anne, you're here to give evidence
3 about your late husband, Keith.

4 **A.** I am.

5 **Q.** And you met him in 1980 and married in 1983?

6 **A.** We did.

7 **Q.** Can you tell us a little of what Keith was like?

8 **A.** When I met him, he was very conservative.

9 **Q.** Jo-Anne, I'm just going to stop you. Would you mind
10 coming a little bit closer to the mic so everyone else
11 can hear what you are saying as well.

12 **A.** He was quite a conservative, cautious person, was
13 getting himself back on track with his education, was
14 doing a Bachelor degree, was very excited to be part
15 of the student community in Sunderland and lived with
16 three other lads who were students with him, who
17 played cricket down the hallway in their student digs,
18 older, a mature student, but still one of the lads.

19 **Q.** You are very softly spoken, Jo-Anne. I am conscious
20 lots of people want to hear what you are saying. So
21 if you can keep your voice up, that would be good.

22 **A.** Right. I will try.

23 **Q.** Keith had severe haemophilia A and from the 1970s you
24 understand he received Factor VIII?

25 **A.** He did.

1 Q. But you recall living a normal life of camping, seeing
2 friends and going out despite Keith's haemophilia.

3 A. Yes. We did a northern tour of Northern Europe before
4 we got married, visiting Germany, Holland,
5 Liechtenstein and enjoying some of the other cultures
6 that we came across, yes.

7 Q. Keith was infected with hepatitis B, hepatitis C and
8 HIV. Can we start off in relation to the HIV? Can
9 you tell us how you came to find out that Keith had
10 been infected with HIV?

11 A. It was during 1984 after we were married we had moved
12 down south and Keith had started a wonderful job as
13 a lecturer, and towards the end of 1984 he lost
14 an awful lot of weight. He was a very small framed
15 man, so to lose over 2 stone was quite a lot. We were
16 very worried and at the time there were news stories
17 in the distance about this new HIV/AIDS. Didn't know
18 a lot about it, but we had already connected with the
19 haemophilia haematology group in Addenbrooke's
20 Hospital. So we knew a little bit. We went back to
21 the consultant, reported the weight loss, and coming
22 up to Christmas she said, "Well, why don't you go and
23 have a test?" So we did and we didn't get the results
24 until the following year.

25 Q. And how did you receive those results?

1 **A.** Just after Christmas we received a letter with
2 "AIDS -- don't die of ignorance" franked on the front
3 of the envelope and I knew what it was. It had come
4 from Addenbrooke's, so I left Keith to open the
5 envelope. It was his mail. I was there, but quietly
6 sort of let him open the letter himself just after
7 Christmas.

8 **Q.** And how did you both feel when you opened that
9 envelope?

10 **A.** Keith cried. Very worried. Didn't know what that
11 meant, because there wasn't a lot of information
12 around at the time. I was very confused. Things were
13 going well in our lives and especially for Keith.
14 Pulled himself up by the boot straps and got himself
15 off to college. Got himself married and got himself
16 a job as a lecturer, something he had always
17 dreamed -- he dreamed for normality and I dreamed for
18 a man who would complement me.

19 I was very flighty, very busy, active in church
20 and Keith was, like I said, very conservative. So we
21 both met and complimented each other, but I was very,
22 very confused. What did it mean? What would happen?
23 All of these thoughts run round your head and there's
24 nobody there really to answer, especially for Keith,
25 what it would mean.

1 Q. How do you feel about being told that information by
2 post rather than face-to-face?

3 A. At the time I didn't -- we didn't really think
4 anything of it. We just expected "Yes, you will be
5 all right. Tick the boxes. You will be fine. Move
6 on", but actually with the news that it bore it would
7 have been very, very helpful if someone who knew about
8 the situation had been there to actually say, "We're
9 there for you. We're there with you. We'll help you
10 through this. We're on top of the medical profession.
11 We will find out what we can bring you, how we can
12 mend this", but it was very quiet, a very quiet time
13 of no support really, not knowing what does it mean?
14 Who do we share this with? What do we do?

15 Q. You then did have some consultations with the treating
16 doctor?

17 A. We did.

18 Q. Were you provided with much information at that stage?

19 A. No. There were no leaflets, pamphlets, books, because
20 it was early in the history of AIDS in this country.
21 So I know Dr [redacted] was a very caring person and
22 she said -- she was very helpful and would have said,
23 you know, "We'll do what we can". I was tested. She
24 did mention that we should take precautions as
25 a married couple and I was adamant that this was my

1 husband. I wasn't going to treat him any differently.
2 I wasn't going to wear rubber gloves or anything else.
3 We were going to have a relationship as a man and
4 wife, although we didn't want to bring a child into
5 the world who may be affected, but that wasn't going
6 to stop us having a normal married life.

7 **Q.** In about 1985/1986 you found out that Keith also had
8 hepatitis C. How did that come about?

9 **A.** I believe it was during a consultation when one of the
10 haematologists was involved in a research project and
11 so he'd left the room and some papers were on the desk
12 and we were sat on the opposite side and I peered
13 over, just moved one or two. I perhaps shouldn't
14 have, I don't know, but I did, and I saw "non-A non-B"
15 and Keith had it.

16 I didn't know much about hepatitis and I was
17 really only learning about haemophilia to be honest,
18 learning a lot more, and, silly me, I used to think
19 "there's hepatitis A, hepatitis B. What's this non-A
20 non-B thing. Why don't they call it hepatitis B.
21 Then if he has hepatitis B, could there be D, E, G,
22 whatever, X, Y, Z. What else is he going to pick up?
23 That was my thinking at the time.

24 **Q.** You have said in your statement that it came as
25 a surprise to both of you, but you didn't question the

1 doctor further on it:

2 "... as we believed that if it was concerning then
3 the doctors would have spoken to us about it. We were
4 more concerned about the HIV than the hepatitis C at
5 the time."?

6 **A.** And that's true. That was more overwhelming, this
7 HIV.

8 **Q.** In the summer of 1985 Keith had pneumonia and was very
9 unwell with that and with oral thrush. Can you tell
10 us about that time?

11 **A.** Well, the pneumonia was very debilitating. It took
12 about three months of hospital care, during which time
13 I was allowed to stay in the room with Keith, and it
14 was quite a rest for him really and they could treat
15 with whatever opportune infection came about. He was
16 there ready for the treatment.

17 At home leading up to that he had been on some
18 different anti-fungals, which would then affect his
19 taste buds and his skin and his mouth. He didn't
20 enjoy food, lost more weight, but the time on the
21 ward -- he was very well looked after.

22 **Q.** Now, at this time you lived in a second floor flat.

23 **A.** Uh-huh.

24 **Q.** You applied for some different housing. What was the
25 reaction you received?

1 **A.** Very -- very little response actually from the local
2 housing authority. "Oh, there's a two-year waiting
3 list for a bungalow" or "there's another big long
4 waiting list for a ground floor apartment" and what
5 have you. Dr [redacted] secretary, I believe she was
6 a social worker, wrote to the local council and
7 said -- well, I don't know. I didn't see the letter,
8 but it was a while after that we were given a newly
9 decorated house with a chair lift, which was
10 fantastic. It was a miracle actually, because it was
11 only -- it was one of seven homes in the local area
12 which even had a stair lift, and they had left it in
13 from the previous occupants, so it was made for Keith
14 really.

15 **Q.** You have described the social worker being on the back
16 of the local authority pestering them --

17 **A.** Yes, she was.

18 **Q.** -- to give you proper accommodation?

19 **A.** Yes, she did. She contacted them several times.

20 **Q.** Not very long after the move Keith contracted
21 pneumonia again and went back into hospital and he was
22 really very unwell again.

23 **A.** Yes.

24 **Q.** When Keith was in hospital, you cared for him
25 considerably and you were regularly told you should

1 wear gloves and at times that you should be masked as
2 well.

3 **A.** Yes.

4 **Q.** What was your reaction to that?

5 **A.** I refused, because I cared for Keith at home. He was
6 my husband and, as I said previously, I wasn't going
7 to treat Keith any differently. He would feel my
8 touch, my hands, if he needed a caress, a cuddle, some
9 support, I was there. I wasn't going to look like
10 a spaceman. I wasn't going to not dare touch him,
11 because we were normal people and he needed a normal
12 wife to care for him and that's what I did.

13 **Q.** At one stage Keith's consultant was asked by the
14 nursing staff to tell you to barrier nurse Keith with
15 masks and gloves?

16 **A.** Yes.

17 **Q.** What was her response to that?

18 **A.** Well, by then she knew me and she said, "Oh, he'll be
19 all right and she will be all right too. Just let
20 them be", and so we were allowed to -- I was allowed
21 to be with my husband as normal.

22 **Q.** You think that it was about 1986 that Keith was given
23 an experimental treatment.

24 **A.** Yes.

25 **Q.** What was that?

1 **A.** It was plasma which was already contaminated with HIV
2 and I think the theory was because Keith's fighting
3 cells and immune system was so low and so weakened,
4 they thought if they introduced more of the
5 contaminated plasma, it might help boost and trigger
6 his fighting cells to then fight off other infections
7 and it didn't. It didn't work. It didn't make any
8 difference at all and we were desperate. That's why
9 we went ahead. Keith was able to think through that
10 and after a couple of these treatments we decided not
11 to go ahead, because it didn't -- after tests they
12 realised it didn't make any difference to his fighting
13 cells and immune system.

14 **Q.** And then in the autumn of 1986 he had been discharged
15 from hospital following the pneumonia and you went
16 upstairs to find him vomiting blood. What happened?

17 **A.** It was horrendous. It was very much like a horror
18 movie. I don't watch horror movies but -- or a war
19 movie, and at one time he both vomited and had
20 an accident and both ends was blood.

21 **Q.** The doctor came and can you tell us what happened in
22 relation to Keith's treatment?

23 **A.** Are you referring to that or the cerebral accident?

24 **Q.** Just when he vomited blood the doctor came and they
25 refused to admit him locally.

1 **A.** Yes. He was very angry, the doctor. Made some other
2 phone calls and he was taken to Addenbrooke's.

3 **Q.** The GP had tried to have him admitted in your local
4 hospital.

5 **A.** He did, because he was such an emergency and he needed
6 treatment. The hospital was only about a mile and
7 a half away -- excuse me -- and the hospital wouldn't
8 allow him to be admitted. So the doctor, Dr Heelis,
9 arranged for an ambulance to come and take him to
10 Addenbrooke's instead, which was 25 mile away.

11 **Q.** When we get to late 1986, about a year before Keith
12 died, he started to show signs of cognitive loss. Can
13 you tell us what that was like?

14 **A.** It's really difficult to say what was the worst part,
15 because it was all dreadful seeing a loved one suffer,
16 but seeing the man, the clever man I loved and married
17 not being capable of being aware of his circumstances,
18 not being able to have a conversation about -- excuse
19 me -- about some film director or some photographs he
20 liked to look at, not have an opinion, not being able
21 to remember very many things, not having a long -- not
22 being able to remember or losing memory from about
23 ten minutes ago.

24 **Q.** You have described he also had mood changes.

25 **A.** He did.

1 Q. And could be like a Jekyll and Hyde with you.

2 A. Yes, something I hadn't -- I had never seen before,
3 because, as I said, he was very -- he was very
4 conservative and considerate person and was very
5 controlled, not giddy or flighty, just -- so to see
6 Keith get really angry or throw dishes on the floor --
7 he could -- he didn't mean to. He just changed.

8 Q. Would you like to take a break before we carry on or
9 are you okay?

10 A. No. I'm okay. And his mood swings were very erratic
11 and it was difficult to tell, when he'd take
12 a downturn, it was difficult to have a conversation,
13 anything meaningful. So yes, it was very, very
14 difficult.

15 Q. And you have described that in some of those mood
16 swings Keith threw dishes or food on the floor or was
17 verbally unpleasant with you.

18 A. He was.

19 Q. Throughout this time you had a lot of support from
20 your church community, particularly from about 1986.
21 Can you tell us about that.

22 A. The church we joined in '86 were very, very
23 supportive. We had at least 14 families would pray
24 and fast one day a week. We had two other friends who
25 would call me every day to say what did we need. Did

1 we need a ride somewhere. Did we need any shopping
2 bringing in. Did we need to go out for
3 an appointment. Did we need the dog walking or any
4 cat food bringing in, anything, always calling and
5 they were always there, which was a saving.

6 **Q.** I know from our discussions your Christian faith has
7 been important both to you and it was to Keith
8 throughout that time.

9 **A.** Yes.

10 **Q.** By 1986 you had given up work and financially things
11 were difficult?

12 **A.** Very.

13 **Q.** So you applied for carer's allowance and you were
14 turned down for it. Can you tell us what happened.

15 **A.** We were interviewed in our home by an officer who
16 filled out the forms and looked at our application.
17 He talked to Keith, who was having a very happy time
18 at the time. He was very able to answer some
19 questions, was very cheerful.

20 If he had talked to him the day before, it might
21 not have been that way because of his condition in
22 temperament, which changed. So the officer would ask,
23 "Well, how are you being cared for?", and Keith would
24 say, "Yes, everything's met. Everything's taken care
25 of and we don't need anything", and I thought, "Well,

1 ask me". He did ask me and I did say, "Well, I need
2 to be here all the time. He's becoming confused", and
3 I didn't really like to say those things in front of
4 Keith, but I did, "We need -- I need some time. Keith
5 needs a different face maybe to sit with for a few
6 hours", and tick, tick, tick. Oh, well "doesn't
7 need" -- I think he must have verbally said this
8 because I can remember "doesn't need this allowance
9 yet".

10 **Q.** You were told Keith had to be ill for over six months
11 before you were eligible for the allowance.

12 **A.** Yes.

13 **Q.** At that point Keith wasn't even able to get himself to
14 the toilet.

15 **A.** No.

16 **Q.** And, in fact, Keith died three months later.

17 **A.** He did.

18 **Q.** Until March 1987, so from the autumn 1986 when he had
19 had the pneumonia, until March 1987, what was Keith's
20 condition like?

21 **A.** He needed 24-hour care. He didn't sleep well and at
22 other times he slept a lot. He was very confused
23 mentally. Didn't know what to eat when or what to do.
24 He would just sit. We had a kitten and a puppy, well,
25 by then were two years old each. He would just be

1 could be content sometimes just to sit with the cat,
2 who would quite often sleep with him in bed if I was
3 downstairs doing laundry or cleaning or whatever
4 needed to be done, but his quality of life really
5 was -- he wasn't -- it wasn't beneficial. It wasn't
6 meaningful. It wasn't a life worth living really.

7 **Q.** And then in March 1987 Keith fell over the threshold
8 of the back door?

9 **A.** He did.

10 **Q.** Can you tell us what happened?

11 **A.** Again, he was quite confused. I was playing the
12 piano. My mum was down for a visit doing some dishes.
13 He'd gone out into the hallway, opened the back door,
14 which I didn't hear, but then I heard him fall, and he
15 mentioned about the toilet and I gathered -- figured
16 he had meant to go up the hallway to the downstairs
17 toilet and instead he had gone -- turned right and
18 went out of the back door and fell over and had
19 a really bad head wound. So then panic. Call 999.
20 Ambulancemen came. They knew us by now and they were
21 dressed up in their space suits. "Come on, Keith. We
22 will take you to the hospital", and I had a feeling in
23 the back of my mind, worry whether they were going to
24 admit him. So I rushed upstairs to put some things
25 together, a bag and some toiletries in case this was

1 another long-term stay.

2 They had taken him to the local hospital, which
3 was about a mile and a half away. So packed a few
4 bits and pieces. By the time I got downstairs, about
5 30 minutes later, he was back home, and I could
6 tell -- he was in a wheelchair and he was in a mess.
7 He had wanted the toilet and he was in a mess in this
8 wheelchair, and the only thing the emergency
9 department had done was put a little bit of antiseptic
10 spray on his wound on his head, and even the
11 ambulancemen were very sorry to bring him back.

12 **Q.** So you put him to bed with your mum.

13 **A.** Mm-hm.

14 **Q.** And then your mum was watching him while you briefly
15 went out.

16 **A.** I did.

17 **Q.** And while you were out you just had a sense that you
18 needed to go back.

19 **A.** Yes.

20 **Q.** And what happened when you got back?

21 **A.** Just not responsive at all, and I contacted Dr Heelis
22 and he came straightaway. I mean, Keith had had
23 a little packet of jelly babies. He had eaten some,
24 but he wasn't -- he wasn't well at all.

25 **Q.** Dr Heelis said that he thought that Keith had had

1 a stroke.

2 **A.** Yes.

3 **Q.** And so he referred Keith to the hospital, to

4 Addenbrooke's.

5 **A.** He did.

6 **Q.** And it was the same ambulance crew that came --

7 **A.** Yes.

8 **Q.** -- for him.

9 **A.** Yes. They took him to Addenbrooke's. I think that

10 was the next -- the next day. He hadn't moved

11 position in bed. Sorry. I'm trying to think of -- he

12 hadn't moved at all in bed, but he was still

13 breathing, because I felt his breath and then, of

14 course, Dr Heelis came and ordered for the ambulance

15 and it was the same ambulancemen again.

16 **Q.** And Keith never regained consciousness.

17 **A.** He didn't.

18 **Q.** And died on 6 March 1987.

19 **A.** Yes, he did.

20 **Q.** After Keith died there was a headline in the paper

21 about his death. Can you tell us about that?

22 **A.** Well, just before that headline there was an article

23 in the paper where the local council -- the local

24 health authority were aware of this person with AIDS

25 and they were giving him all the help and support they

1 could. They didn't realise actually my husband had
2 already passed.

3 **Q.** And at that stage you weren't receiving any help from
4 the local health authority.

5 **A.** No.

6 **Q.** And they hadn't even picked up the yellow plastic bags
7 of medical items from outside your door.

8 **A.** They had actually made quite a fuss about any medical
9 waste that Keith had in the house and they provided
10 the very luminous yellow plastic huge bags to put
11 everything in and three weeks after he died they were
12 still outside the front door -- outside the back
13 door -- sorry -- but people could see, and it was --
14 it was so stigmatising and so uncaring, and no
15 actually the health authority or the local authority
16 didn't -- weren't able to help, didn't help at all
17 and, yes, there was a headline in the paper, "Local
18 man days of AIDS", and a few innuendos and wonder what
19 type of lifestyle they had.

20 **Q.** And that article arose because the day before the
21 funeral a journalist had come to your door.

22 **A.** Yes, wanting some no doubt salacious titbits for
23 a newspaper, again thinking or wondering did we have
24 parties -- well, they didn't say that, but, you know,
25 this is my mind thinking, oh, they wanted to dig and

1 find out the truth about this person who died of AIDS.

2 **Q.** After Keith died, you described immersing yourself in
3 lots of activities to try to cope with being a young
4 widow. One of those was to get involved in a local
5 AIDS helpline. What was the reaction you got when you
6 asked to be a volunteer?

7 **A.** They knew I was a Christian and I think some expected
8 me to judge perhaps, to condemn, and actually when
9 I told them my story and how my thinking had changed
10 and that this wasn't a punishment, these people,
11 anybody who was sick would need help, would need
12 support and we had lack of support from the
13 authorities, so anybody in that position of need
14 really needed people on their side.

15 **Q.** And subsequently you have said that the helpline made
16 a significant difference.

17 **A.** They did. They were there for people who needed to
18 call and talk to people, who could give them contacts,
19 who could point them in directions where they would
20 find help. It became Stevenage AIDS helpline became
21 quite a thing in the area, a novel idea really at the
22 time, and there was quite a drug community in
23 Stevenage itself who needed support.

24 **Q.** And also in doing battle with the local authority you
25 have described getting people the help they needed.

1 **A.** Yes, absolutely.

2 **Q.** Can you tell us what the financial impact was on you
3 prior to Keith's death and after he died?

4 **A.** Well, when we first got married, we were -- we had
5 both been students. So we didn't have a great lot of
6 money. However, when we got married, moved down south
7 and Keith was a lecturer. I did some too and I also
8 worked in a local day centre. So we had double income
9 and no kids and so we went on little trips abroad here
10 and there.

11 In the next year, as his health declined, it meant
12 he had to cut work hours. He couldn't manage as much.
13 So I worked a little more to help make up any
14 shortfalls. We didn't have any financial commitments
15 anywhere really, other than weekly food and living
16 costs and as he became more poorly, he had to leave
17 his job altogether because of the ongoing sickness and
18 diarrhoea. Eventually my job came to an end and there
19 was a job going to replace my job, which I applied
20 for, but I prayed to God, "Lord, I don't know what the
21 answer is, whether I should be at home all the time,
22 whether I should have money to look after Keith", so
23 it was in his hands. I didn't get the job. My
24 colleagues were amazed I didn't get the job, but
25 I knew that I needed to be home with Keith, so then we

1 were on benefits.

2 **Q.** And it was a struggle?

3 **A.** It was definitely a struggle. Absolutely.

4 **Q.** You received a payment from the MacFarlane Trust some
5 time after Keith died. Did you have to sign anything
6 before receiving that?

7 **A.** I did. I had to sign a statement that said I wouldn't
8 be involved in any future -- I don't know what the
9 wording was -- but I wouldn't be involved in any
10 litigation, yes. That was back in '91 I think it was,
11 1991.

12 **Q.** And you also received a payment from the Skipton Fund
13 in 2010 or 2011?

14 **A.** I did.

15 **Q.** How did you come to hear about them?

16 **A.** Keith's brother -- I was living in America at the time
17 and Keith's brother had contacted my dad and mentioned
18 this Skipton Fund and if I needed help, financial
19 help, then I could apply for it, but I was living in
20 America at the time, so I appointed my dad as the
21 person to handle that affair and legally did what
22 I could through an attorney in America just filling
23 out paperwork. I couldn't get medical records, but
24 Skipton, the team there were very helpful and, yes,
25 I was awarded a payment.

1 Q. Now, as far as you are aware Keith wasn't offered any
2 counselling or psychological support throughout his
3 illness and neither were you until about six months
4 after Keith's death.

5 A. Uh-huh.

6 Q. It's right that about six months after his death your
7 widow's allowance had come to an end?

8 A. It did.

9 Q. And you were, you have described it as being wiped out
10 and very distraught and it was only that point that
11 you were offered some counselling?

12 A. Yes, it was, yes. I had had friends in church, but as
13 far as sort of professional help and counselling that
14 didn't come until much later at that time.

15 Q. And it was only because you sought it out and your GP
16 was proactive?

17 A. Yes. I actually collapsed. A nurse friend -- we sat
18 and talked a little bit and I broke down.

19 Q. And you have described that process as feeling like
20 walking through a blackberry bush and being torn?

21 A. It was, yes.

22 Q. Those are the questions I have for you. Is there
23 anything else you would like to say?

24 A. Well, we did have an awful lot of support in other
25 ways, day-to-day support, for which I am extremely

1 grateful, especially to Dr Heelis, who still is
2 practising in Letchworth. He is a very caring doctor.
3 I saw him cry at Keith's demise, especially when he
4 said Keith had had a stroke. He cried.

5 The ambulance station which was about half a mile
6 from where we lived and the people who came to take
7 Keith to hospital various times, our friends in
8 church, it is [redacted] and [redacted] were there on
9 the phone, at the end of the phone, or even in the
10 house, the prayer team, [redacted], our pastor, a very
11 caring man and the church body really.

12 Had it not been for those people I think Keith's
13 care would have -- would have suffered, because
14 I wouldn't have been upheld myself. I wouldn't have
15 been supported as well. I'm very grateful to those
16 people.

17 **Q.** I am just going to turn and ask Mr Snowden, who, as
18 you know, represents you, if there's any points he
19 wishes for me to raise. He has nothing else.

20 **SIR BRIAN LANGSTAFF:** Well, there is something I'd like to
21 ask. Did you write a book?

22 **A.** I did.

23 **SIR BRIAN LANGSTAFF:** What was it called?

24 **A.** "Stigma: an AIDS widow's story".

25 **SIR BRIAN LANGSTAFF:** In 1989 was that?

1 **A.** It was.

2 **SIR BRIAN LANGSTAFF:** What were you wanting to say in that
3 book?

4 **A.** It was really to say that people going through this
5 situation there was hope and there is hope. There's
6 a God who cares. So it was very much from our
7 Christian point of view and he is a compassionate God
8 and we had to have hope and we do have hope -- we did
9 have hope and I did too and I still do, and it was to
10 help other people in a similar situation who might not
11 have had a faith, but who might have reached out to
12 people of a faith in God to find support in people, in
13 a caring community.

14 **SIR BRIAN LANGSTAFF:** And when you called it "Stigma:
15 an AIDS widow's story", what was the stigma that you
16 had in mind particularly?

17 **A.** Collectively I think you could put it all in a big
18 yellow plastic medical refuse bag. That was the
19 stigma.

20 **SIR BRIAN LANGSTAFF:** Thank you very much indeed.

21 **A.** Thank you.

22 **SIR BRIAN LANGSTAFF:** Thank you for your quiet and calm
23 courage.

24 **A.** Thank you.

25 **SIR BRIAN LANGSTAFF:** There's no rush. You can stay there

1 or sit back where you came from, as you wish.

2 Well, Ms Fraser Butlin, that's the end of the
3 witness evidence that we have for today.

4 **MS FRASER BUTLIN:** It is.

5 **SIR BRIAN LANGSTAFF:** And tomorrow we start at 10.30 and
6 who are we due to hear from? There is a change, is
7 there not, to tomorrow's published programme.

8 **MS FRASER BUTLIN:** There is.

9 **SIR BRIAN LANGSTAFF:** For reasons I spoke about briefly
10 this morning.

11 **MS FRASER BUTLIN:** The witnesses we will be hearing from
12 are Martin Beard, David Gort and Darren Rawson.

13 **SIR BRIAN LANGSTAFF:** So was David Gort who is taking what
14 had been the time in which we had hoped to hear from
15 Mr Ahearn?

16 **MS FRASER BUTLIN:** That's correct, sir.

17 **SIR BRIAN LANGSTAFF:** I am sure everyone here will
18 understand the reason for the change and sympathise
19 with Mr Ahearn at this moment. It just remains for me
20 to say thank you and I look to forward as many of you
21 as wish to come tomorrow, 10.30.

22 **(2.59 pm)**

23 **(Adjourned until 10.30 am the following day)**

24

25

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25

I N D E X

Opening statement by SIR BRIAN LANGSTAFF1
JOHN CORNES, sworn10
Questioned by MS RICHARDS10
GRAHAM BINKS, sworn46
Questioned by MS FRASER BUTLIN46
JO-ANNE COHRS, sworn67