

Tuesday, 30 April 2019

(10.34 am)

SIR BRIAN LANGSTAFF: Today is a significant day for the Inquiry. It's the day we first hear evidence given orally.

Thank you for being here in such numbers to take part in it and by your presence in such numbers, to demonstrate the importance of this Inquiry. That together with the force of your feelings, is no doubt why the press have been attracted. I thank them too for being here. Do what the press do best, to report fairly and fearlessly.

I hope that while doing that they may help to spread the message that those who are struggling with the infections of HIV or hepatitis through blood or blood products are not alone.

Anything they can do to increase public knowledge of the symptoms, the causes, and as so many of you have told me movingly in your witness statements, the consequences of late discovery of hepatitis C in particular will be of great value to the public because so many symptoms of that disease seem to mimic a range of common conditions.

Anything that they can do to raise awareness is particularly important given that there are some 180

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gathering in witness evidence from so many, identifying repositories of documents and interrogating them and making the practical arrangements which come with such a large inquiry all take time, though I have promised you that the Inquiry will be as quick as it can. This has always been accompanied by the assurance that it will be as thorough as is reasonable and I mean to keep my promise to you, whatever your perspectives on the Inquiry.

At the preliminary hearings I set out the principles that were to guide this Inquiry. They were first and foremost putting people at its heart, being as quick as reasonable thoroughness permits, paying proper respect to a person's right to be heard, being as open and transparent as is legally possible, being independent of Government and frightened of no-one in the conclusions it draws and listening.

Though all apply, four are of particular importance now as we start hearing evidence orally. First, I promised that the Inquiry would put people at its heart. The room you are in is, I hope, visible evidence that this Inquiry honours its principles. The witness is centre stage. The public in front. Lawyers and me to the side. The Inquiry is not about

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million people worldwide who suffer from it and the World Health Organisation has recently announced ambitious plans to eliminate hepatitis C by 2030. It may be possible, I am told, for that to happen even earlier in this country, but it depends upon people who think that they might possibly be suffering knowing enough to be tested because otherwise the risks of transmission remain and it takes longer to eliminate what has been a dreadful disease.

I want particularly to thank those of you who have given statements. I have already read a large number more than once, some a number of times. Some are harrowing, some incredibly moving and some chillingly factual. All are valuable.

There are more to come. For many making a statement has been and for some it yet will be an act of bravery. I would like to acknowledge that publicly here and now. It may have stirred up and it may yet stir up distressing memories. I understand some simply cannot bring themselves to make a statement because it is too much.

I want to acknowledge too your patience. It may have seemed a long gap between the end of the preliminary hearings and the start of these oral hearings but you have I believe understood that

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them, it's not about me, it's about the evidence which the witness can give.

There are rooms to the side and downstairs where anyone who needs space during the hearings can find it. The Red Cross are on hand to assist anyone who finds some of the evidence or their own memories difficult. But it's also about giving people time as much as physical space and practical arrangements.

You know now that the Inquiry will spend until October travelling round the UK to make it easier for many to access the hearings and you can be assured that although it will never be possible to hear orally from everyone who would wish to be heard, those affected and infected will come first and last in the Inquiry, not only in the first few weeks but the last weeks.

Every new written statement the Inquiry receives is important. Each will be read, each will be different, each has value and the evidence of those who have made or will make statements is of real value, whether or not they gave evidence orally.

Second, can I repeat what I said last September about paying respect to a person's right to be heard. Putting people at the heart of the Inquiry must recognise that people have different perspectives to

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bring to the Inquiry. It cannot be just a favoured few or for that matter a favoured many who are at its heart.

Those wishing to attribute blame, those wishing to escape blame, those who wish neither but just seek for an explanation, trying to understand what happened, those who received blood products, those who were transfused with infected blood, those who are patients, those who are doctors, all are people and all are entitled to be heard with respect. I would ask participants to respect that entitlement, however unpalatable they may find some of the ideas or explanations or accusations which are being expressed.

Linked with that, and third, openness demands that the statement of a witness, redacted where appropriate, be published when that witness gives oral evidence. Openness and fairness includes giving those subject to criticism a reasonable opportunity to answer that criticism. Where the response is available at the time a witness statement is published, so too will the responses of any criticised individuals.

There may be moments in the testimonies you are about to hear, now and over the coming days, which may bring you close to tears or they may excite

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individuals who were infected with HIV, with hepatitis C, in some cases with other infections in direct consequence of being treated with infected blood or infected blood products by the National Health Service.

You will hear from people whose spouse or partner died, whose parents died, whose sibling died, whose child died in direct consequence of being treated with infected blood or infected blood products by the National Health Service.

You will hear how lives have been cut short or irrevocably damaged or altered. You will hear how, in a phrase used in one of the many statements received by the Inquiry, people have been forced to live a life that was not the life they were meant to lead.

It is important that this evidence is heard and brought out into the open. Firstly, sir, because as you have said you have pledged to put people at the heart of the Inquiry and that means hearing directly from those who have suffered and doing so before any other evidence is heard.

Secondly, because the fulfilment of the Inquiry's terms of reference requires the Inquiry to examine the treatment of men, women and children who were given infected blood or infected blood products,

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indignation in any reasonable person. That is only human and I do not ask you to be anything else. But do please respect the fact that a witness will be giving evidence. It is never easy to give evidence. Please bear that in mind. Although breaks are always available for witnesses when needed, they will not want to be so overcome themselves by the reaction around them that they cannot bring themselves to finish.

Finally, I am here to listen. From reading both witness statements and documents, I know more now than I did last September and more than I did when the terms of reference were finalised. Thank you for that. But I know enough to realise that I have much more to learn and that the oral evidence will be an important part of that.

I would ask you now for your part, having listened to me so patiently, to listen to what counsel to the Inquiry, Jenni Richards QC, has to say before our first witness, Derek Martindale, comes to be heard. Thank you.

Opening statement by MS RICHARDS

MS RICHARDS: Sir, over the 11 weeks of hearings between now and mid-October you will hear and the world will hear evidence from some of the thousands of

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to examine the extent of any warnings or advice provided to them about the risks, to examine the impact of infection from blood or blood products on those who were infected, their partners, children, parents and others close to them, to examine the adequacy of the information that was or was not provided to them and to consider the nature and adequacy of the treatment, care and support that was or was not provided in response. The evidence that you will hear, sir, over the coming weeks touches on all of those matters.

Thirdly, it is important that this evidence is heard not only by you, sir, and by the Inquiry team but that it should be heard by others including those in Government and in the NHS, pharmaceutical companies, medical practitioners and those who regulate them and by the general public.

As one of the witnesses whom you will hear this week says in her statement, "I'm angry that I haven't been heard for all these years". The witnesses who tell their stories over the coming weeks will be heard.

As Sir Brian has said, it will not be possible to hear orally from every witness who has given a statement to the Inquiry. There are simply too many

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for that to be achievable, but those who are not being called to give oral evidence should know that every statement is read and considered by you, sir, and by the Inquiry team. Every statement forms part of the material which will in due course inform your recommendations and findings and every statement will in due course be published by the Inquiry.

I should say a little about how the evidence will be heard and how these hearings are structured. As many of you already know, over the next three months the Inquiry will be hearing evidence from people who have been infected or affected in London, Leeds, Belfast, Edinburgh and Cardiff. The Inquiry will return to London for two weeks in October to hear further evidence from people who have been infected or affected.

Witnesses have been selected to ensure that evidence is heard covering a range of conditions, sources of infection and time periods to help to get to the truth of what happened. There are many who have lived with infection and its terrible consequences for years and you will hear from them. There are others who have only been very recently diagnosed and you will hear from them.

There will usually be three witnesses heard

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website either at the same time as the witness's statement or subsequently.

I should emphasise that not all of the criticisms in the statement of people who are infected or affected will go through this process and that is for the simple reason that many of the statements raise criticisms which will inevitably be the focus and subject of further investigation and examination of later stages of the Inquiry's work.

Some of the witnesses from whom you will hear have chosen for entirely understandable reasons to give their evidence anonymously, although in each case their identity is known to the Inquiry. It is absolutely essential in such cases that their anonymity is preserved and a range of different measures have been devised to protect their identity. Some witnesses, if they choose to do so, will give evidence via a video link.

The Chair has in exercise of his powers under the Inquiries Act made a general restriction order which prohibits the disclosure or publication of the name, address, and any other identifying information of anonymous witnesses. This order has been published on the Inquiry's website and there are copies available in the hearing room and I hope all members

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each day. Some days, particularly where there are family groups, there may be four or more. The witnesses will be asked questions either by or my colleague, Ms Fraser Butlin. Where the witness has legal representation, we will ask their barrister at the conclusion of our questions if there are further questions they consider should be asked.

The hearings are being live streamed on the Inquiry's website and a transcript of the evidence will be published at the end of each day and, as the Chair has indicated, the statement of each witness who gives oral evidence will also be published on the Inquiry's website after each hearing day.

Unsurprisingly, given the nature of the issues that are being investigated in this Inquiry, many of the witness statements that the Inquiry has received criticise named individuals, particularly clinicians. Because the Inquiry is under a legal duty to act fairly, those criticisms are in some cases, depending on the nature of the criticism, brought to the attention of the relevant individual in advance of the witness giving evidence and the person criticised is afforded an opportunity to respond in writing. Where the person criticised provides the Inquiry with such a written response it will be published on the Inquiry's

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of the press have access to them.

There are other statements which although not anonymous have had particular personal information, particularly information about third parties, redacted and any disclosure or publication of such redacted material could also contravene the restriction order.

Before we call the first witness, there are two further matters to which I should refer. The first is an update as to the work which the Inquiry has been undertaking, the further work which it needs to undertake and the timetabling of future hearings. The second is to raise public awareness of the importance of testing for those at risk of hepatitis from blood and blood products.

So update on the work of the Inquiry. The scale of this Inquiry is unprecedented. It's been referred to as the biggest public inquiry the United Kingdom has ever undertaken. So far the Inquiry's received 1,200 witness statements approximately from individuals who were infected or affected and we expect to receive at least a further 1,200 statements over the coming months.

The Inquiry is gathering information and documentation, many of it going back decades, from a very large number of sources. Large scale searches

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both physical and electronic are being undertaken by the Inquiry. By way of example, and these are examples only, a hard copy search of approximately two and a half million pages of information held by the Department of Health and the Medicines and Healthcare Products Regulatory Agency has been completed and the Inquiry is now moving on to searches of material held by them electronically.

The Inquiry has searched approximately 2 million hard copy pages of material held by NHSBT. There are approximately 5.7 million pages still to search as well as material held electronically. The Inquiry is also working through the documentation which comprised the disclosed material in the *A v National Blood Authority* litigation and that is likely to be the next tranche of material disclosed to core participants.

A very large amount of material, particularly Central Government material, is held at the National Archives. Some has already been scrutinised but in the next few weeks, a team of Inquiry searchers will be based there full time and their search of those archives is expected to take roughly six months.

Across the country the Inquiry has identified some 341 separate repositories of documents to be

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of enquiry and investigation are inevitably generated through this work. In this respect the process is an iterative and ongoing one, a close review of the documents obtained will often generate further requests for more specific information.

All this work inevitably takes time and in turn this impacts upon the timetable for hearings. The Inquiry's current plan for further hearings is as follows: there are two weeks in October already dedicated to hearing further oral evidence from those who have been infected or affected. Following those hearings and probably running into November, the Inquiry intends to build upon the evidence that will have been heard from affected individuals by calling clinical evidence exploring issues of treatment and care and psychosocial evidence looking in particular at issues of impact.

After November, there will be a pause in the Inquiry's hearings. The Inquiry is currently gathering such a vast amount of material as I hope the information I have given you indicates that a pause is necessary to allow that material to be analysed, to be disclosed to core participants and to enable the Inquiry and core participants to prepare for the next set of hearings.

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searched either electronically or manually.

The Inquiry team has carried out electronic searches and undertaken reviews of hard copy material held by the Welsh Government, the Northern Ireland Government, the Northern Ireland Blood and Transplant Service, the Welsh Blood Service, the Public Records Office Northern Ireland and other core participant organisations in Northern Ireland. Further visits are underway to continue this process and further searches planned with regard to material held by the Scottish Government and the Scottish National Blood Transfusion Service.

12,000 electronic documents and 63 hard copy boxes of material have been delivered to the Inquiry by BPL Limited and disclosure exercises are underway in relation to a number of the pharmaceutical companies.

Once potentially relevant material has been identified through these investigations, and substantial quantities of potentially relevant material are indeed being identified. That material has to be analysed, scanned, reviewed further, and every page has to be reviewed for redactions before any of it can be disclosed to core participants or the public. It is also right to note that further lines

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The Inquiry is aiming for the next set of hearings which will focus on the knowledge, decisions, actions and omissions of all relevant decision-makers and the response of Government and others to begin in late spring 2020 not before Easter 2020, with a precise date to be announced in due course.

We do not believe it will be possible to do justice to the issues that must be investigated under the Inquiry's terms of reference in any shorter timescale.

The final point is to emphasise a point you have already made and that is the vital importance of testing those at risk of hepatitis from infected blood or infected blood products. Those listening will recall that somewhat controversially the only recommendation from the Penrose Inquiry was for a look back screening program.

It is apparent from the statements which the Inquiry has been studying that there are people who have been living with undiagnosed hepatitis C for years, even decades, and you will hear over the coming weeks from witnesses who have only recently been diagnosed with HCV caused by transfusions from blood or blood products many years ago.

The Hepatitis C Trust continues to receive

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calls from people who have only recently been diagnosed and who contracted the virus through infected blood or blood products and it seems likely that there may be many people, potentially many thousands of people, who remain unaware that they may have been so infected as a result of the receipt of infected blood or infected blood products.

One further issue which has emerged from the witness statements is a lack of information in particular on the part of general practitioners about hepatitis C and NHS England has this month issued a letter to all GP practitioners the stated aim of which is to help them support patients who may have been exposed to risks associated with infected blood or blood products.

Could we have that letter on screen. Could you go to the second page.

You will see there under the heading "Action" -- I hope most of you can see screens, I am sorry not all of you can but we can make available a copy of this letter on the Inquiry website for those who can't -- that NHS England have drawn to the attention of clinicians the fact that hepatitis C often doesn't have noticeable systems until the liver has been significantly damaged and when symptoms do occur they

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Questioned by MS RICHARDS

MS RICHARDS: Derek, you are here to give evidence about what happened to you and your family and you have got your son John sitting beside you --

A. Yes.

Q. -- and your wife Margaret in the front row to provide you with support. If at any time during your evidence you need a break please don't hesitate to say so.

You should I hope also have, in case you need to refer to it, a copy of your witness statement there.

A. *(The witness nodded)*

Q. Derek, you have haemophilia A?

A. Yes.

Q. And the vast majority of people here will I know be familiar with it but it's a bleeding disorder, in effect, which is characterised by a deficiency of factors in the blood which are essential for blood clotting?

A. Yes.

Q. And the type of haemophilia that you have is haemophilia A?

A. Yes.

Q. So a deficiency of clotting Factor 8?

A. Correct.

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can be mistaken for another condition. Common symptoms are identified and NHS England's letter continues that:

"... the only way to know for certain if these symptoms are caused by hepatitis C is to get tested. Clinical staff should therefore consider asking patients who present with non-specific symptoms whether they may have had blood or blood products and offering them a screen for blood-borne viruses."

The Inquiry brings that letter to public attention, particularly given the presence of so many of the press today in the hope that it may encourage greater awareness on the part of clinicians as well as greater awareness amongst the public more widely of these issues.

Sir, that is all I propose to say by way of any opening submissions or statement and we are now ready to call the first witness, Derek Martindale.

SIR BRIAN LANGSTAFF: Thank you very much, Ms Richards.

Mr Martindale, I think you want to be known as Derek for the purposes obvious the Inquiry.

THE WITNESS: Yes.

DEREK MARTINDALE, affirmed

SIR BRIAN LANGSTAFF: Derek, the questions are going to come from Ms Richards.

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Q. Your haemophilia is classed as severe. What does that mean in practice for you?

A. A very low percentage of clotting factor, almost zero, which means that spontaneous bleeds, traumatic bleeds, accidents causing internal bleeding and some external bleeding and the blood takes a long time to clot.

SIR BRIAN LANGSTAFF: Ms Richards, can I just ask you to pause there for a moment. I think we are losing some of the force of what Derek is saying because of the position of the microphone. I wonder if it can just be moved around a little bit in front of him or for that matter if he comes a little bit this way it might be easier. I am sorry for interrupting.

Are you happy with that, Derek?

A. Yes, that's fine.

MS RICHARDS: Your haemophilia A was diagnosed, I think, when you were very young.

A. Yes.

Q. You had a younger brother, Richard?

A. Yes.

Q. Who was diagnosed also with severe haemophilia A at a very young age?

A. Around the same age, yes.

Q. You have said in your witness statement that you were under the care of York District Hospital for most of

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1 your childhood through to about 1987; is that right?

2 A. Correct.

3 Q. There wasn't I think a dedicated haemophilia centre

4 there but you were under the care of a haemophilia

5 consultant called Dr Wylie for much of that time?

6 A. *(The witness nodded)*

7 Q. You received blood products on account of your

8 haemophilia over a number of years; is that right?

9 A. Yes.

10 Q. You have very helpfully produced as an exhibit to your

11 witness statement, and hopefully the documents will

12 come up on screen for you in a moment, extracts from

13 your medical records.

14 Paul, could we have please document 1688002.

15 If you could just carry on through, Paul, until we get

16 to page 14.

17 We can see here, Derek, a list of the factor

18 products that you received over the years.

19 Paul, would you go to the next page, please.

20 Here we have 1984 receiving different types of

21 Blood products, NHS VIII and then ARM VIII,

22 Armour VIII. Is that Factor VIII products that you

23 received?

24 A. Yes.

25 Q. And then if we could go, please, Paul, to 1688003. It

21

1 A. Yes.

2 Q. Is that the basis for your understanding that you were

3 infected with HIV as a result of receiving blood

4 products at some point between those two dates?

5 A. It is.

6 Q. Thank you. That can go down now. Do you know whether

7 your parents were told anything, given any information

8 or advice, about the risk of infection from blood

9 products during your childhood?

10 A. No, no, I doubt very much that they had.

11 Q. By 1984 you were about 20 years old and so an adult.

12 A. Yes.

13 Q. Were you ever told anything about the risk of

14 infection from blood products at any of the clinical

15 appointments you attended?

16 A. No, no.

17 Q. Can you tell us how it was you found out that you had

18 been infected with HIV.

19 A. I recall around some time in August '85, following all

20 the reports, the articles in the newspapers regarding

21 AIDS, how this plague was spreading across the globe

22 and how there were some high risk groups, high risk of

23 infection, haemophiliacs being one of them. I felt in

24 August '85 I should go and ask the hospital to be

25 tested.

23

1 should come up, Derek, in a moment another extract

2 from your records. Next page, thank you. If you

3 could highlight, Paul, please, 1985 and 1984. Do you

4 see there, Derek, the extract from your records which

5 summarises the blood products which you were receiving

6 in particular in 1984 and 1985?

7 A. I do, yes.

8 Q. Can I ask you to tell the Inquiry what illnesses you

9 were infected with as a result of being given those

10 blood products.

11 A. HIV and hepatitis C.

12 Q. It's right, I think, that you don't know the precise

13 date of your infection or the precise batch that

14 caused your infection or, indeed, batches, but you

15 have estimated in your witness statement that it

16 appears to have been some time between August 1984 and

17 August 1985?

18 A. Based on similar records that were sent by the UK

19 National Haemophilia Database, yes.

20 Q. I think we can put that up again. It's 1688003,

21 please, Paul, through to what might be about page 7,

22 please.

23 If we look here, Derek, we've got an entry

24 "date last negative 3 August 1984", "date first

25 positive 15 August 1985."

22

1 Q. So you proactively went to ask to be tested. No-one

2 invited you for a test?

3 A. That's correct.

4 Q. The test was undertaken and came back positive.

5 A. Yes.

6 Q. Can you recall anything about how those test results

7 were communicated to you?

8 A. I was told -- I remember the date because it was

9 Friday the 13th, September '85. I went at lunchtime

10 to get the results and I was told that I was HIV

11 positive. I was told I had about a year to live and I

12 was told not to tell anybody, including my family and

13 my parents.

14 Q. And you were 23 years old then, I think?

15 A. Yes.

16 Q. You've described in your statement having been told

17 not to tell anyone because of the stigma associated

18 with the infection would mean you would become a

19 social pariah.

20 A. That's pretty much what was said, yes.

21 Q. This was by Dr Wylie?

22 A. Yes.

23 Q. Who I think you said was very upset as he communicated

24 this information to you?

25 A. He was. He had been my and my brother's doctor for

24

1 many years, so he was a friend of the family, in a
 2 sense, not just a doctor.
 3 Q. What information or advice other than the bleak
 4 prognosis and the advice not to tell anyone were you
 5 given at that stage? Was there anything else said to
 6 you?
 7 A. Positively no in the sense there was no treatment, no
 8 treatment, and the idea that you would have a year to
 9 live.
 10 Q. You kept the secret, I think, for a while.
 11 A. I did.
 12 Q. What kind of burden did that impose upon you?
 13 A. Difficult. It's a bit of a -- it's more in the sense
 14 that when you're young, you're invincible. When
 15 you're 23, you have life, you are generally fit, apart
 16 from bleeds, but then you are told you have 12 months
 17 to live. It's very hard to comprehend that. So there
 18 was the fear that there was -- it became more and more
 19 prominent in the media and the Government health
 20 warnings that AIDS was a killer and we would all -- we
 21 were all going to die but again it's the confidence of
 22 youth that I can't believe it's going to happen to me.
 23 Q. You described in your statement how in those early
 24 years the worst thing was the mental impact rather
 25 than the physical impact of the infection?

25

1 A. Yes.
 2 Q. Can you tell us what happened to Richard, please.
 3 A. That's one of those things that I've always wondered
 4 being genetically very similar why our -- why things
 5 went the way they did. He became ill, things didn't
 6 work out for him and he died in 1990.
 7 Q. As a direct result of HIV having developed into AIDS?
 8 A. Yes.
 9 Q. I think you feel in part you are here to give evidence
 10 for Richard?
 11 A. For Richard and for everybody else who doesn't have a
 12 voice anymore, yes.
 13 Q. Is there anything you would like to tell us about
 14 Richard, the kind of person that he was?
 15 A. He was full of life. He was a crazy youngster. He
 16 was a haemophiliac. He got a job as a painter and
 17 decorator so he spent half his days standing on a
 18 ladder. His haemophilia doctor wasn't very pleased
 19 about that. He worked for a painter and decorator's.
 20 He did some work in Castle Howard in North Yorkshire;
 21 so we always say my brother has some painting in the
 22 art gallery up in Castle Howard. He was a very
 23 full-of-life person.
 24 Q. How old was Richard when he died?
 25 A. He was 23.

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1 A. That is correct.
 2 Q. And that is partly, is it, because of the sense that
 3 you only had a limited amount of time ahead of you?
 4 A. There was that. Yes, there was no future. The
 5 likelihood of getting married and having children was
 6 very unlikely and the fact that you were told that
 7 you're going to infect people if you have a
 8 relationship, sharing toothbrushes, kissing. In those
 9 early days there was so much uncertainty on how the
 10 infection was going to happen, how you could
 11 contaminate somebody else.
 12 Q. In those early days were you able to talk to anybody
 13 at all about what you were going through?
 14 A. I don't recall the exact date and time but my brother
 15 was infected, so we could talk, and a small group of
 16 friends became very supportive, but not my parents.
 17 Q. In April 1987, you moved to London and I think you
 18 came under the care then of St Thomas' Hospital?
 19 A. Yes.
 20 Q. You mentioned your brother, Richard. He was also
 21 infected with HIV --
 22 A. Yes.
 23 Q. -- again, as a direct result of the treatment with
 24 infected blood products he had been given for his
 25 haemophilia A?

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1 Q. Just shortly before --
 2 A. Just shortly before his 24th birthday.
 3 Q. You have described something in your statement and I
 4 know you are happy to be asked about it, if that's the
 5 right way of putting it, you described something you
 6 called the biggest regret of your life in your
 7 statement and it concerns you and Richard.
 8 What would you like to say about that?
 9 A. Yes, I was down in London, having moved down to
 10 London. My sister was getting married back in York.
 11 This was in August 1990. Richard was -- he was very
 12 ill at the time and he was probably wasting away, in a
 13 sense, but I went up for my sister's wedding. The
 14 night before we all went out, friends, relatives, and
 15 my sister had moved out of a flat back into our
 16 parents' house just for the night before the wedding.
 17 So Richard and I were staying there, just the two of
 18 us at the end of the night.
 19 He knew he was dying. He knew he had AIDS and
 20 that he didn't have long to live and he just wanted to
 21 talk. He wanted to talk about this, talk about his
 22 fears, how scared he was but I couldn't. It was too
 23 close to home for me and I wasn't there for him. I
 24 wasn't there for him and three months later he died.
 25 The biggest regret of my life because he's gone and I

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1 can't do anything to make amends for that.

2 Q. You have also said in your statement that your

3 diagnosis, that of your brother, tore your family

4 apart.

5 A. Yes.

6 Q. Your parents reacted badly.

7 A. I think that emotionally they just couldn't cope with

8 it and the death of Richard was obviously a horrendous

9 thing for the whole family.

10 Q. Your father took to seeking solace in alcohol and died

11 in 2000 aged 61.

12 A. Yes.

13 Q. Your mother struggled to cope with the diagnosis and

14 simply wasn't able to talk about it.

15 A. Yes.

16 Q. What was the ongoing effect of your HIV diagnosis on

17 relationships and your private life?

18 A. Not an option. Firstly, you're going to die very

19 soon; secondly, sexual relationships were the main

20 cause of infection and the fear and the stigma in

21 general society. Who would want to know somebody who

22 is infected with HIV and is going to die very shortly?

23 Q. I think you had, before you met your wife, you had one

24 long-term relationship you describe which lasted about

25 two years.

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1 Q. You married in March 1992.

2 A. Yes.

3 Q. But at that time how long did you think you were going

4 to have in this marriage?

5 A. Two or three years good health and then she'd be

6 nursing me.

7 Q. What was the impact of that shared knowledge that you

8 then had in the early years of your married life?

9 A. One of the things that Margaret said just when we met

10 when she found -- "if we're going to make a

11 relationship, you know, there should be no secrets".

12 She'd seen how I had been before and how not talking

13 to anybody, not being able to say anything to anybody

14 about this, how messed up that had made me. So she

15 said, "If we're going to make a relationship and we're

16 going to get married, we have to be truthful. We

17 don't hide anything".

18 Q. You took the decision, I think, not to tell your son

19 until he was an adult.

20 A. Yes.

21 Q. That I think you say in your statement was because you

22 wanted to spare him the worry that you and Margaret

23 had of a potential impending death sentence and wanted

24 him to have a normal childhood and, as far as he was

25 concerned, a healthy Dad.

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1 A. Yes.

2 Q. There came a point as your relationship developed that

3 you felt you had to tell your then girlfriend about

4 the HIV status?

5 A. *(The witness nodded)*

6 Q. What was the eventual outcome of that?

7 A. She was very upset, tears of course, but then after

8 a few weeks she left me. She said she couldn't stand

9 and watch me die.

10 Q. In 1991 you met Margaret.

11 A. Yes.

12 Q. Your wife. Again, how did the impact of your HIV

13 diagnosis affect the early stages of that

14 relationship?

15 A. Not well. There was that playing hot and cold. You

16 relax, you probably go out and have a few drinks and

17 you start to think, "I'm normal, I'm okay, this is

18 going to work", and you wake up the next day and think

19 I can't do this, this is so wrong, this is so wrong to

20 hurt this person and that's how it went.

21 Q. There came a point where you did tell her?

22 A. I did.

23 Q. What was Margaret's reaction?

24 A. "Is that it? Is that it?" It was a wonderful

25 response.

30

1 A. Yes.

2 Q. In 1997, you became aware I think that you had also

3 been infected with hepatitis C.

4 A. Correct.

5 Q. Can you recall anything about being told that or what

6 was said?

7 A. I don't a lot, to be honest. My wife recalls it

8 better than I do in that she was recounting when we

9 were with relatives how it had been mentioned on a

10 visit to the hospital. It obviously didn't strike me,

11 sink in, but she did remember that they had said

12 hepatitis C.

13 Q. Had you consented to being tested for hepatitis C?

14 A. No.

15 Q. Were you even aware that you were being tested for

16 hepatitis C?

17 A. No.

18 Q. Now, in the mid-1990s you were advised to start taking

19 AZT as the only available HIV treatment at the time.

20 A. That's correct.

21 Q. You had been reluctant to do that for a while. Why

22 was that?

23 A. Because AZT was the only treatment available for HIV

24 at that time and I had been lucky I had been well and

25 AZT was my safety net, maybe if anything went wrong

32

1 start AZT, but then I thought if I start taking the
 2 AZT and that doesn't work and it didn't work for a lot
 3 of people, no more safety net.
 4 Q. When you did take it, what side effects, if any, did
 5 it have?
 6 A. Side effects were pretty bad, times of nausea, I
 7 developed a foot fungus. I developed a nose
 8 infection, so a blunderbuss kind of treatment.
 9 Q. You told us that you remained reasonably physically
 10 well but you have, in fact, had pneumonia, pleurisy,
 11 other infections in consequence of your HIV diagnosis;
 12 is that right?
 13 A. Yes.
 14 Q. You had to have periods in hospital and you have had
 15 to have periods off work as a result?
 16 A. Yes.
 17 Q. Treatment for the HCV: in 2002, I think, you started
 18 on a course of interferon. What was that like in
 19 terms of side effects?
 20 A. That was the worst. That was horrendous, both
 21 physically and mentally. It led to the onset of
 22 depression and how -- it's like having flu all the
 23 time, so you lose your appetite, you lose weight, you
 24 are feeling down, depressed, so you stop interacting
 25 with people around you, with family around you.

33

1 A. I think it did. It did.
 2 Q. But the physical side effects were just as bad?
 3 A. Having had the experience of it before, knowing what
 4 to expect a bit more. But physically, yes, just as
 5 bad or -- six months' worse than the previous time.
 6 Q. That treatment did clear the HCV?
 7 A. Yes.
 8 Q. Do you know whether there has been lasting damage to
 9 your liver as a result of the years before that was
 10 cleared?
 11 A. There is scarring and there is some cirrhosis
 12 I believe, yes.
 13 Q. What current treatments do you take in relation to the
 14 HIV infection?
 15 A. I take three tablets a day for that. I can never
 16 remember what they are.
 17 Q. Do those have side effects?
 18 A. Touch wood, no, no.
 19 Q. Have you experienced any difficulties or obstacles in
 20 obtaining these treatments, whether for the HIV,
 21 hepatitis C or indeed for your haemophilia?
 22 A. No.
 23 Q. What about dental treatment?
 24 A. Dental treatment has been generally good. I used to
 25 go to Guy's Hospital a lot to their dental school.

35

1 Q. The phrase in your witness statement was you became
 2 a shadow of yourself.
 3 A. Yes.
 4 Q. That treatment, was it successful?
 5 A. No.
 6 Q. So you continued to be co-infected with HIV and HCV
 7 and then in 2010 you tried another course of treatment
 8 interferon for the HCV.
 9 What can you tell us about that second
 10 treatment experience?
 11 A. The first one was for six months and didn't work. The
 12 second one was for 12 months. We approached it having
 13 had a bit more experience of this; so I like to think
 14 we were a bit more prepared.
 15 One of the stipulations of my wife was I start
 16 taking antidepressants when I start the 12 months'
 17 treatment and the organisation I was working for at
 18 the time, Kew Gardens, they were incredibly supportive
 19 of me during this time, periods that I was off work,
 20 the flexibility within the working environment.
 21 Q. As well as the antidepressants, you had regular
 22 appointments with a psychiatrist during that course of
 23 treatment?
 24 A. Yes, yes.
 25 Q. That helped you cope better?

34

1 Now it's a local dental practitioner for general work.
 2 If there were to be an extraction it would be back to
 3 the hospital.
 4 Do you want me to carry on?
 5 Q. Absolutely.
 6 A. Just at that time, early on during the period of CJD
 7 being in the headlines, being a -- haemophiliacs being
 8 a high risk group for infection, from that going to
 9 the dentist at the time you would be felt to feel
 10 a bit unclean. Everybody would be sort of suited,
 11 protective clothing, everything that they were going
 12 to treat you with would then be destroyed, fumigated
 13 afterwards. It wasn't -- I know some dental practices
 14 wouldn't take high risk people because of the danger
 15 of CJD infection but I didn't have any problems
 16 getting the treatment. It just felt unclean.
 17 Q. There came a point when you were offered counselling
 18 when you or after you had moved under the care of St
 19 Thomas' Hospital. What form did that take and how did
 20 you find it?
 21 A. There was a Saturday afternoon support group, other
 22 haemophiliacs who were infected and their spouses,
 23 partners, friends, would get together -- self-support
 24 group.
 25 Q. Did you find that helpful?

36

1 A. To start with, yes. It was good to know you weren't
2 in the same -- all that feeling of isolation, the
3 stigma became the stigma. It was good to know --
4 sorry, it's not good to know -- you weren't alone.
5 Somebody would say something and I had been feeling
6 that same thing and you thought you were the only one
7 who had those feelings.

8 But over time it unfortunately changed. People
9 started to get ill; people started to die, and, when
10 you were going up for the next, you would be wondering
11 who would be turning up, who's looking worse than they
12 were last time, so I'm afraid it didn't end as well as
13 it started.

14 Q. Your statement makes very clear that for you, your
15 main source of support, your bastion of support has
16 been your wife, Margaret.

17 A. Yes. There's my time before Margaret and there's my
18 time since Margaret.

19 Q. How has everything that's happened, everything that
20 you've related in your evidence, how has it affected
21 and shaped your life?

22 A. Apart from the social issues we talked about, there
23 are the career, professional effects on that.
24 I started working in the public sector in 1985 --
25 a bit earlier actually, than 1985, 1983 I think it was

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1 relation to those.

2 You received an ex gratia payment as a single
3 person in 1991. Were there any stipulations or
4 conditions attached to the receipt of that payment, as
5 far as you can recall?

6 A. We had to sign a waiver that we would not seek or take
7 action against the Government, any further action with
8 regards to the HIV infection or any possible future
9 infection, whatever that may be, and I believe
10 everybody had to sign it otherwise nobody would get
11 a pay-out. So if you didn't want to sign it, it
12 wasn't just your choice. You were affecting other
13 people as well.

14 Q. You have received some financial payments from the
15 Macfarlane Trust and the Skipton Fund and you now
16 receive some payments from the English Infected Blood
17 Support Scheme.

18 A. Yes.

19 Q. Do you have any particular views or experiences in
20 relation to the operation of the scheme or the nature
21 of the payments that you want to make?

22 A. I don't, no.

23 Q. The final question I wanted to ask you, Derek, arising
24 out of your statement is just about medical records.
25 You sought your medical records at a point in time in

39

1 -- and I was working with them in the public sector
2 when I was diagnosed HIV and I then knew that if
3 I wanted to go somewhere else I would never get
4 through the pre-employment examination. This would
5 come up and I wouldn't be able to -- they wouldn't
6 take me on. So my freedom of career, my ability to
7 move, was restricted.

8 Q. You felt that you had to remain in the public sector
9 for that reason for the majority of your working life?

10 A. There were two reasons. One, yes, nobody else would
11 take me on and the other one was that the public
12 sector had a reasonable, had a good death in service
13 benefit; so I knew that if anything happened to me,
14 there would be something to look after my wife and my
15 son.

16 Q. You, I think, made clear in your statement you have
17 been unable to get any form of life insurance.

18 A. No, there was no life insurance.

19 Q. You described feeling trapped but unable to pursue
20 a career in the private sector:

21 "Whilst my wife and son were dependent upon me,
22 in a sense, I was worth more dead than alive."

23 A. Yes.

24 Q. Can I ask then just ask you about the schemes, the
25 financial assistance schemes, and your experiences in

38

1 which you were part of some litigation that was
2 ongoing in the US.

3 A. Yes.

4 Q. The records that you sought in the course of that
5 litigation were fairly comprehensive from 1964 for
6 about 20 years but there was very little at all in
7 relation to the period July '84 through to your move
8 to London in April 1987; is that right?

9 A. Yes.

10 Q. So in terms of the critical period in terms of
11 infection and testing and diagnosis in relation to the
12 HIV, you found almost nothing in your records.

13 A. Nothing.

14 Q. You have asked St Thomas' if notes were transferred
15 from York when you first came under their care and
16 I think the answer to that was no?

17 A. They said no.

18 Q. You also say in your statement you've spoken to others
19 who were in a similar position to you, people with
20 haemophilia involved in that US litigation who have
21 reported to you a similar experience in relation to
22 their medical records?

23 A. Yes.

24 Q. Derek, those are the questions I have for you. Is
25 there anything else you would like to say?

40

1 A. I'm honoured to be here today for one thing. It is
 2 about -- it good that this is happening now. Although
 3 things may have changed over the past 30 years or so,
 4 HIV, Hep C, I believe there is still a stigma
 5 associated with it even today and I think society
 6 needs to move on from that and I hope this helps that.

7 Q. Derek, I'm just going to turn my back and ask Mr
 8 Snowden who as you know represents you if there's
 9 anything else.

10 (Pause) Just one point which Mr Snowden asks me to
 11 raise.

12 It goes back to the UKHCDO data, the
 13 haemophilia database data I don't think we need to put
 14 it on screen but if you recall I showed you the
 15 document with the dates which showed when you first
 16 tested negative and then first tested positive and the
 17 date of the first test gives a date of 1984.

18 Were you aware of being tested at all in
 19 relation to HIV at any point in 1984 or at any point
 20 prior to the time you went to the hospital and asked
 21 to be tested in 1985?

22 A. No.

23 MS RICHARDS: Thank you.

24 SIR BRIAN LANGSTAFF: Thank you very much indeed, Derek,
 25 for coming to give your evidence and being the first

41

1 Q. You found that out I think only in the course of
 2 investigations for other health problems?

3 A. Yes.

4 Q. Can I take you back to January 1987 then and can you
 5 tell us a little about how the need for a transfusion
 6 arose and what happened.

7 A. I had suffered from menorrhagia for some years, heavy
 8 periods for those who don't know what that is, lots of
 9 heavy bleeding. I was treated with hormones and other
 10 types of treatment which didn't work for me. I was
 11 investigated at one of the London hospitals internally
 12 and found no sign of any cause. So I was in the state
 13 where I was getting more and more anaemic to a very
 14 critical degree and it became apparent that I needed
 15 a blood transfusion quite urgently at that time.

16 Q. Your statement describes a very vivid memory of the
 17 circumstances in which you had the blood transfusion.

18 Are you able to tell us a little about that?

19 A. Yes. We were snowed in for a start; so I don't
 20 remember why it was decided that had to be the day but
 21 I was driven to the hospital in a four-by-four owned
 22 by a friend. The hospital was virtually inaccessible
 23 in Cromer in Norfolk and I was told that blood was
 24 being flown in by helicopter along with the sliced
 25 bread. That was the only information I was given.

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1 of our witnesses in particular and thank you, John
 2 Paul, for supporting your father.

3 We will take a break. We may be able to start
 4 I think the next witness, Dr Hill, in about quarter of
 5 an hour but we will just take a break until then.

6 (11.40 am)

7 (A short break)

8 (12.10 pm)

9 SIR BRIAN LANGSTAFF: The next witness wishes to be known,
 10 does she, as Dr Hill?

11 MS RICHARDS: Yes, sir.

12 CAROLE ANNE HILL, sworn
 13 Questioned by MS RICHARDS

14 MS RICHARDS: Dr Hill, yours is an academic not a medical
 15 doctorate?

16 A. Yes.

17 Q. You discovered in January 2017, just over two years
 18 ago, that you had hepatitis C?

19 A. Yes.

20 Q. And that you were infected with hepatitis C as
 21 a result of a blood transfusion you had in 1987?

22 A. Yes.

23 Q. So for 30 years you were unaware that you had
 24 hepatitis C?

25 A. Indeed.

42

1 I was eventually lashed up to the machinery and
 2 it took about two days to transfuse five units.

3 Q. You have a memory, I think, of whilst that transfusion
 4 was ongoing of listening to the radio, to Radio 4, and
 5 hearing something. What did you hear?

6 A. Yes. I thought it was quite amusing at the time.
 7 There was a broadcast about the growing information
 8 about the transmission of HIV via blood transfusion,
 9 so I was lying there feeling a bit like a rat in
 10 a trap unable to move and then I started to have
 11 a rigor, which is a severe tooth chattering shaking
 12 which I had never experienced before and nurses came
 13 rushing in thinking I might be being transfused with
 14 the wrong group, checked the wrist band, perfectly all
 15 right, and went off and left me to it.

16 Q. In 1987 when you were having that transfusion, were
 17 you given any information at all or any advice about
 18 any risk of infection that might be associated with
 19 the transfusion?

20 A. No, not at all.

21 Q. You have had a number of medical investigations since
 22 then. We'll come on to those that are particularly
 23 relevant for the purposes of your evidence today, but
 24 in the course of the various multiple investigations
 25 you have had over the years, has anyone asked you

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1 whether you have had a transfusion in the past?
 2 A. No, despite my weird blood tests.
 3 Q. Yes, I was going to ask you about that, Dr Hill. You
 4 related in your statement abnormalities or
 5 irregularities being reported to you as early as May
 6 1987.
 7 A. Yes.
 8 Q. Was any explanation ever given to you as to what those
 9 abnormalities were?
 10 A. No, not in a full sense although it would have been
 11 probably lost on me. I'm not a scientist. But they
 12 were various aspects, threads in my blood test didn't
 13 hold together, but everybody said -- started to say --
 14 this was through several GPs, three different GPs over
 15 30 years, "Oh well, I guess that's normal for you."
 16 Q. And no-one ever asked about your medical history, the
 17 history of transfusion in the '80s?
 18 A. No, not at any time.
 19 Q. If we come forward in time to November 2016, you were
 20 having various blood tests and scans at the local
 21 hospital.
 22 If we have on screen, please, Paul, 002407. It
 23 should come up on the screen in front of you,
 24 Dr Hill, I hope -- no, sorry, I must have given
 25 you the wrong reference there. It's the exhibits to

45

1 properly. In response I was cross about that and
 2 I wrote a letter in reply, which I think you've
 3 probably got on record as well, suggesting that
 4 although I understood that this might be one of
 5 a tranche of tests that would take place, it seemed to
 6 me that the patient should be informed in advance of
 7 that testing and warned accordingly and would he
 8 kindly not tell people by letter in future, but I
 9 gather that's standard procedure.
 10 Q. Let's see if we can get that letter up on screen,
 11 Paul. The letter that you received from the
 12 consultant, January 2017 -- I hope we will be able to
 13 find it -- here we are.
 14 A. Yes.
 15 Q. "Dear Dr Hill, I have now seen all the results from
 16 your liver blood tests and follow-up bloods from
 17 clinic. Rather surprisingly they have shown you have
 18 a chronic viral infection with a hepatitis virus
 19 called hepatitis C and I would like to see you in
 20 clinic to discuss the implications of this and what we
 21 can do about it."
 22 So that was the first you knew that you had
 23 been tested?
 24 A. Yes.
 25 Q. That's how the diagnosis was communicated to you?

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1 Dr Hill's statement, please. *(Pause)*
 2 I might deal with it simply by reading out to
 3 you a passage whilst we try and sort that out. You
 4 received a letter in November 2016 from your
 5 consultant hepatologist and gastroenterologist
 6 indicating that they were going to do a blood test
 7 looking out for markers of gynaecological problems and
 8 then they'd see you back in clinic to discuss whether
 9 they needed to do anything further about your liver.
 10 Do you recall?
 11 A. Yes.
 12 Q. Here we are. We have it on screen, thank you. We can
 13 see there there's a passing reference to discussions
 14 about your liver?
 15 A. Mm-hm.
 16 Q. I think it's the case that, in fact, the blood tests
 17 that were actually carried out included a test for
 18 hepatitis C?
 19 A. Yes, but I didn't know that.
 20 Q. That was my next question indeed, Dr Hill. Were you
 21 told you were going to be tested for hepatitis C?
 22 A. No, not at any time.
 23 Q. You can take that down, thanks. How was your
 24 diagnosis of hepatitis C communicated to you?
 25 A. By letter, which was half-opened and not sealed

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1 A. Yes.
 2 Q. I think we have the letter you have referred to, the
 3 follow-up letter, that you wrote on 29 January. Could
 4 we just highlight the second paragraph, please.
 5 "To receive such a diagnosis ..."
 6 This is what you wrote in response:
 7 "To receive such a diagnosis by letter was an
 8 incredible shock and, in my view, totally
 9 inappropriate for a patient who had not even been told
 10 that she was being tested for Hep C. On reflection,
 11 I realise such testing may be standard, but some
 12 indication should be given to the patient."
 13 You were writing that to try and ensure that
 14 other patients weren't put in a similar position.
 15 Thank you, you can take that down, Paul. You
 16 are very critical in your statement of the information
 17 being communicated to you in that way. I think you
 18 describe it as entirely inappropriate?
 19 A. It is.
 20 Q. How do you feel such a potentially life-altering piece
 21 of medical information and diagnosis should be
 22 communicated to a patient?
 23 A. How it should be, I think you need to be fully
 24 informed of what you're being tested for. I realise
 25 I turned up as a blank page, as it were, but I think

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1 if you were having banks of blood tests, as I was, at
2 each stage, perhaps a bit of information wouldn't go
3 astray so you had some idea of where you were being
4 pointed.

5 There was very little communication with the
6 consultant at this level anyway. I think I only saw
7 him twice ever, so it's -- I think if you are only
8 going to see a consultant on that sort of basis,
9 information please.

10 Q. In terms of the actual communication of the diagnosis,
11 you think that should be done in person rather than by
12 letter?

13 A. Of course it should, of course it should, yes.
14 Absolutely.

15 Q. You did see the consultant after that?

16 A. Mmm, after my letter.

17 Q. After your letter. What information or guidance or
18 advice can you recall being given about the hepatitis
19 C infection, for example, about the risks of
20 transmission, further transmission?

21 A. Not a lot, really. I don't remember discussing that.
22 He did talk to me about priorities and waiting lists
23 and so on but I don't think we discussed transmission.

24 Q. You had, and have had, a number of other health
25 problems which I think looking back now you wonder

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1 GP about something else.

2 Q. You've suggested in your witness statement that there
3 might be a link between the hepatitis C and the cancer
4 and you've done some of your own research with the
5 assistance of your husband, who is a retired doctor?

6 A. Yes, he found it rather than I did. I can't say I was
7 eager to research at that point. But, yes, he does
8 a lot of reading of research papers, American research
9 papers largely, and he told me that there had been
10 intimations that there may be some links but more than
11 that I don't know. I've since tried to recover this
12 information but haven't been able to find it but I'm
13 -- as I say, I'm not a science person.

14 Q. You have also experienced a lot of joint pain?

15 A. Oh, yes.

16 Q. Osteoarthritis and --

17 A. That got very suddenly worse.

18 Q. That pain's got worse and you think that increase in
19 severity of the pain and discomfort may have been
20 related to the treatment you subsequently have
21 undertaken for the hepatitis C?

22 A. Yes, indeed.

23 Q. You've also, I think, had a skin reaction. Can you
24 tell us about that?

25 A. Yes, my skin started to fall off. It looked red,

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1 whether some of them may have been at the very least
2 contributed to by the hepatitis C of which you were
3 unaware for so many years?

4 A. Mmm.

5 Q. You have had a diagnosis and been treated for cancer?

6 A. Yes.

7 Q. Can you tell us a little about that?

8 A. Well, during these many tests which crossed me over
9 into a different department, gynaecology and oncology
10 at the same time within weeks of each other really
11 I had a diagnosis of ovarian cancer which I'm assuming
12 wouldn't have been found had I not been starting off
13 with the blood testing for the liver query problems at
14 the time.

15 It was a sort of double whammy. I was being
16 bounced from department to department, I felt, and
17 nobody was talking to each other. In fact, I think
18 I mentioned it in a letter to the doctor concerned to
19 say "Is this my responsibility to communicate with the
20 other consultant or can I take it that you will do it,
21 because there is a lot happening for me at the moment
22 and nobody seems to know what's happening". Phone
23 calls -- it took me -- I was a month finding out about
24 the cancer because nobody would answer the phone and
25 I found out by accident when I was talking to a junior

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1 a bit like eczema to start with, but then it sort of
2 crept around a bit and started flaking off. I did
3 mention it to a consultant in passing but it was very
4 much in passing and I was really patted on the head
5 and told, "Well, you've nearly finished the antivirals
6 now. Let's not. We won't be bothering with it".

7 Q. Again, you think that may have been --

8 A. Well, I didn't have it before.

9 Q. -- an effect of the treatment you underwent for the
10 hepatitis C?

11 A. Yes.

12 Q. Then you also describe in your statement a degree of
13 bleeding and swelling that you've experienced for many
14 years since the transfusion?

15 A. Yes.

16 Q. Can you tell us a little bit about that.

17 A. Yes, I had bleeds in my fingers and feet. Just
18 turning a door handle can do it. I have tried to get
19 advice on it over a 20-year period but unless people
20 can actually see it, by the time you've got to see
21 somebody the colour changes and the blackness of the
22 fingers and toes has gone by the time you get your
23 appointment and so another -- it was another question
24 of being patted on the head and sent away really.

25 Q. So there's not been any investigations or follow-ups

52

1 to explore whether there's any interrelationship
 2 between that --
 3 A. Even now, no, although I have mentioned it recently.
 4 Q. Then you've also been suffering from high blood
 5 pressure?
 6 A. Yes, that's a new thing.
 7 Q. Which again you have attributed in part, not I think
 8 in full, but in part to the stress arising from the
 9 belated diagnosis and the treatment that you have had
 10 to undergo for it?
 11 A. Yes, I didn't know about it before. I did not have it
 12 before, as far as I'm aware. I've always had a low
 13 pressure.
 14 Q. Can I ask you then to tell us about the treatment that
 15 you received for the hepatitis C. What information or
 16 options were given to you about the treatment at the
 17 outset?
 18 A. Well, the nurses were the star turns in the whole
 19 treatment, in my experience, because they seemed to do
 20 all the work and all the support and all the
 21 information, and I was told at the beginning that at
 22 the moment they were using a one dose a day treatment
 23 and how much better it was, but by the time I had gone
 24 through the oncology department and been bounced back
 25 again because I refused treatment, chemotherapy for

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1 dramatic. It certainly does weird things to your head
 2 as well as your body. I know Derek was saying about
 3 feeling like flu. It was a bit like walking through
 4 deep water. I can't really explain how it was but it
 5 was unbearable.
 6 Q. You've said in your statement:
 7 "It wasn't so much like a physical feeling but
 8 very much in my head. It was both depressing and
 9 debilitating and I was reluctant to leave the house.
 10 I became very short-tempered, upset, lacking patience
 11 and generally felt very overwhelmed."
 12 A. Yes, I think that's about a good summary.
 13 Q. A summary in your own words --
 14 A. Indeed, yes.
 15 Q. The treatment for the hepatitis C concluded in January
 16 2018.
 17 A. Yes.
 18 Q. What was the outcome of that treatment?
 19 A. I responded very quickly. In fact, I think I was
 20 clear of virus after a month's treatment. I was very
 21 lucky. I was one of the fortunate ones. I feel a bit
 22 fraudulent being here because I'm -- I haven't had the
 23 extremes that obviously so many people have.
 24 Q. At the time you drafted your statement, you were due
 25 to have another check-up in January of this year?

55

1 the cancer, on the statistics given me, I was told
 2 that the monthly budgeting had changed and that we
 3 were now up to four, sometimes five tablets a day. So
 4 that's what I would be getting. So that's as it was,
 5 but I reacted so badly to the Ribavirin that I could
 6 only tolerate it for about ten days and I had to come
 7 off it.

8 It was a very weird experience.

9 Q. So you had your diagnosis of hepatitis C in January
 10 2017?
 11 A. Yes.
 12 Q. I think was it October 2017 when you started to
 13 receive treatment?
 14 A. Yes, months later after I had had surgery.
 15 Q. That's in part because you were having investigations
 16 and surgery in relation to the cancer?
 17 A. Yes.
 18 Q. What other side effects did you experience from that
 19 treatment? How did it affect you?
 20 A. Well, the Ribavirin was the worst because, although
 21 you don't feel as you normally feel when you are on
 22 antivirals, I think your mind is set on the fact you
 23 are doing it for 12 weeks and that's the way it's
 24 going to be, but the Ribavirin was almost like an
 25 out-of-body experience, although that sounds a bit

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1 A. Yes.
 2 Q. I think you have had that check-up and you are still
 3 clear?
 4 A. Yes, yes, thank you.
 5 Q. Obviously you lived for very many years, for decades,
 6 with hepatitis C but not knowing that you had
 7 hepatitis C. Looking back at your life during that
 8 period, do you see now that you were experiencing
 9 symptoms, symptoms such as fatigue and other symptoms
 10 during that time.
 11 A. Absolutely, but I think a lot of women think that's
 12 normal. Especially at certain age.
 13 Q. You have again described in your statement sensations
 14 throughout that period of time of feeling plagued by
 15 fatigue?
 16 A. Yes.
 17 Q. You put it this way:
 18 "I used to be a very proactive ... but since my
 19 transfusion have been plagued by fatigue."
 20 Indeed, you say you began to think it was
 21 anaemia or normal but now you think unlikely, now you
 22 understand that it was almost certainly the
 23 consequence of the hepatitis C?
 24 A. Yes.
 25 Q. What was the reaction of your family to this late

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1 diagnosis?

2 A. Well, I was very lucky in my family because I come

3 from a family of medics so I didn't get a shock horror

4 at the sort of horror result. My husband is very much

5 older than me and he was immensely shocked. In fact,

6 he had [redacted] and it certainly affected his health

7 but I think he had never had to think that I might die

8 before he did before.

9 Q. Yes, I think you said in your statement again that

10 your husband had to confront the possibility that you

11 might not outlive him?

12 A. Yes.

13 Q. What about the reaction of your children?

14 A. My children were great because they know me and there

15 wasn't -- how could it be other than shock and

16 disbelief really. I mean, everybody's story's

17 unbelievable when you hear the details and they know

18 the sort of life I've lived, so...

19 Q. You tried at one point after the diagnosis

20 counselling?

21 A. Yes.

22 Q. You ended up arranging privately, paying for yourself?

23 A. Yes.

24 Q. How was that?

25 A. To be honest and I'm never against counselling having

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1 would like to take this opportunity to say?

2 A. Yes, thank you. I don't think it's particularly

3 helpful at this juncture to start pointing fingers at

4 medical professionals who largely didn't know what

5 they were dealing with when they were prescribing

6 transfusions. That's not where the problem started.

7 But the awareness should have been very much more than

8 it is, has been in the last couple of years, than 30

9 years ago when we were all in the dark to some degree

10 except people were beginning to know about HIV.

11 I think it's -- I understand the NHS is

12 imploding and shortages of suitably qualified people

13 to deal with us all, certainly as we age, but we do

14 need to be informed better than we are and I have to

15 say I've spent a lot of time communicating myself

16 between different departments because they just didn't

17 do it or, if they did it at all, it wasn't effectively

18 done and it causes great loss of time and time is of

19 the essence if you're mortally ill.

20 I think we need to change that and I think

21 that's one of the key things that this Inquiry can do,

22 is to increase that awareness and the fact that the

23 thousands of people out there who, like me, didn't

24 have the least idea that they've got hepatitis C and

25 there may be a whole wave of more work coming from

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1 practised it a bit in the past in part of my life, but

2 I didn't find it helpful. It was abreactive in as

3 much as I would just sit there and cry and I can do

4 that for free at home.

5 Q. Dr Hill, you have discussed in your statement the

6 application you made to the Skipton Fund and then to

7 the EIBSS scheme for financial assistance. I am not

8 going to ask you about the detail of any of the

9 payments you received but I just wanted to ask you

10 about the application process.

11 You're an academic who is used to dealing with

12 a lot of words, a lot of text, but so you were able,

13 you say, to complete the form?

14 A. It did cross my mind that some people might struggle

15 with it, though, who had not had to do anything like

16 that.

17 Q. You said in your statement it wasn't always clear

18 precisely what questions were being asked or for what

19 purpose --

20 A. Yes.

21 Q. -- in the course of the application?

22 A. It wasn't sort of linear in some respects.

23 Q. Dr Hill, those are the only questions I have for you

24 but is there anything else that you would like to say

25 about your experiences or the late diagnosis that you

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1 that and I hope it's going to be handled a darn site

2 better than it has been up to now.

3 MS RICHARDS: Thank you very much, Dr Hill.

4 SIR BRIAN LANGSTAFF: There was just one thing I wanted to

5 ask. When Ms Richards asked you and you said about

6 your children's reaction and how they were just

7 astounded, flabbergasted at what had happened, you

8 said because they knew the sort of life you'd led.

9 A. Yes.

10 SIR BRIAN LANGSTAFF: Can you just tell me what you meant

11 by that?

12 A. I think when the consultant informed me by letter and

13 expressed their surprise, I was given many more tests

14 I think than lots of people were, blood tests, because

15 I didn't fit the stereotype it seems to me and he was

16 so surprised that I would have it and that seemed

17 a bit out of order to me to ...

18 SIR BRIAN LANGSTAFF: What did you think the stereotype

19 was?

20 A. Well, I assumed from what he said that I wasn't an

21 obvious drug injector and I hadn't been a sex worker

22 and I've only had one sexual partner in a lifetime, so

23 I wasn't maybe what they were looking for. That's a

24 stereotype in itself, I understand that, but I don't

25 understand why you'd express such extreme surprise at

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1 finding that I had an infection that thousands of
 2 other people have got.
 3 **SIR BRIAN LANGSTAFF:** So when you are calling for greater
 4 awareness, you're calling for that amongst people who
 5 have no reason to think that they might be infected by
 6 hepatitis C because they haven't turned their mind to
 7 any transfusion they might have had.
 8 **A.** Indeed, and one thing that struck me when I was
 9 talking to somebody yesterday was that I became aware
 10 because of the sort of household I live in that there
 11 was much more public information broadcasting around
 12 the time that AIDS was becoming known, so like other
 13 people who had donated blood before I knew that if I
 14 had received blood before 1992 if I went back and
 15 offered to donate I would be turned away, not because
 16 I thought there was anything wrong with me but because
 17 I became -- I was within that time margin where it was
 18 an unknown for thousands of people, so I never did
 19 donate blood knowing that information.
 20 But there are lots of people who either didn't
 21 hear it or have been transfused and infected that way.
 22 But it can become a vicious circle if people who are
 23 infected in ignorance went on donating blood, although
 24 I know there are tests now to check the blood, but in
 25 the early days I don't think there was much available.

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1 I played football and cricket and volleyball and
 2 basketball and I did expeditions and stuff like that.
 3 **Q.** You were under the care of the Hammersmith Hospital
 4 from the 1960s through to 1984; is that right?
 5 **A.** That's correct, yes.
 6 **Q.** Then from 1985 you came under the care of the
 7 Royal Free Hospital in London under Professor
 8 Christine Lee and her team there?
 9 **A.** That's correct, yes.
 10 **Q.** You regularly received blood products during your
 11 childhood and young adulthood?
 12 **A.** I did. I received cryoprecipitate as a child up until
 13 the '70s.
 14 **Q.** I think we can have a look at the record from the
 15 haemophilia database. It's 1212002, please, Paul. If
 16 you go down a couple of pages, please.
 17 We can see, Perry, if you look at the screen
 18 look at the bottom of that first screen, we can see
 19 1969 through to 1971 a record of you receiving
 20 cryoprecipitate?
 21 **A.** Yes.
 22 **Q.** Then we can see from 1974 onwards and if we look up
 23 through to the 1980s we see you receiving a variety of
 24 different factor products?
 25 **A.** That is correct, yes.

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1 **SIR BRIAN LANGSTAFF:** That's all that I was going to ask.
 2 I am sorry to bring you back to answer that but thank
 3 you very much indeed, Dr Hill.

4 Thank you, Ms Richards. We will take a break
 5 now, shall we, until, let us say, 1.40.

6 **MS RICHARDS:** Sir, yes, and then we have one witness for
 7 this afternoon, Mr Evans.

8 **SIR BRIAN LANGSTAFF:** Thank you.

9 (12.38 pm)

10 (Luncheon Adjournment)

11 (1.48 pm)

12 **SIR BRIAN LANGSTAFF:** Ms Richards, we have Perry Evans.
 13 You want to be called Perry.

14 **PERRY EVANS, sworn**

15 **Questioned by MS RICHARDS**

16 **MS RICHARDS:** Perry, you were diagnosed I think as a young
 17 child with haemophilia A, classified as mild.

18 **A.** That's correct, yes.

19 **Q.** Prior to the infection that we're going to come on to
 20 talk about, I think you led a pretty active childhood.

21 **A.** I did, yes.

22 **Q.** What kind of things did you do?

23 **A.** So normal boy things, just running around, playing,
 24 certainly at school I did many sports, even though
 25 I was advised not to, but boys will be boys and so

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1 **Q.** If we could just leave that on screen for a moment,
 2 please.

3 What advice or information, if any, was given
 4 as far as you know to your parents about the risks of
 5 any of these products?

6 **A.** There was as far as I was aware there was never any
 7 advice given associated with the risks to these
 8 products.

9 **Q.** What about to you? You turned 18 I think in 1979 or
 10 thereabouts?

11 **A.** Yes.

12 **Q.** What information or advice was given to you then as
 13 a young adult?

14 **A.** Again, no advice associated with the risks of these
 15 products.

16 **Q.** We can see from this record that the type of product
 17 given to you changed from time to time. We'll see
 18 references to Factor VIII (BPL), and then to Factorate
 19 and then to various other products throughout the
 20 1980s?

21 **A.** Yes.

22 **Q.** Do you recall the products being given to you changing
 23 at all?

24 **A.** I do recall seeing different bottles in subsequent
 25 visits to the hospital. So some bottles might be

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1 thicker and have a different label on or a different
 2 colour and maybe the nurse would say "this is Hemofil"
 3 or "this is something else" and you think, "oh, okay".
 4 But generically it was the Factor VIII that was
 5 missing from my body so it never kind of struck a
 6 chord with me to think why are they changing the
 7 products all the time. In hindsight, I assume that
 8 it's to do with kind of their suppliers or their
 9 budgetary contracts that they'd made.

10 Q. Did anyone ever sit down and talk to you or you and
 11 your parents about these changes and why one product
 12 was being used rather than another or whether there
 13 were different risks associated with different
 14 products?

15 A. No, never.

16 Q. Could we go on to I think it is letter 13 July, the
 17 same exhibit, should be roughly page 5. Could we make
 18 that a bit bigger.

19 Perry, if you look at this letter here, you
 20 will see it's a letter from a Dr Worsley to your GP?

21 A. Yes.

22 Q. Could we highlight the last main paragraph, please.
 23 You will see it says there:

24 "We have recently been inviting all our
 25 haemophiliacs to visit the clinic as many of them do

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1 Q. That gives the date when last tested negative as 10
 2 January 1984. Do you recall any discussions about
 3 being tested for HIV at that time?

4 A. No.

5 Q. Do you recall giving any consent to being tested for
 6 HIV at that time?

7 A. No.

8 Q. Do you recall the outcome of any tests being
 9 communicated to you at that time?

10 A. No.

11 Q. When was it that you were told that you had tested
 12 positive?

13 A. I think it was in August '85, if memory serves me
 14 right.

15 Q. I think you have said in your statement you remember
 16 that as a date, you and your wife have remembered that
 17 as a date?

18 A. Because it was five years on from that date we
 19 celebrated the fact that I was still alive and we
 20 invited that -- celebrated that with some close
 21 friends.

22 Q. So that was 5 August 1985 is when you recall being
 23 told for the first time that you had contracted HIV?

24 A. Yes.

25 Q. What can you recall about that communication, that

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1 not see a senior haematologist regularly, particularly
 2 people like Perry who has only moderate haemophilia
 3 and does not develop many problems. We have been
 4 particularly concerned because of the development of
 5 AIDS in some haemophilia patients in the United States
 6 who have been using pooled factor products which have
 7 probably included donation from people who were
 8 incubating AIDS."

9 Then it goes on to discuss the early signs of
 10 the disease. That's July 1983.

11 Did you ever see that letter?

12 A. No.

13 Q. Were the contents of that letter ever communicated to
 14 you at the time that there might be a risk of AIDS in
 15 1983?

16 A. No.

17 Q. Could we go to the next page of the exhibit, please.
 18 Could you just make that more visible. We have here
 19 an extract from the UKHCDO haemophilia database and if
 20 you see, Perry, date last negative 10 January 1984,
 21 date first positive 10 July 1984.

22 Is that material the basis for your
 23 understanding that you were infected at some point in
 24 the first half of 1984?

25 A. That is correct, yes.

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1 conversation? Who was it with?

2 A. It was with Dr Goldman and a social worker at the
 3 Royal Free. They explained that -- I thought it was
 4 just a routine appointment, so as a haemophiliac we
 5 constantly are in hospital for either treatment or if
 6 we're not going in for treatment and we're on home
 7 treatment then we will regularly go in for check ups
 8 every quarter. So I just thought it was one of those
 9 to go on just to see how I was but it transpired that
 10 they started talking about the stuff that had been in
 11 the news about HIV and haemophiliacs being at risk and
 12 I said oh yeah and then they informed me that actually
 13 I was HIV.

14 Q. That date is, as you say, embedded in your memory
 15 because of the celebrations you and your wife
 16 subsequently had five years later still being alive.

17 A. Yes.

18 Q. Could we get up on the screen in the same exhibit
 19 1212002 what I think will be page 8 of the exhibit.
 20 It's a letter from June 1990. That's the one, I'm
 21 sorry, June 1988. If we just look at the first
 22 paragraph, if you could highlight that first
 23 paragraph, please, it's not terribly easy to read but
 24 if we pick it up the second sentence:

25 "He has mild haemophilia [refers to the factor

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level] ... has been HIV positive since at least February 1985."

So whether it was February 1985 or as the earlier records suggest 1984, July 1984, you weren't told until August 1985?

A. Correct, yes.

Q. You can take that down, thank you. What prognosis were you given at that meeting in August 1985?

A. I recollect being told that I had -- my life expectancy was going to be two to three years, I think, at that stage and it was unexpected piece of news and also slightly -- I think there was slight disbelief in as much as I had no ill symptoms at that time. I was still playing five aside football even though I probably shouldn't have been. I was still quite young, doing crazy stuff, and full of life.

Q. You say in your statement you felt numb, you couldn't grasp the news that was being given you.

A. Yes. I mean, I come from a sort of an engineering sciences background and you're always -- kind of part of my training was to kind of look at the evidence of what you're being told and then, you know, translate it back to what's actually happening and it just didn't -- it didn't make sense. It just didn't make sense.

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suffering and for those people who have cared or looked on as other people have suffered. It is a very stark and bleak prognosis and there's nowhere to go. There is nowhere to go with those kind of feelings, so yeah.

Q. That was 1985. Can we look at a letter from 26 September 1986.

Paul, it is 1212002. I think it should be pages 8 or 9 or thereabouts. That's the one, thank you. Can we go down to the next page, thank you. Could you highlight, please, the last paragraph.

This letter, 26 September 1986, says this:

"In conclusion, Perry Evans is clinically well at the present time. His abnormal liver function tests are almost certainly due to chronic non-A non-B hepatitis which is commonly seen in people receiving factor concentrates."

Then there is a reference to recent weight loss and other matters being kept under review. Were you told in 1986 that you almost certainly had non-A non-B hepatitis?

A. No, I was told I had non-A non-B, but that was a few years later.

Q. If we look at an earlier document in the same exhibit, please, Paul -- I think it is the fifth page of the

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Q. Can you remember what, if any, advice or information was given to you in that meeting?

A. I don't believe there was much advice at all because still at that stage it was a prognosis which was fairly bleak, so there was no advice because there was nothing you could do.

Q. You say you knew presumably from the news about the risks from sexual transmission?

A. Yes.

Q. You can't recall whether that was discussed or not in that meeting?

A. No, I'm pretty sure it wasn't discussed. They may well have known that I was a Christian and that I wouldn't be practising sex outside of marriage anyway.

Q. The way you have described the impact of that information being given to you in your statement is this:

"I was left to my own devices to go home and absorb the information that I would die young. I would suffer and die a horrible and painful death. The outlook was bleak and terminal."

That pretty much sums it up in your words.

A. Yes. I mean, it's like I suspect for many people here, either for those people that have suffered, are

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exhibit, that's it, thank you -- this is November 1990. Could we highlight the second paragraph beginning "Many haemophiliacs", and the paragraph after that as well.

So this is a letter which refers to exposure to non-A non-B hepatitis for many haemophiliacs who had been treated with clotting factors or other blood products and it tells you that you tested positive on that date in 1990.

A. Mm-hm.

Q. Is that the first you knew that you had what is now referred to as hepatitis C?

A. Yes, but at that stage, you know, they hadn't isolated the Hep C part so -- so yes.

Q. That information contained in that 1986 letter that you almost certainly had non-A non-B was not shared with you?

A. No.

Q. We can take that down, thanks. Then I think a number of years later, I don't think we need to look at the documents for the purposes of your evidence but in about 2004 you then received information to suggest that you were at risk of vCJD?

A. That's correct, yes. I'd been exposed to it but again that was via a letter. I think I'd heard that there

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1 was a risk, a theoretical risk, that that might have
2 happened and then I got the letter. But again
3 I didn't -- there's not a lot of communication around
4 that information in terms of what I should do, what
5 kind of impact that was, what treatments I should have
6 or explore. So, again, it was just news, move on.

7 **Q.** We can see, Perry, from the documents that you have
8 exhibited to your witness statement infected with HIV
9 probably from infected blood products in the first
10 half of 1984 but told for the first time in August
11 1985. Infected with HCV known to doctors since 1986
12 as non-A non-B but 1990 that you were told.

13 One thing that you say in your statement is
14 that you believe you were repeatedly tested for
15 various infections, including hepatitis B?

16 **A.** Mm-hm.

17 **Q.** But without your knowledge; is that right?

18 **A.** That's correct, yes, and I -- that's just by me going
19 back over my notes and seeing what was written.
20 I mean, it's not -- maybe I'm slightly ignorant but
21 I didn't think it was commonplace to request your
22 notes and go through them to check to see what people
23 are writing about you. It's only in these, kind of
24 circumstances that you necessarily need to do that.

25 **Q.** Can I ask you that impact then that early diagnosis in

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1 know someone you take the relationship into a place
2 that is so deep you think it was always a risk because
3 it was always a risk that, you know, I wouldn't feel
4 bad for the person or the young lady if she turned
5 round said I don't want anything to do with you
6 because that's too much or I thought we were just
7 going out. This is a bit heavy, you know, whatever.
8 What other small talk have you got?

9 So I would never feel bad about it but equally,
10 you know, I like to think I'm fairly open, honest and
11 upfront and I could not live with myself without
12 sharing that with someone who I wanted to be intimate
13 with. So it either -- it was either a kind of very
14 short relationship or it was a relationship which got
15 to a point and then it went really deep very quickly,
16 so I don't know if that answers the question.

17 **Q.** It does. It answers it beautifully, thank you. You
18 then met Heather your wife in 1987.

19 **A.** Yes.

20 **Q.** How did telling Heather happen?

21 **A.** Well, we'd been -- started going out once. I mean,
22 I got to know her through the church that we both went
23 to. The interesting thing was that she was never at
24 the church that I went to because her job was doing
25 schools theatre work, so she was in the car all the

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1 the 1980s had on your personal and family life, so the
2 HIV diagnosis. Before you met Heather, your wife,
3 what impact did it have on your relationships and on
4 your everyday life?

5 **A.** So on relationships, it made me think that having
6 relationships would be out of the question, certainly
7 becoming a father would definitely be out of the
8 question, and really it put a big question mark on
9 what my life was going to be like.

10 Up until that time, you know, I had dreams of
11 getting married, having a family, reaching retirement.
12 But once that news came through, all of those dreams
13 were gone and the impact on my mother and my sister
14 was, you know, sadness and, you know, especially for
15 my mother who I think maybe in the haemophilia
16 community mums feel it a lot harder because they feel
17 responsible for passing that gene down. So to now
18 have HIV as a consequence of the haemophilia in terms
19 of the treatments was, you know, it's not great.

20 So when I did start -- I did start having
21 relationships with young ladies but what I found was
22 this thing, this HIV, this terminal illness that I had
23 was so big that I could not not share that news with
24 those people and so usually within the first couple of
25 dates when you're, you know, still trying to get to

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1 time with her theatre team and so she was very rarely
2 at the church on Sundays, which is when I was there.

3 Anyway, we met up and we got to know each other
4 a little and then I asked her out and then after
5 I think the second date we went out, taking her dog
6 for a walk and it was a nice leisurely walk and we
7 were talking and I just said, "I need to tell you
8 something", and that was it.

9 **Q.** What was Heather's response?

10 **A.** Oh, that's a good one. Well, foolishly I think I said
11 something like, "It's all right, I'm not going to
12 die", which I don't remember saying but Heather swears
13 that I did say this.

14 I think Heather understood a little of the
15 enormity of what I was sharing but it wasn't until she
16 shared it with some close friends that she was living
17 with that she understood the full enormity of what it
18 was.

19 **Q.** You said in your statement, Perry, that when you
20 became engaged there was, as it were, a common
21 understanding between the two of you that you'd die
22 soon, that things would get nasty and that you
23 wouldn't be able to have a family.

24 **A.** That's correct and I -- going back to this point
25 I made about relationships becoming very serious very

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quickly. We started going out in the June or July of '87, I went off overseas for two months in September but I'd said to Heather, "I'll know by the time I come back whether I'm going to marry you". So that's, like -- it's like fast-track marriage really, you know, and then we were engaged by Christmas and then we were married within the year and that being, you know, HIV was probably part of that as well.

Q. There was an occasion you've described in your statement when Heather came with you to the Royal Free --

A. Yes.

Q. -- to meet the consult consultant and the social worker.

A. Yes.

Q. What can you recall about that?

A. So, again, it was a meeting just to kind of have a consultation with the doctors and see how we're getting on and I thought it would be a great opportunity for Heather to come and go to the Royal Free and see what I've had to put up with through all my life and meet the doctors who were generally nice and pleasant. The way it turned out was somewhat different.

They grilled her and laid it on her that, the

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So the drugs are very toxic and they have a variety -- depending on which one, they have a variety of side effects. The AZT made me extremely anaemic. I had to have full blood transfusions to accommodate the anaemia. I just thought I was getting unfit because I would walk up a flight of stairs and then have to... you know, I think I was still in my 20s then so I just thought I was unfit, but it transpired that my haemoglobin was very low.

With the interferon, at that time I only had a short course. I had some slight flu symptoms but it wasn't particularly bad at that time.

Q. By the time you got to 1995, you had to stop work for a long -- for a while, because of the -- whether it was the original infection or the consequences of the treatment, it was simply too much for you?

A. Essentially, what's happened was that my T cell count had been at zero for two years so there was -- there were no effective drugs that I was aware of and that I was being prescribed and so my condition had gone, you know, from a reduced CD4 count down to a zero and so the CD4 count is an indication of how well you can fight the disease and so -- in 1995 I got to a point where I was just so tired, so, so tired that I could only just, you know, get up, get to work and then come

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consequences of what she was doing in marrying me and did she really, really want to go through with it, which was a little surprising to me and to Heather as well. Walking away from the hospital, I was in shock really, and I think Heather was as well. So it was just like I didn't expect that and that was, like -- that was not good. It was not a good experience, yes.

Q. You and Heather did marry.

A. I think so, yes.

Q. But your health started to deteriorate in the sense that you began to suffer chest infections, pneumonias night sweats and then you began AZT treatment in August 1990 --

A. Yes.

Q. -- for the HIV and then interferon in 1992, June 1992, for the HCV.

How were those treatments?

A. So the AZT was horrible. It's just with a lot of HIV and potentially -- and also HCV drugs that they've used, I always recognised that we were being guinea pigs and I was very, very happy to be a guinea pig if it would -- you know, in the knowledge that I might not come through this but if they learn something and they can use something, or discard something then that's better for the people that come behind.

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home, eat and go to bed and I did that for a few months and then I thought this is crazy, you know, absolutely crazy, so I had to stop work.

Q. There was a course of anti-retrovirals you describe as making you violently sick and you didn't think you would be able to carry on with them?

A. Yes, that was like the first generation of anti-retrovirals in 1996 I think and there was only a couple that were around at that stage but the one that I was on, just on occasions, on many occasions you take them but within half-an-hour to an hour you'd see them again, but I don't know. You know, I started to tolerate them more or I managed them better and they started to work.

Q. Then there came a point I think you were able to go back to work around 1997?

A. Yes.

Q. Then having believed, you and Heather, for the first years of your marriage that you wouldn't be able to have children you started to explore the possibility of having children through sperm washing?

A. Correct, yes.

Q. You described that in your statement as a physical and highly emotional journey?

A. Yes.

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1 Q. But your son Isaac who I think is sitting there with
 2 you was born in 2001 as a result of that treatment?
 3 A. That's correct, yes.
 4 Q. But August 2002 you had a further diagnosis?
 5 A. I did. I contracted non-Hodgkin's lymphoma which at
 6 the time and it may -- yes, at the time it was
 7 directly related to the HIV virus in as much as it was
 8 an AIDS-defining illness associated with HIV.
 9 Q. What was the impact of that diagnosis on you and
 10 Heather?
 11 A. So that was enormous.
 12 Q. You were hospitalised for near enough six months.
 13 A. Yes, yes. So having trained as a project manager,
 14 I was able to project manage the treatment and the
 15 doctors to the point where if they came into my room
 16 and they didn't have the answers that I expected, then
 17 I would make them accountable.
 18 I'm not a particularly nice patient when I'm in
 19 that mood, but it was extremely effective to the point
 20 where they would need to huddle outside my room and
 21 have a pre-meeting before they came in to my room to
 22 explain what was happening and what the progress was.
 23 So for six months I was on chemotherapy and
 24 then I would have a week of rest for my blood counts
 25 to recover so that they need to recover to get to the

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1 in when they pull it out, or whatever they do, it's
 2 nice bruising. I think all the haemophiliacs can
 3 relate to that.
 4 Q. You and Heather decided that you would try for another
 5 child --
 6 A. We did.
 7 Q. -- a little while later and your daughter was born in
 8 early 2005.
 9 A. Correct, yes.
 10 Q. One of the things you've told us in your statement is
 11 that around this time you appeared in a documentary?
 12 A. I did.
 13 Q. A BBC documentary called Stephen Fry, HIV and Me.
 14 A. Yes.
 15 Q. We're going to show a clip from that with your
 16 permission but can you just tell us, at the time that
 17 was being filmed can you recall what you had been told
 18 about your prognosis and life expectancy?
 19 A. Yes, I was suffering with not only HIV, chest
 20 infections, pneumonias but also the impact of the
 21 hepatitis C. My body weight, I'd kind of lost loads
 22 of body weight and I was frail and weak and I really
 23 -- you know, I felt as though maybe I wouldn't have
 24 that long.
 25 One of the drivers for doing it was to try and

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1 next cycle; so yes.
 2 But the devastating thing about having the
 3 cancer was that Isaac was just about a year or so,
 4 just over a year, and ... yeah, it was hard.
 5 Q. I think you've put it beautifully in your statement,
 6 Perry, where you say:
 7 "I had survived HIV 17 years from being told
 8 I had it and we found joy in the birth of our son
 9 Isaac", and then you had the devastating news of the
 10 cancer and the need for chemotherapy?
 11 A. Yes.
 12 Q. We've got a picture which you very kindly provided
 13 which gives an indication of the gruelling nature of
 14 the chemotherapy.
 15 I wonder if we can put it on the screen,
 16 please, Paul. It should be 1212005. That is later
 17 on, I'm sorry. In that case it's the other photo,
 18 please.
 19 A. I think it should have a spoiler alert on some of
 20 these.
 21 Q. That's it. That's you at the time that we're talking
 22 about.
 23 A. Yes. One of my better-looking photos, yes, I mean,
 24 it's typical chemotherapy and, being a haemophiliac,
 25 obviously where the cannula or the Hickman line goes

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1 remove some of the stigma and educate people about HIV
 2 and I know that, you know, lots of people can't do
 3 that and I, you know, I respect that but I felt as
 4 though I could so I did.
 5 Q. We're going to play that if we can, I hope. It's a
 6 few minutes.
 7 *(Video played)*
 8 A. Can I just say that there was some reference to dates
 9 while I was speaking and I don't think that those
 10 dates were actually accurate whereas the dates you
 11 have are accurate.
 12 Q. Don't worry about that. We understand. After the
 13 birth of your daughter in January 2005 you, because of
 14 the chemotherapy, because of the compromised immune
 15 system, you experienced a range of chest infections,
 16 pneumonia, you were admitted to hospital and then
 17 April 2005 with a particular lung condition you were
 18 diagnosed?
 19 A. Yes.
 20 Q. Bronchiectasis.
 21 A. Bronchiectasis.
 22 Q. Then 2006 you started on a new drug Truvada and then
 23 you began to experience stomach pains?
 24 A. Yes.
 25 Q. What can you tell us about that?

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1 A. So periodically I would get these incredible cramps
2 which weren't normal cramps but they were excruciating
3 kind of doubled-up pain and then they would subside
4 and the hospital couldn't really find out what was
5 going on until August or July/August 1998 when I --
6 Q. 2008?
7 A. 2008, sorry, yes, when I was taken into hospital.
8 Q. Just prior to that I think you'd also started
9 receiving treatment for the hepatitis C; is that
10 right?
11 A. Yes.
12 Q. Interferon?
13 A. And Ribavirin.
14 Q. Ribavirin, 48 weeks?
15 A. Yes.
16 Q. What was that like?
17 A. That was worse than the chemo. It just sucks the very
18 life out of you physically. It's okay for the first
19 few weeks because your body is getting used to it but
20 you soon get on a very low, kind of a low trajectory
21 down, and it's not only physical but it's mental.
22 You're depressed, you haven't got any energy, you
23 haven't got anything, you're short-tempered and like,
24 but I didn't -- I couldn't contemplate stopping. I'm
25 not the type of person to stop. That might be a good

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1 take me out of the induced coma. I didn't want to
2 come out of the induced coma, so then they started to
3 get a bit worried and our vicar, who's now a bishop
4 actually, he came and visited and I had my funeral
5 arranged.
6 Q. I think we've got a picture. It's the other picture
7 that we had up you have provided us with, which is you
8 in hospital in this time when you were in a coma.
9 A. It's lovely.
10 Q. You weren't expected to survive.
11 A. No, no. I was missing the Olympics as well at the
12 same time.
13 Q. I think you spent quite a few weeks in hospital.
14 A. Yeah.
15 Q. And months of recovery.
16 A. Yeah, and I cried when I came out because I didn't
17 think I would come out.
18 Q. You did manage to return to work I think in 2010.
19 A. I did.
20 Q. You had a further course of treatment for the hep C in
21 2015 --
22 A. I did.
23 Q. -- which resulted in the virus clearing?
24 A. Absolutely, yes.
25 Q. But that's not been the end in terms of health

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1 thing and it might be a bad thing. So I just carried
2 on.

3 But then I did have to stop after 43 weeks
4 because I got some complications whereby I started to
5 manifest a de-compensated liver and ascites and portal
6 hypertension so a whole raft of liver disease-related
7 illnesses.

8 Q. Then August 2008 you were admitted to hospital and
9 placed in intensive care and in an induced coma. What
10 can you tell us about that?

11 A. I was going to say very little because I was asleep at
12 the time. I have it on good authority that I was
13 talking rubbish before they took me off to the
14 theatre, apparently, because I had some sepsis at the
15 time and my heart stopped when I was on the theatre
16 table. They did a laparotomy on me and they took out
17 what they could but it all came out in one lump
18 because it was all fused together.

19 They found a bit of debris in there like
20 something had burst out of my guts and they cleaned it
21 out and they thought, well, we can't see anything,
22 we'd better put him all back together again. So they
23 did that, put it all back in, sewed me up and put me
24 on to ICU.

25 Unfortunately, once they'd -- they wanted to

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1 problems. You've had subsequent hospital
2 readmissions?

3 A. Yes, yes. So right now every day's an exciting day
4 health-wise. You don't know what your night's going
5 to be like, whether you're still going to have night
6 sweats and so my liver is cirrhotic and so I have to
7 be constantly aware of things that may or may not be
8 going wrong.

9 My lungs are extremely damaged because of the
10 bronchiectasis and, as a consequence of that, I had
11 a couple of years ago a number of infections but
12 particularly on two occasions the infection was in and
13 around where the scarring in my lungs was which then
14 resulted in bleeding into my lungs which then meant
15 that I was generating a lot of fresh blood, which is
16 not a particularly good thing if you're a
17 haemophiliac.

18 Q. You described all the side effects or some of the side
19 effects of the many treatments and drugs you have had
20 to have.

21 A. Yes.

22 Q. Vomiting, osteoporosis, anaemia, memory gaps,
23 tiredness, fatigue, dizziness.

24 A. Yes.

25 Q. What about overall the emotional and mental impact of

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1 everything that you've been recounting to us?

2 **A.** Good question. Emotionally I think that what it's

3 done is actually sharpened my sense for life and

4 relationships. I tend and have tended for a while now

5 to not worry about small talk so much and I have

6 tried, although I'm not particularly great at this but

7 tried to -- for those people that I have invested in

8 and for those people that I get to meet, I will give

9 them time because I think relationships is something

10 that is worthwhile and life gets in the way of

11 relationships sometimes.

12 When you go through near-death experiences, for

13 me anyway, it kind of re-balances, it kind of puts

14 things in a different perspective, so I don't --

15 I tend not to worry so much about things that I

16 probably should worry about but I tend to worry more

17 about people and whether I'm being honest and true to

18 them.

19 The other thing about emotional impact is for

20 a while at the beginning of all of my illnesses or my

21 infections we didn't share the news with many people

22 because we didn't want to be always the people who had

23 HIV. We didn't want it to be the sole conversation

24 that we had because that would be boring and that

25 would be wearing and we hoped that we were a bit more

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1 that.

2 Work has been extremely supportive in as much

3 as they, yes, they've stood by me and they understand

4 so... but it's slightly disappointing that I've missed

5 out on certain career progression and also probably

6 associated with that some financial remuneration as

7 well but hey-ho, that's life.

8 **Q.** On the question of travelling abroad you and your

9 family went on holiday to the States to Disneyland in

10 2014?

11 **A.** We did.

12 **Q.** So what happened?

13 **A.** I had previously with work gone to America and this

14 was during the time you needed to declare your HIV

15 status because it is a communicable disease, so before

16 you went you needed to get a visa and then associated

17 with that visa you needed to demonstrate you were

18 going to come back and you weren't going to be

19 a burden on the American state, et cetera. In of

20 itself it's, you know, it's not an easy process but

21 you can do it.

22 In 2014 the visa restriction had been removed

23 and so we went to on holiday to Florida. We were

24 fortunate to have that opportunity and I thought it

25 would be fine. So didn't have a -- I didn't go for

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1 interesting than that.

2 But there is a definite impact and cost to your

3 friends when you share stuff and whilst I'm and many

4 of you are the ones going through those illnesses, and

5 also those who are no longer here, there is a huge

6 impact on family because they carry you and -- but the

7 focus is always on the patient, the person who's

8 suffering. But I know that I wouldn't be here without

9 friends and family.

10 **Q.** Can I ask you about your work and career and how

11 that's been affected by your diagnoses and your

12 illnesses.

13 **A.** Yes. So I had or have a fantastic job. I'm not

14 there, I'm off sick at the moment. It's challenging,

15 it's interesting, it's intellectually demanding and

16 it's great. I loved it and I felt as though I was

17 making a difference and, you know, I was doing well.

18 But my illnesses have meant that I work for -- it's

19 a global organisation and there are always

20 opportunities to go overseas and, in fact, there's

21 kind of some expectation that you will go overseas so

22 that it's part of your career progression. But that's

23 not -- that's never been a practical option for me,

24 one, because of the medical treatment overseas and,

25 two, because of my health not being sustainable to do

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1 a visa because there was no need because it wasn't

2 a communicable disease listed on their entry criteria

3 but, because of my previous visas on their system,

4 they pulled me to one side. Heather and the kids were

5 left in luggage reclaim or Customs or somewhere and

6 I was taken round into a room and held there for

7 half-an-hour while they tried to see whether I was

8 eligible to come in or not.

9 It wasn't until I told them to Google entry

10 requirements into the United States that they believed

11 what I was saying, so that was fun.

12 **Q.** You have talked also in your statement about some of

13 the practical consequences of the infections that you

14 have, cost of travel insurance prohibitively high?

15 **A.** Yes. I mean, I think it's -- I can understand why it

16 is so high but I didn't ask to be in this situation

17 and it just seems so -- it just seems so wrong that if

18 you have got multiple illnesses that aren't your --

19 you haven't asked for them, that you're actually then

20 being penalised, you know. So essentially travel

21 insurance, the quotes are family of four can go on

22 holiday but it's actually a family of five, let's say,

23 because your insurance will actually be at least

24 equivalent to another individual adult going on

25 holiday. That's my experience.

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1 Q. And difficulties in obtaining any form of life
2 insurance as well?
3 A. Well, that's completely out of the question, so ...
4 Q. The treatment that you described that you and Heather
5 had in order to be able to start your family --
6 A. Yes.
7 Q. -- you paid for that privately?
8 A. We did, yes. There was no -- there was no opportunity
9 within the Macfarlane Trust to -- it wasn't part of
10 their criteria to actually fund those things and there
11 was no other kind of NHS because even though it was
12 through the NHS and the Chelsea & Westminster
13 Hospital, it was still viewed as partially private,
14 I think, so you had to pay.
15 Q. Dental care has been problematic as well?
16 A. It has, yes. So earlier I have also experienced
17 turning up for dental treatment and being confronted
18 by what can only be described as someone that looks
19 like they've just come from Mars. So they all suited
20 and booted, masks like this and then you go into the
21 room and everything's covered in plastic and then they
22 kind of talk to you in this -- through their mask and
23 say, "You okay", yeah, yeah, and they'll do the
24 treatment and then that was it.
25 Then more latterly, because of the variant CJD,

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1 actually ask you for some more information.
2 So it's -- what strikes me is that there tends
3 to be a lack of transparency around the criteria and
4 I don't know why that is but, you know, that's what it
5 strikes me as and also like the level of fortitude
6 that you need to get through the process is -- it
7 wouldn't surprise me if people just gave up, to be
8 honest.
9 Q. In relation to the current scheme, the EIBSS
10 funding --
11 A. Yes.
12 Q. -- what's been your experience in relation to that?
13 A. I think in the previous incarnations of the trust, the
14 Macfarlane Trust and the Skipton Fund, because they
15 had been there for such a long time or relatively long
16 time, I did sense that there were people there who had
17 understood the community a bit more and had a
18 relationship.
19 With the new body, that isn't there. I guess
20 that would make sense, given that they are all
21 relatively new to the job and they're new to the
22 community. So there's not that level of interaction
23 certainly -- well, maybe others have had more
24 interaction but I certainly haven't.
25 Q. You have expressed a concern in your statement about

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1 I was not able to get dental care from the first
2 dentist I went to and then had to kind of go to the
3 health authority to actually find someone within the
4 area to actually provide dental care.
5 Q. Can I then ask you, you mentioned the Macfarlane
6 Trust --
7 A. Yes.
8 Q. -- and you've said in your statement that you've had
9 certain payments from the Macfarlane Trust, from the
10 Skipton Fund?
11 A. Yes.
12 Q. But you have talked about the time-consuming nature of
13 the applications, seeing why others can struggle and
14 having to jump through hoops and I wondered if you
15 could elaborate upon that.
16 A. Yes. So it's great that these grants are made
17 available, let me just say that, and what's not so
18 great is the fact that the forms and the justification
19 of some of the applicants that you make are just
20 really convoluted and so you might have to get three
21 quotes for something before you submit it, you might
22 have to get various letters from medical practitioners
23 to demonstrate you are who you say you are or you have
24 what you say you have and then when you submit the
25 claim, then you might actually find that they will

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1 the impact of it being means tested.
2 A. Yes. So I don't have a problem with people being
3 means tested, I just think that sometimes people who
4 are able to save will save because they want to save
5 for their dependants. If you get to a point where
6 you've saved too much, then that will then exclude you
7 from something that you need because on the basis of
8 that then you would need to use your savings because
9 you have savings but you've got your savings because
10 that's, you know, in my head anyway, I kind of
11 earmarked that for when I'm not here.
12 I can understand I think that definitely, you
13 know, if funding is available then it should go to the
14 most needy for sure, you know. I don't have an issue
15 with that, I just think means testing is very -- is
16 again another huge hurdle to jump in terms of like you
17 create your own budget for a week or for a month or
18 whatever and demonstrate that you have no residual
19 income at the end of it. Okay, where do I start?
20 So~...
21 Q. Perry, those were my questions for you but do you have
22 anything else you want to say, anything that's not
23 been covered?
24 A. I did make a note. I'll just see if you've covered
25 it. Just to say that I really welcome this Inquiry

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1 and I wouldn't want to be in your or your shoes
 2 particularly because I think you have a mammoth task.
 3 I would love and my own desire would be that there is
 4 transparency around what's happened in the past so
 5 that people in the future can learn and so that some
 6 people will be able to get some closure. You can't --
 7 you know, I think it's impossible to reach closure for
 8 those that you've lost when they shouldn't have been
 9 lost, so I think that was the only thing wanted to
 10 say.

11 **MS RICHARDS:** I'm just going to turn my back, Perry, and
 12 ask Mr Snowden if he has any questions.

13 No, nothing further.

14 **A.** Thank you.

15 **SIR BRIAN LANGSTAFF:** Perry, thank you very much. It's
 16 been a privilege listening to you.

17 **A.** Thank you.

18 **SIR BRIAN LANGSTAFF:** And thank you, Isaac. What we will
 19 now do is we shall take a break.

20 I hope that there may be coffee and tea and
 21 biscuits already there. I hope I'm not disappointed
 22 in that as I was at lunch but some things the Inquiry
 23 can't do! We shall go on trying.

24 We shall meet again tomorrow at 10.00.

25 Ms Richards, who shall we hear from tomorrow?

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1 **MS RICHARDS:** We will be hearing again from three
 2 witnesses Ms Challis, Mr Nicholls and Ms Ashton.

3 **SIR BRIAN LANGSTAFF:** So I look forward to seeing many of
 4 you, those who can come tomorrow.

5 (3.01 pm)

6 (Adjourned until 10.00 am the following day)

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