1 Tuesday, 30 April 2019 million people worldwide who suffer from it and the 2 (10.34 am) 2 World Health Organisation has recently announced 3 3 SIR BRIAN LANGSTAFF: Today is a significant day for the ambitious plans to eliminate hepatitis C by 2030. It 4 Inquiry. It's the day we first hear evidence given 4 may be possible, I am told, for that to happen even 5 5 earlier in this country, but it depends upon people orally. 6 6 Thank you for being here in such numbers to who think that they might possibly be suffering 7 take part in it and by your presence in such numbers. 7 knowing enough to be tested because otherwise the 8 8 to demonstrate the importance of this Inquiry. That risks of transmission remain and it takes longer to 9 9 together with the force of your feelings, is no doubt eliminate what has been a dreadful disease. 10 why the press have been attracted. I thank them too 10 I want particularly to thank those of you who 11 for being here. Do what the press do best, to report 11 have given statements. I have already read a large 12 fairly and fearlessly. 12 number more than once, some a number of times. Some 13 13 I hope that while doing that they may help to are harrowing, some incredibly moving and some 14 spread the message that those who are struggling with 14 chillingly factual. All are valuable. 15 the infections of HIV or hepatitis through blood or 15 There are more to come. For many making a 16 blood products are not alone. 16 statement has been and for some it yet will be an act 17 17 Anything they can do to increase public of bravery. I would like to acknowledge that publicly 18 18 knowledge of the symptoms, the causes, and as so many here and now. It may have stirred up and it may yet 19 of you have told me movingly in your witness 19 stir up distressing memories. I understand some 20 statements, the consequences of late discovery of 20 simply cannot bring themselves to make a statement 21 hepatitis C in particular will be of great value to 21 because it is too much. 22 22 the public because so many symptoms of that disease I want to acknowledge too your patience. It 23 seem to mimic a range of common conditions. 23 may have seemed a long gap between the end of the 24 24 preliminary hearings and the start of these oral Anything that they can do to raise awareness is hearings but you have I believe understood that 25 25 particularly important given that there are some 180 1 gathering in witness evidence from so many, 1 them, it's not about me, it's about the evidence which 2 2 identifying repositories of documents and the witness can give. 3 interrogating them and making the practical 3 There are rooms to the side and downstairs 4 arrangements which come with such a large inquiry all 4 where anyone who needs space during the hearings can 5 take time, though I have promised you that the Inquiry 5 find it. The Red Cross are on hand to assist anyone 6 will be as quick as it can. This has always been 6 who finds some of the evidence or their own memories 7 7 accompanied by the assurance that it will be as difficult. But it's also about giving people time as 8 8 thorough as is reasonable and I mean to keep my much as physical space and practical arrangements. 9 9 promise to you, whatever your perspectives on the You know now that the Inquiry will spend until 10 10 October travelling round the UK to make it easier for Inquiry. 11 At the preliminary hearings I set out the 11 many to access the hearings and you can be assured 12 principles that were to guide this Inquiry. They were 12 that although it will never be possible to hear orally 13 first and foremost putting people at its heart, being 13 from everyone who would wish to be heard, those as quick as reasonable thoroughness permits, paying 14 14 affected and infected will come first and last in the 15 15 proper respect to a person's right to be heard, being Inquiry, not only in the first few weeks but the last 16 16 as open and transparent as is legally possible, being weeks. 17 independent of Government and frightened of no-one in 17 Every new written statement the Inquiry 18 the conclusions it draws and listening. 18 receives is important. Each will be read, each will 19 Though all apply, four are of particular 19 be different, each has value and the evidence of those 20 importance now as we start hearing evidence orally. 20 who have made or will make statements is of real 21 First, I promised that the Inquiry would put people at 21 value, whether or not they gave evidence orally. 22 22 Second, can I repeat what I said last September its heart. The room you are in is, I hope, visible 23 23 evidence that this Inquiry honours its principles. about paying respect to a person's right to be heard. 24 The witness is centre stage. The public in front. 24 Putting people at the heart of the Inquiry must 25 Lawyers and me to the side. The Inquiry is not about 25 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

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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

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,

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 then 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 6

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

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

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

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.

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

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

blood products.

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

is to help them support patients who may have been

exposed to risks associated with infected blood or

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 --

5 A. Yes.

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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.

- 12 A. (The witness nodded)
- 13 Q. Derek, you have haemophilia A?
- 14 **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?
- 20 **A.** Yes.
- Q. And the type of haemophilia that you have ishaemophilia A?
- 23 A. Yes
- 24 Q. So a deficiency of clotting Factor 8?
- 25 A. Correct.

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.

22 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.
- 7 SIR BRIAN LANGSTAFF: Ms Richards, can I just ask you to
 8 pause there for a moment. I think we are losing some
 9 of the force of what Derek is saying because of the
 10 position of the microphone. I wonder if it can just
 11 be moved around a little bit in front of him or for
 12 that matter if he comes a little bit this way it might
 13 be easier. I am sorry for interrupting.

Are you happy with that, Derek?

14 Are you happy15 A. Yes, that's fine.

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

- 18 A. Yes.
- 19 Q. You had a younger brother, Richard?
- 20 A. Yes
- Q. Who was diagnosed also with severe haemophilia A ata very young age?
- 23 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?	1		should come up, Derek, in a moment another extract
2	Δ	Correct.	2		from your records. Next page, thank you. If you
3		There wasn't I think a dedicated haemophilia centre	3		could highlight, Paul, please, 1985 and 1984. Do you
4	Œ.	there but you were under the care of a haemophilia	4		see there, Derek, the extract from your records which
5		consultant called Dr Wylie for much of that time?	5		summarises the blood products which you were receiving
6	Δ	(The witness nodded)	6		in particular in 1984 and 1985?
7		You received blood products on account of your	7	Δ	I do, yes.
8	u.	haemophilia over a number of years; is that right?	8		Can I ask you to tell the Inquiry what illnesses you
9	Δ	Yes.	9	w.	were infected with as a result of being given those
10	Q.		10		blood products.
11	w.	witness statement, and hopefully the documents will	11	Δ	HIV and hepatitis C.
12		come up on screen for you in a moment, extracts from	12	Q.	
13		your medical records.	13	Œ.	date of your infection or the precise batch that
14		Paul, could we have please document 1688002.	14		caused your infection or, indeed, batches, but you
15		If you could just carry on through, Paul, until we get	15		have estimated in your witness statement that it
16		to page 14.	16		appears to have been some time between August 1984 and
17		We can see here, Derek, a list of the factor	17		August 1985?
18		products that you received over the years.	18	Δ	Based on similar records that were sent by the UK
19		Paul, would you go to the next page, please.	19	Λ.	National Haemophilia Database, yes.
20		Here we have 1984 receiving different types of	20	0	I think we can put that up again. It's 1688003,
21		Blood products, NHS VIII and then ARM VIII,	21	w.	please, Paul, through to what might be about page 7,
22		Armour VIII. Is that Factor VIII products that you	22		please.
23		received?	23		If we look here, Derek, we've got an entry
24	۸	Yes.	23 24		
2 4 25			2 4 25		"date last negative 3 August 1984", "date first positive 15 August 1985."
25	Q.	And then if we could go, please, Paul, to 1688003. It	25		· ·
		21			22
1	Α.	Yes	1	Q.	So you proactively went to ask to be tested. No-one
1 2	_	Yes. Is that the basis for your understanding that you were	1 2	Q.	So you proactively went to ask to be tested. No-one invited you for a test?
2	A. Q.	Is that the basis for your understanding that you were	2		invited you for a test?
2 3	_	Is that the basis for your understanding that you were infected with HIV as a result of receiving blood	2 3	Α.	invited you for a test? That's correct.
2 3 4	Q.	Is that the basis for your understanding that you were infected with HIV as a result of receiving blood products at some point between those two dates?	2 3 4	A. Q.	invited you for a test? That's correct. The test was undertaken and came back positive.
2 3 4 5	Q.	Is that the basis for your understanding that you were infected with HIV as a result of receiving blood products at some point between those two dates? It is.	2 3 4 5	A. Q. A.	invited you for a test? That's correct. The test was undertaken and came back positive. Yes.
2 3 4 5 6	Q.	Is that the basis for your understanding that you were infected with HIV as a result of receiving blood products at some point between those two dates? It is. Thank you. That can go down now. Do you know whether	2 3 4 5 6	A. Q. A.	invited you for a test? That's correct. The test was undertaken and came back positive. Yes. Can you recall anything about how those test results
2 3 4 5 6 7	Q.	Is that the basis for your understanding that you were infected with HIV as a result of receiving blood products at some point between those two dates? It is. Thank you. That can go down now. Do you know whether your parents were told anything, given any information	2 3 4 5 6 7	A. Q. A. Q.	invited you for a test? That's correct. The test was undertaken and came back positive. Yes. Can you recall anything about how those test results were communicated to you?
2 3 4 5 6 7 8	Q.	Is that the basis for your understanding that you were infected with HIV as a result of receiving blood products at some point between those two dates? It is. Thank you. That can go down now. Do you know whether your parents were told anything, given any information or advice, about the risk of infection from blood	2 3 4 5 6 7 8	A. Q. A.	invited you for a test? That's correct. The test was undertaken and came back positive. Yes. Can you recall anything about how those test results were communicated to you? I was told I remember the date because it was
2 3 4 5 6 7 8 9	Q. A. Q.	Is that the basis for your understanding that you were infected with HIV as a result of receiving blood products at some point between those two dates? It is. Thank you. That can go down now. Do you know whether your parents were told anything, given any information or advice, about the risk of infection from blood products during your childhood?	2 3 4 5 6 7 8 9	A. Q. A. Q.	invited you for a test? That's correct. The test was undertaken and came back positive. Yes. Can you recall anything about how those test results were communicated to you? I was told I remember the date because it was Friday the 13th, September '85. I went at lunchtime
2 3 4 5 6 7 8 9	Q. A. Q.	Is that the basis for your understanding that you were infected with HIV as a result of receiving blood products at some point between those two dates? It is. Thank you. That can go down now. Do you know whether your parents were told anything, given any information or advice, about the risk of infection from blood products during your childhood? No, no, I doubt very much that they had.	2 3 4 5 6 7 8 9	A. Q. A. Q.	invited you for a test? That's correct. The test was undertaken and came back positive. Yes. Can you recall anything about how those test results were communicated to you? I was told I remember the date because it was Friday the 13th, September '85. I went at lunchtime to get the results and I was told that I was HIV
2 3 4 5 6 7 8 9 10	Q. A. Q.	Is that the basis for your understanding that you were infected with HIV as a result of receiving blood products at some point between those two dates? It is. Thank you. That can go down now. Do you know whether your parents were told anything, given any information or advice, about the risk of infection from blood products during your childhood? No, no, I doubt very much that they had. By 1984 you were about 20 years old and so an adult.	2 3 4 5 6 7 8 9 10	A. Q. A. Q.	invited you for a test? That's correct. The test was undertaken and came back positive. Yes. Can you recall anything about how those test results were communicated to you? I was told I remember the date because it was Friday the 13th, September '85. I went at lunchtime to get the results and I was told that I was HIV positive. I was told I had about a year to live and I
2 3 4 5 6 7 8 9 10 11	Q. A. Q. A. Q.	Is that the basis for your understanding that you were infected with HIV as a result of receiving blood products at some point between those two dates? It is. Thank you. That can go down now. Do you know whether your parents were told anything, given any information or advice, about the risk of infection from blood products during your childhood? No, no, I doubt very much that they had. By 1984 you were about 20 years old and so an adult. Yes.	2 3 4 5 6 7 8 9 10 11	A. Q. A. Q.	invited you for a test? That's correct. The test was undertaken and came back positive. Yes. Can you recall anything about how those test results were communicated to you? I was told I remember the date because it was Friday the 13th, September '85. I went at lunchtime to get the results and I was told that I was HIV positive. I was told I had about a year to live and I was told not to tell anybody, including my family and
2 3 4 5 6 7 8 9 10 11 12 13	Q. A. Q.	Is that the basis for your understanding that you were infected with HIV as a result of receiving blood products at some point between those two dates? It is. Thank you. That can go down now. Do you know whether your parents were told anything, given any information or advice, about the risk of infection from blood products during your childhood? No, no, I doubt very much that they had. By 1984 you were about 20 years old and so an adult. Yes. Were you ever told anything about the risk of	2 3 4 5 6 7 8 9 10 11 12 13	A. Q. A. Q.	invited you for a test? That's correct. The test was undertaken and came back positive. Yes. Can you recall anything about how those test results were communicated to you? I was told I remember the date because it was Friday the 13th, September '85. I went at lunchtime to get the results and I was told that I was HIV positive. I was told I had about a year to live and I was told not to tell anybody, including my family and my parents.
2 3 4 5 6 7 8 9 10 11 12 13 14	Q. A. Q. A. Q.	Is that the basis for your understanding that you were infected with HIV as a result of receiving blood products at some point between those two dates? It is. Thank you. That can go down now. Do you know whether your parents were told anything, given any information or advice, about the risk of infection from blood products during your childhood? No, no, I doubt very much that they had. By 1984 you were about 20 years old and so an adult. Yes. Were you ever told anything about the risk of infection from blood products at any of the clinical	2 3 4 5 6 7 8 9 10 11 12 13 14	A. Q. A. Q.	invited you for a test? That's correct. The test was undertaken and came back positive. Yes. Can you recall anything about how those test results were communicated to you? I was told I remember the date because it was Friday the 13th, September '85. I went at lunchtime to get the results and I was told that I was HIV positive. I was told I had about a year to live and I was told not to tell anybody, including my family and my parents. And you were 23 years old then, I think?
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- 1 many years, so he was a friend of the family, in a 2 sense, not just a doctor.
- Q. What information or advice other than the bleak
 prognosis and the advice not to tell anyone were you
 given at that stage? Was there anything else said to
 you?
- A. Positively no in the sense there was no treatment, no
 treatment, and the idea that you would have a year to
 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
- Q. You described in your statement how in those early
 years the worst thing was the mental impact rather
 than the physical impact of the infection?

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youth that I can't believe it's going to happen to me.

1 A. Yes.

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- 2 Q. Can you tell us what happened to Richard, please.
- A. That's one of those things that I've always wondered being genetically very similar why our -- why things went the way they did. He became ill, things didn't work out for him and he died in 1990.
- 7 Q. As a direct result of HIV having developed into AIDS?
- 8 A. Yes.

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- Q. I think you feel in part you are here to give evidence for Richard?
- A. For Richard and for everybody else who doesn't have avoice anymore, yes.
- Q. Is there anything you would like to tell us aboutRichard, 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.Q. How old was Richard when he died?
- 25 A. He was 23.

- A. That is correct.
- Q. And that is partly, is it, because of the sense thatyou 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 anybody13 at all about what you were going through?
- A. I don't recall the exact date and time but my brother
 was infected, so we could talk, and a small group of
 friends became very supportive, but not my parents.
- 17 Q. In April 1987, you moved to London and I think you18 came under the care then of St Thomas' Hospital?
- 19 **A.** Yes.
- Q. You mentioned your brother, Richard. He was alsoinfected with HIV --
- 22 A. Yes.

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Q. -- again, as a direct result of the treatment with
 infected blood products he had been given for his
 haemophilia A?

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- 1 Q. Just shortly before --
- 2 A. Just shortly before his 24th birthday.
 - Q. You have described something in your statement and I know you are happy to be asked about it, if that's the right way of putting it, you described something you called the biggest regret of your life in your statement and it concerns you and Richard.

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 night before we all went out, friends, relatives, and 14 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.

He knew he was dying. He knew he had AIDS and that he didn't have long to live and he just wanted to talk. He wanted to talk about this, talk about his fears, how scared he was but I couldn't. It was too close to home for me and I wasn't there for him. I wasn't there for him and three months later he died. The biggest regret of my life because he's gone and I

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(7) Pages 25 - 28

- 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.

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

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- Q. What was the ongoing effect of your HIV diagnosis on 16 relationships and your private life? 17
- 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

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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- Q. You married in March 1992. 1
- 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?
- 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 about this, how messed up that had made me. So she 14 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".
- Q. You took the decision, I think, not to tell your son 18 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.

- 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 you start to think, "I'm normal, I'm okay, this is
- 17 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 "Is that it? Is that it?" It was a wonderful

25 response.

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- A. Yes. 1
- 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
- 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 Α.
- 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

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(8) Pages 29 - 32

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- start AZT, but then I thought if I start taking the
 AZT and that doesn't work and it didn't work for a lot
 of people, no more safety net.
- 4 Q. When you did take it, what side effects, if any, did 5 it have?
- A. Side effects were pretty bad, times of nausea, I
 developed a foot fungus. I developed a nose
 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 had15 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?
- A. That was the worst. That was horrendous, both physically and mentally. It led to the onset of depression and how -- it's like having flu all the time, so you lose your appetite, you lose weight, you are feeling down, depressed, so you stop interacting with people around you, with family around you.

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- 1 A. I think it did. It did.
- 2 Q. But the physical side effects were just as bad?
- A. Having had the experience of it before, knowing what to expect a bit more. But physically, yes, just as bad or -- six months' worse than the previous time.
- 6 Q. That treatment did clear the HCV?
- 7 **A.** Yes.
- Q. Do you know whether there has been lasting damage to
 your liver as a result of the years before that was
 cleared?
- 11 A. There is scarring and there is some cirrhosis
- 12 I believe, yes.
- Q. What current treatments do you take in relation to theHIV infection?
- A. I take three tablets a day for that. I can neverremember what they are.
- 17 **Q.** Do those have side effects?
- 18 A. Touch wood, no, no.
- Q. Have you experienced any difficulties or obstacles in
 obtaining these treatments, whether for the HIV,
- 21 hepatitis C or indeed for your haemophilia?
- 22 A. No.
- 23 Q. What about dental treatment?
- A. Dental treatment has been generally good. I used to go to Guy's Hospital a lot to their dental school.

- 1 **Q.** The phrase in your witness statement was you became a shadow of yourself.
- 3 A. Yes.

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- Q. That treatment, was it successful?
- 5 A. No.
- 6 **Q.** So you continued to be co-infected with HIV and HCV and then in 2010 you tried another course of treatment interferon for the HCV.

What can you tell us about that second treatment experience?

A. The first one was for six months and didn't work. The second one was for 12 months. We approached it having had a bit more experience of this; so I like to think we were a bit more prepared.

One of the stipulations of my wife was I start taking antidepressants when I start the 12 months' treatment and the organisation I was working for at the time, Kew Gardens, they were incredibly supportive of me during this time, periods that I was off work, the flexibility within the working environment.

- Q. As well as the antidepressants, you had regular appointments with a psychiatrist during that course of treatment?
- 24 **A.** Yes, yes.
- 25 Q. That helped you cope better?

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- Now it's a local dental practitioner for general work.

 If there were to be an extraction it would be back to the hospital.
 - 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 wouldn't take high risk people because of the danger 14 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?
- A. There was a Saturday afternoon support group, other
 haemophiliacs who were infected and their spouses,
 partners, friends, would get together -- self-support
 group.
- 25 Q. Did you find that helpful?

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(9) Pages 33 - 36

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

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

- Q. Your statement makes very clear that for you, your main source of support, your bastion of support has been your wife, Margaret.
- 17 A. Yes. There's my time before Margaret and there's my18 time since Margaret.
 - Q. How has everything that's happened, everything that you've related in your evidence, how has it affected and shaped your life?
- A. Apart from the social issues we talked about, there
 are the career, professional effects on that.
 I started working in the public sector in 1985 -a bit earlier actually, than 1985, 1983 I think it was

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1 relation to those.

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

- A. We had to sign a waiver that we would not seek or take action against the Government, any further action with regards to the HIV infection or any possible future infection, whatever that may be, and I believe everybody had to sign it otherwise nobody would get a pay-out. So if you didn't want to sign it, it wasn't just your choice. You were affecting other people as well.
- Q. You have received some financial payments from the
 Macfarlane Trust and the Skipton Fund and you now
 receive some payments from the English Infected Blood
 Support Scheme.
- 18 **A.** Yes.
- Q. Do you have any particular views or experiences in
 relation to the operation of the scheme or the nature
 of the payments that you want to make?
- 22 A. I don't, no.
- Q. The final question I wanted to ask you, Derek, arising
 out of your statement is just about medical records.
 You sought your medical records at a point in time in

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

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

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

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

18 A. No, there was no life insurance.

move, was restricted.

Q. You described feeling trapped but unable to pursuea 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.

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

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

3 A. Yes.

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

A. Yes.

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

13 A. Nothing

Q. You have asked St Thomas' if notes were transferred
 from York when you first came under their care and
 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.

Q. Derek, those are the questions I have for you. Isthere anything else you would like to say?

40 (10) Pages 37 - 40

1 A. I'm honoured to be here today for one thing. It is of our witnesses in particular and thank you, John 2 about -- it good that this is happening now. Although 2 Paul, for supporting your father. 3 3 things may have changed over the past 30 years or so, We will take a break. We may be able to start I think the next witness, Dr Hill, in about quarter of 4 4 HIV, Hep C, I believe there is still a stigma 5 associated with it even today and I think society 5 an hour but we will just take a break until then. 6 needs to move on from that and I hope this helps that. 6 (11.40 am) 7 Q. Derek, I'm just going to turn my back and ask Mr 7 (A short break) 8 8 Snowdon who as you know represents you if there's (12.10 pm) 9 9 SIR BRIAN LANGSTAFF: The next witness wishes to be known, anything else. 10 10 (Pause) Just one point which Mr Snowdon asks me to does she, as Dr Hill? 11 raise. 11 MS RICHARDS: Yes, sir. 12 It goes back to the UKHCDO data, the 12 CAROLE ANNE HILL, sworn 13 haemophilia database data I don't think we need to put 13 Questioned by MS RICHARDS 14 it on screen but if you recall I showed you the 14 MS RICHARDS: Dr Hill, yours is an academic not a medical 15 15 document with the dates which showed when you first doctorate? 16 tested negative and then first tested positive and the 16 A. Yes. date of the first test gives a date of 1984. 17 17 Q. You discovered in January 2017, just over two years 18 ago, that you had hepatitis C? 18 Were you aware of being tested at all in 19 relation to HIV at any point in 1984 or at any point 19 A. Yes. 20 prior to the time you went to the hospital and asked 20 Q. And that you were infected with hepatitis C as 21 to be tested in 1985? 21 a result of a blood transfusion you had in 1987? 22 22 A. No. 23 MS RICHARDS: Thank you. 23 Q. So for 30 years you were unaware that you had 24 SIR BRIAN LANGSTAFF: Thank you very much indeed, Derek, 24 hepatitis C? 25 for coming to give your evidence and being the first 25 A. Indeed. 41 42 1 Q. You found that out I think only in the course of 1 I was eventually lashed up to the machinery and 2 2 investigations for other health problems? it took about two days to transfuse five units. 3 A. Yes. 3 Q. You have a memory, I think, of whilst that transfusion 4 4 Q. Can I take you back to January 1987 then and can you was ongoing of listening to the radio, to Radio 4, and 5 tell us a little about how the need for a transfusion 5 hearing something. What did you hear? 6 arose and what happened. 6 A. Yes. I thought it was quite amusing at the time. 7 7 A. I had suffered from menorrhagia for some years, heavy There was a broadcast about the growing information 8 8 periods for those who don't know what that is, lots of about the transmission of HIV via blood transfusion, 9 9 heavy bleeding. I was treated with hormones and other so I was lying there feeling a bit like a rat in 10 types of treatment which didn't work for me. I was 10 a trap unable to move and then I started to have 11

- investigated at one of the London hospitals internally 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 critical degree and it became apparent that I needed 14

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15 a blood transfusion quite urgently at that time. 16 Q. Your statement describes a very vivid memory of the

> circumstances in which you had the blood transfusion. Are you able to tell us a little about that?

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

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

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?

right, and went off and left me to it.

20 A. No. not at all.

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

> 44 (11) Pages 41 - 44

4		whathan was base had a tanastician in the wart?	4		Dallilla statement planes (Barra)
1		whether you have had a transfusion in the past?	1		Dr Hill's statement, please. (Pause)
2	Α.	,,,,	2		I might deal with it simply by reading out to
3	Q.		3		you a passage whilst we try and sort that out. You
4		related in your statement abnormalities or	4		received a letter in November 2016 from your
5		irregularities being reported to you as early as May	5		consultant hepatologist and gastroenterologist
6		1987.	6		indicating that they were going to do a blood test
7	Α.		7		looking out for markers of gynaecological problems and
8	Q.	Was any explanation ever given to you as to what those	8		then they'd see you back in clinic to discuss whether
9		abnormalities were?	9		they needed to do anything further about your liver.
10	A.	-	10	_	Do you recall?
11		probably lost on me. I'm not a scientist. But they	11		Yes.
12		were various aspects, threads in my blood test didn't	12	Q.	Here we are. We have it on screen, thank you. We can
13		hold together, but everybody said started to say	13		see there there's a passing reference to discussions
14		this was through several GPs, three different GPs over	14		about your liver?
15		30 years, "Oh well, I guess that's normal for you."	15	A.	
16	Q.	And no-one ever asked about your medical history, the	16	Q.	I think it's the case that, in fact, the blood tests
17		history of transfusion in the '80s?	17		that were actually carried out included a test for
18	A.	No, not at any time.	18		hepatitis C?
19	Q.	If we come forward in time to November 2016, you were	19	Α.	Yes, but I didn't know that.
20		having various blood tests and scans at the local	20	Q.	That was my next question indeed, Dr Hill. Were you
21		hospital.	21		told you were going to be tested for hepatitis C?
22		If we have on screen, please, Paul, 002407. It	22	A.	No, not at any time.
23		should come up on the screen in front of you,	23	Q.	You can take that down, thanks. How was your
24		Dr Hill, I hope no, sorry, I must have given	24		diagnosis of hepatitis C communicated to you?
25		you the wrong reference there. It's the exhibits to	25	A.	By letter, which was half-opened and not sealed
		45			46
		10			10
1		properly in response I was cross about that and	1	Α.	Yes
1 2		properly. In response I was cross about that and	1		Yes. I think we have the letter you have referred to the
2		I wrote a letter in reply, which I think you've	2		I think we have the letter you have referred to, the
2 3		I wrote a letter in reply, which I think you've probably got on record as well, suggesting that	2		I think we have the letter you have referred to, the follow-up letter, that you wrote on 29 January. Could
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2 3 4 5		I wrote a letter in reply, which I think you've probably got on record as well, suggesting that although I understood that this might be one of a tranche of tests that would take place, it seemed to	2 3 4 5		I think we have the letter you have referred to, the follow-up letter, that you wrote on 29 January. Could we just highlight the second paragraph, please. "To receive such a diagnosis"
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if you were having banks of blood tests, as I was, at each stage, perhaps a bit of information wouldn't go astray so you had some idea of where you were being pointed.

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

- Q. In terms of the actual communication of the diagnosis,
 you think that should be done in person rather than by
 letter?
- A. Of course it should, of course it should, yes.Absolutely.
- 15 **Q.** You did see the consultant after that?
- 16 A. Mmm, after my letter.

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- Q. After your letter. What information or guidance or
 advice can you recall being given about the hepatitis
 C infection, for example, about the risks of
 transmission, further transmission?
- A. Not a lot, really. I don't remember discussing that.
 He did talk to me about priorities and waiting lists
 and so on but I don't think we discussed transmission.
- Q. You had, and have had, a number of other healthproblems which I think looking back now you wonder

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1 GP about something else.

- Q. You've suggested in your witness statement that there might be a link between the hepatitis C and the cancer and you've done some of your own research with the assistance of your husband, who is a retired doctor?
- A. Yes, he found it rather than I did. I can't say I was eager to research at that point. But, yes, he does a lot of reading of research papers, American research papers largely, and he told me that there had been intimations that there may be some links but more than that I don't know. I've since tried to recover this information but haven't been able to find it but I'm -- 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 severity of the pain and discomfort may have been related to the treatment you subsequently have undertaken for the hepatitis C?
- 22 A. Yes, indeed.
- Q. You've also, I think, had a skin reaction. Can youtell us about that?
- 25 A. Yes, my skin started to fall off. It looked red,

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

- 4 A. Mmm.
 - Q. You have had a diagnosis and been treated for cancer?
- 6 A. Yes.

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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.

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

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- a bit like eczema to start with, but then it sort of
 crept around a bit and started flaking off. I did
 mention it to a consultant in passing but it was very
 much in passing and I was really patted on the head
 and told, "Well, you've nearly finished the antivirals
 now. Let's not. We won't be bothering with it".
 - 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 thehepatitis C?
- 11 A. Yes.
- Q. Then you also describe in your statement a degree of
 bleeding and swelling that you've experienced for many
 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.
 - Q. So there's not been any investigations or follow-ups

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4		to explore whether there's any interrelationship	1		the concer on the statistics given me. I was told
1 2		to explore whether there's any interrelationship between that	2		the cancer, on the statistics given me, I was told that the monthly budgeting had changed and that we
	۸	Even now, no, although I have mentioned it recently.			
3			3		were now up to four, sometimes five tablets a day. So
4	Q.	Then you've also been suffering from high blood pressure?	4 5		that's what I would be getting. So that's as it was,
5	٨	·			but I reacted so badly to the Ribavirin that I could
6		Yes, that's a new thing.	6		only tolerate it for about ten days and I had to come
7	Q.	Which again you have attributed in part, not I think	7		off it.
8		in full, but in part to the stress arising from the	8	_	It was a very weird experience.
9		belated diagnosis and the treatment that you have had	9	Q.	So you had your diagnosis of hepatitis C in January
10		to undergo for it?	10	_	2017?
11	A.	Yes, I didn't know about it before. I did not have it	11		Yes.
12		before, as far as I'm aware. I've always had a low	12	Q.	I think was it October 2017 when you started to
13		pressure.	13		receive treatment?
14	Q.	Can I ask you then to tell us about the treatment that	14		Yes, months later after I had had surgery.
15		you received for the hepatitis C. What information or	15	Q.	That's in part because you were having investigations
16		options were given to you about the treatment at the	16		and surgery in relation to the cancer?
17		outset?	17	A.	Yes.
18	A.	Well, the nurses were the star turns in the whole	18	Q.	What other side effects did you experience from that
19		treatment, in my experience, because they seemed to do	19		treatment? How did it affect you?
20		all the work and all the support and all the	20	Α.	Well, the Ribavirin was the worst because, although
21		information, and I was told at the beginning that at	21		you don't feel as you normally feel when you are on
22		the moment they were using a one dose a day treatment	22		antivirals, I think your mind is set on the fact you
23		and how much better it was, but by the time I had gone	23		are doing it for 12 weeks and that's the way it's
24		through the oncology department and been bounced back	24		going to be, but the Ribavirin was almost like an
25		again because I refused treatment, chemotherapy for	25		out-of-body experience, although that sounds a bit
		53			54
1		dramatic. It certainly does weird things to your head	1	Α.	Yes.
1 2		dramatic. It certainly does weird things to your head as well as your body. I know Derek was saying about	1 2		Yes. I think you have had that check-up and you are still
2		as well as your body. I know Derek was saying about	2	Q.	I think you have had that check-up and you are still
2		as well as your body. I know Derek was saying about feeling like flu. It was a bit like walking through	2	Q. A.	I think you have had that check-up and you are still clear?
2 3 4	Q.	as well as your body. I know Derek was saying about feeling like flu. It was a bit like walking through deep water. I can't really explain how it was but it was unbearable.	2 3 4	Q. A.	I think you have had that check-up and you are still clear? Yes, yes, thank you. Obviously you lived for very many years, for decades,
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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 might not outlive him? 11 12 A. Yes. 13 Q. What about the reaction of your children? 14

A. My children were great because they know me and there wasn't -- how could it be other than shock and disbelief really. I mean, everybody's story's unbelievable when you hear the details and they know the sort of life I've lived, so...

19 Q. You tried at one point after the diagnosis20 counselling?

21 A. Yes.

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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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would like to take this opportunity to say?

A. Yes, thank you. I don't think it's particularly helpful at this juncture to start pointing fingers at medical professionals who largely didn't know what they were dealing with when they were prescribing transfusions. That's not where the problem started. But the awareness should have been very much more than it is, has been in the last couple of years, than 30 years ago when we were all in the dark to some degree except people were beginning to know about HIV.

I think it's -- I understand the NHS is imploding and shortages of suitably qualified people to deal with us all, certainly as we age, but we do need to be informed better than we are and I have to say I've spent a lot of time communicating myself between different departments because they just didn't do it or, if they did it at all, it wasn't effectively done and it causes great loss of time and time is of the essence if you're mortally ill.

I think we need to change that and I think that's one of the key things that this Inquiry can do, is to increase that awareness and the fact that the thousands of people out there who, like me, didn't have the least idea that they've got hepatitis C and there may be a whole wave of more work coming from

practised it a bit in the past in part of my life, but I didn't find it helpful. It was abreactive in as much as I would just sit there and cry and I can do 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.

You're an academic who is used to dealing with a lot of words, a lot of text, but so you were able, you say, to complete the form?

A. It did cross my mind that some people might struggle
with it, though, who had not had to do anything like
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.

Q. Dr Hill, those are the only questions I have for you
 but is there anything else that you would like to say
 about your experiences or the late diagnosis that you

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that and I hope it's going to be handled a darn site better than it has been up to now.

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

SIR BRIAN LANGSTAFF: There was just one thing I wanted to ask. When Ms Richards asked you and you said about your children's reaction and how they were just astounded, flabbergasted at what had happened, you said because they knew the sort of life you'd led.

A. Yes.

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10 SIR BRIAN LANGSTAFF: Can you just tell me what you meant 11 by that?

A. I think when the consultant informed me by letter and expressed their surprise, I was given many more tests
I think than lots of people were, blood tests, because
I didn't fit the stereotype it seems to me and he was so surprised that I would have it and that seemed a bit out of order to me to ...

SIR BRIAN LANGSTAFF: What did you think the stereotype was?

A. Well, I assumed from what he said that I wasn't an obvious drug injector and I hadn't been a sex worker and I've only had one sexual partner in a lifetime, so I wasn't maybe what they were looking for. That's a stereotype in itself, I understand that, but I don't understand why you'd express such extreme surprise at

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SIR BRIAN LANGSTAFF: That's all that I was going to ask. 1 finding that I had an infection that thousands of other people have got. 2 2 I am sorry to bring you back to answer that but thank 3 3 SIR BRIAN LANGSTAFF: So when you are calling for greater you very much indeed, Dr Hill. Thank you, Ms Richards. We will take a break 4 4 awareness, you're calling for that amongst people who 5 have no reason to think that they might be infected by 5 now, shall we, until, let us say, 1.40. 6 6 hepatitis C because they haven't turned their mind to MS RICHARDS: Sir, yes, and then we have one witness for 7 any transfusion they might have had. 7 this afternoon, Mr Evans. 8 8 A. Indeed, and one thing that struck me when I was SIR BRIAN LANGSTAFF: Thank you. 9 9 talking to somebody yesterday was that I became aware (12.38 pm) 10 10 because of the sort of household I live in that there (Luncheon Adjournment) 11 was much more public information broadcasting around 11 (1.48 pm) 12 the time that AIDS was becoming known, so like other 12 SIR BRIAN LANGSTAFF: Ms Richards, we have Perry Evans. people who had donated blood before I knew that if I 13 You want to be called Perry. 13 14 had received blood before 1992 if I went back and 14 PERRY EVANS, sworn 15 15 offered to donate I would be turned away, not because Questioned by MS RICHARDS 16 16 I thought there was anything wrong with me but because MS RICHARDS: Perry, you were diagnosed I think as a young 17 child with haemophilia A, classified as mild. 17 I became -- I was within that time margin where it was 18 18 an unknown for thousands of people, so I never did A. That's correct, yes. 19 donate blood knowing that information. 19 Q. Prior to the infection that we're going to come on to 20 But there are lots of people who either didn't 20 talk about, I think you led a pretty active childhood. 21 hear it or have been transfused and infected that way. 21 A. I did, yes. 22 22 Q. What kind of things did you do? But it can become a vicious circle if people who are 23 infected in ignorance went on donating blood, although 23 A. So normal boy things, just running around, playing, 24 I know there are tests now to check the blood, but in 24 certainly at school I did many sports, even though 25 the early days I don't think there was much available. 25 I was advised not to, but boys will be boys and so 61 62 1 I played football and cricket and volleyball and 1 Q. If we could just leave that on screen for a moment, 2 basketball and I did expeditions and stuff like that. 2 please. 3 Q. You were under the care of the Hammersmith Hospital 3 What advice or information, if any, was given 4 4 from the 1960s through to 1984; is that right? as far as you know to your parents about the risks of 5 A. That's correct, yes. 5 any of these products? 6 Q. Then from 1985 you came under the care of the 6 A. There was as far as I was aware there was never any 7 7 Royal Free Hospital in London under Professor advice given associated with the risks to these 8 8 Christine Lee and her team there? products. 9 9 Q. What about to you? You turned 18 I think in 1979 or A. That's correct, yes. 10 Q. You regularly received blood products during your 10 thereabouts? A. Yes. 11 childhood and young adulthood? 11 12 A. I did. I received cryoprecipitate as a child up until 12 What information or advice was given to you then as 13 the '70s. 13 a young adult? Q. I think we can have a look at the record from the 14 A. Again, no advice associated with the risks of these 14 15 haemophilia database. It's 1212002, please, Paul. If 15 products. 16 16 you go down a couple of pages, please. Q. We can see from this record that the type of product 17 We can see, Perry, if you look at the screen 17 given to you changed from time to time. We'll see 18 look at the bottom of that first screen, we can see 18 references to Factor VIII (BPL), and then to Factorate 19 1969 through to 1971 a record of you receiving 19 and then to various other products throughout the 20 cryoprecipitate? 20 1980s? 21 A. Yes. 21 A. Yes. 22 22 Q. Then we can see from 1974 onwards and if we look up Q. Do you recall the products being given to you changing 23 through to the 1980s we see you receiving a variety of 23 24 different factor products? 24 A. I do recall seeing different bottles in subsequent 25 A. That is correct, yes. 25 visits to the hospital. So some bottles might be 63 64

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1 thicker and have a different label on or a different not see a senior haematologist regularly, particularly 2 colour and maybe the nurse would say "this is Hemofil" 2 people like Perry who has only moderate haemophilia 3 3 or "this is something else" and you think, "oh, okay". and does not develop many problems. We have been 4 4 But generically it was the Factor VIII that was particularly concerned because of the development of 5 missing from my body so it never kind of struck a 5 AIDS in some haemophilia patients in the United States 6 6 chord with me to think why are they changing the who have been using pooled factor products which have 7 products all the time. In hindsight, I assume that 7 probably included donation from people who were 8 8 it's to do with kind of their suppliers or their incubating AIDS." 9 9 budgetary contracts that they'd made. Then it goes on to discuss the early signs of 10 10 the disease. That's July 1983. Q. Did anyone ever sit down and talk to you or you and 11 your parents about these changes and why one product 11 Did you ever see that letter? 12 was being used rather than another or whether there 12 A. No. 13 were different risks associated with different 13 Were the contents of that letter ever communicated to 14 products? 14 you at the time that there might be a risk of AIDS in 15 1983? 15 A. No, never. 16 Q. Could we go on to I think it is letter 13 July, the 16 A. No. 17 same exhibit, should be roughly page 5. Could we make 17 Q. Could we go to the next page of the exhibit, please. 18 18 that a bit bigger. Could you just make that more visible. We have here 19 Perry, if you look at this letter here, you 19 an extract from the UKHCDO haemophilia database and if 20 will see it's a letter from a Dr Worsley to your GP? 20 you see, Perry, date last negative 10 January 1984, 21 A. Yes. 21 date first positive 10 July 1984. 22 Q. Could we highlight the last main paragraph, please. 22 Is that material the basis for your 23 You will see it says there: 23 understanding that you were infected at some point in 24 "We have recently been inviting all our 24 the first half of 1984? 25 haemophiliacs to visit the clinic as many of them do 25 A. That is correct, yes. 65 66 1 Q. That gives the date when last tested negative as 10 1 conversation? Who was it with? 2 2 January 1984. Do you recall any discussions about A. It was with Dr Goldman and a social worker at the 3 being tested for HIV at that time? 3 Royal Free. They explained that -- I thought it was 4 A. No. 4 just a routine appointment, so as a haemophiliac we 5 Q. Do you recall giving any consent to being tested for 5 constantly are in hospital for either treatment or if 6 HIV at that time? 6 we're not going in for treatment and we're on home 7 7 treatment then we will regularly go in for check ups 8 8 Q. Do you recall the outcome of any tests being every quarter. So I just thought it was one of those 9 9 communicated to you at that time? to go on just to see how I was but it transpired that 10 10 they started talking about the stuff that had been in A. No. the news about HIV and haemophiliacs being at risk and 11 Q. When was it that you were told that you had tested 11 12 positive? 12 I said oh yeah and then they informed me that actually 13 A. I think it was in August '85, if memory serves me 13 Q. That date is, as you say, embedded in your memory 14 right. 14 15 15 because of the celebrations you and your wife Q. I think you have said in your statement you remember 16 16 that as a date, you and your wife have remembered that subsequently had five years later still being alive. A. Yes. 17 as a date? 17 18 A. Because it was five years on from that date we 18 Q. Could we get up on the screen in the same exhibit 19 celebrated the fact that I was still alive and we 19 1212002 what I think will be page 8 of the exhibit. 20 invited that -- celebrated that with some close 20 It's a letter from June 1990. That's the one, I'm 21 21 sorry, June 1988. If we just look at the first friends 22 22 Q. So that was 5 August 1985 is when you recall being paragraph, if you could highlight that first 23 23 told for the first time that you had contracted HIV? paragraph, please, it's not terribly easy to read but 24 A. Yes. 24 if we pick it up the second sentence: 25 Q. What can you recall about that communication, that 25 "He has mild haemophilia [refers to the factor 67 68 (17) Pages 65 - 68

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.

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

Q. Can you remember what, if any, advice or informationwas 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.

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

9 A. Yes.

10 Q. You can't recall whether that was discussed or not in11 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

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.

10 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?

18 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.
 - Q. We can see, Perry, from the documents that you have exhibited to your witness statement infected with HIV probably from infected blood products in the first half of 1984 but told for the first time in August 1985. Infected with HCV known to doctors since 1986 as non-A non-B but 1990 that you were told.

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

16 A. Mm-hm.

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

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

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

- Q. It does. It answers it beautifully, thank you. You then met Heather your wife in 1987.
- A. Yes.
- 20 Q. How did telling Heather happen?
 - A. Well, we'd been -- started going out once. I mean, I got to know her through the church that we both went to. The interesting thing was that she was never at the church that I went to because her job was doing schools theatre work, so she was in the car all the

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

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

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

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

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

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

- Q. What was Heather's response?
- A. Oh, that's a good one. Well, foolishly I think I said something like, "It's all right, I'm not going to die", which I don't remember saying but Heather swears that I did say this.

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

- 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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- 1 quickly. We started going out in the June or July of 2 '87, I went off overseas for two months in September 3 but I'd said to Heather, "I'll know by the time I come 4 back whether I'm going to marry you". So that's, like 5 -- it's like fast-track marriage really, you know, and 6 then we were engaged by Christmas and then we were 7 married within the year and that being, you know, HIV 8 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 --
- 12 A. Yes.
- Q. -- to meet the consult consultant and the socialworker.
- 15 A. Yes.

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- 16 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

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.

- 8 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 --
- 14 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 18 19 and potentially -- and also HCV drugs that they've 20 used, I always recognised that we were being guinea 21 pigs and I was very, very happy to be a guinea pig if 22 it would -- you know, in the knowledge that I might 23 not come through this but if they learn something and 24 they can use something, or discard something then 25 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
- 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?
- 7 A. Yes, that was like the first generation of 8 anti-retrovirals in 1996 I think and there was only 9 a couple that were around at that stage but the one 10 that I was on, just on occasions, on many occasions 11 you take them but within half-an-hour to an hour you'd 12 see them again, but I don't know. You know, I started 13 to tolerate them more or I managed them better and 14 they started to work.
- 15 Q. Then there came a point I think you were able to go16 back to work around 1997?
- 17 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?
- 22 A. Correct, yes.
- Q. You described that in your statement as a physical andhighly emotional journey?
- 25 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.

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- 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.
 - 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.

I'm not a particularly nice patient when I'm in that mood, but it was extremely effective to the point where they would need to huddle outside my room and have a pre-meeting before they came in to my room to explain what was happening and what the progress was.

So for six months I was on chemotherapy and then I would have a week of rest for my blood counts 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 that long. 24

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One of the drivers for doing it was to try and

next cycle; so yes.

But the devastating thing about having the cancer was that Isaac was just about a year or so, just over a year, and ... yeah, it was hard.

Q. I think you've put it beautifully in your statement, Perry, where you say:

> "I had survived HIV 17 years from being told I had it and we found joy in the birth of our son Isaac", and then you had the devastating news of the 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.

I wonder if we can put it on the screen, please, Paul. It should be 1212005. That is later on, I'm sorry. In that case it's the other photo, please.

- 19 A. I think it should have a spoiler alert on some of 20
- 21 Q. That's it. That's you at the time that we're talking 22
- 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.
 - Q. We're going to play that if we can, I hope. It's a few minutes.

(Video played)

- A. Can I just say that there was some reference to dates while I was speaking and I don't think that those dates were actually accurate whereas the dates you 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 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 What can you tell us about that?

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1	Α.	So periodically I would get these incredible cramps	1		thing and it might be a bad thing. So I just carried
2		which weren't normal cramps but they were excruciating	2		on.
3		kind of doubled-up pain and then they would subside	3		But then I did have to stop after 43 weeks
4		and the hospital couldn't really find out what was	4		because I got some complications whereby I started to
5		going on until August or July/August 1998 when I	5		manifest a de-compensated liver and ascites and portal
6	Q.		6		hypertension so a whole raft of liver disease-related
7	Α.		7		illnesses.
8	Q.		8	Q.	Then August 2008 you were admitted to hospital and
9		receiving treatment for the hepatitis C; is that	9		placed in intensive care and in an induced coma. What
10		right?	10		can you tell us about that?
11	Α.	Yes.	11	Α.	I was going to say very little because I was asleep at
12	Q.	Interferon?	12		the time. I have it on good authority that I was
13	Α.		13		talking rubbish before they took me off to the
14	Q.	Ribavirin, 48 weeks?	14		theatre, apparently, because I had some sepsis at the
15	Α.	Yes.	15		time and my heart stopped when I was on the theatre
16		What was that like?	16		table. They did a laparotomy on me and they took out
17		That was worse than the chemo. It just sucks the very	17		what they could but it all came out in one lump
18		life out of you physically. It's okay for the first	18		because it was all fused together.
19		few weeks because your body is getting used to it but	19		They found a bit of debris in there like
20		you soon get on a very low, kind of a low trajectory	20		something had burst out of my guts and they cleaned it
21		down, and it's not only physical but it's mental.	21		out and they thought, well, we can't see anything,
22		You're depressed, you haven't got any energy, you	22		we'd better put him all back together again. So they
23		haven't got anything, you're short-tempered and like,	23		did that, put it all back in, sewed me up and put me
24		but I didn't I couldn't contemplate stopping. I'm	24		on to ICU.
25		not the type of person to stop. That might be a good	25		Unfortunately, once they'd they wanted to
		85	20		86
		00			00
1		take me out of the induced coma. I didn't want to	1		problems. You've had subsequent hospital
2		come out of the induced coma, so then they started to	2		readmissions?
3		get a bit worried and our vicar, who's now a bishop	3	A.	Yes, yes. So right now every day's an exciting day
4		actually, he came and visited and I had my funeral	4		health-wise. You don't know what your night's going
5		arranged.	5		to be like, whether you're still going to have night
6	Q.	I think we've got a picture. It's the other picture			sweats and so my liver is cirrhotic and so I have to
7		i think we've got a picture. It's the other picture	6		Sweats and so my liver is climble and so i have to
		that we had up you have provided us with, which is you	6 7		
8		that we had up you have provided us with, which is you			be constantly aware of things that may or may not be going wrong.
8 9	Α.	that we had up you have provided us with, which is you in hospital in this time when you were in a coma.	7		be constantly aware of things that may or may not be going wrong.
	A. Q.	that we had up you have provided us with, which is you	7 8		be constantly aware of things that may or may not be
9	_	that we had up you have provided us with, which is you in hospital in this time when you were in a coma. It's lovely. You weren't expected to survive.	7 8 9		be constantly aware of things that may or may not be going wrong. My lungs are extremely damaged because of the
9 10	Q.	that we had up you have provided us with, which is you in hospital in this time when you were in a coma. It's lovely. You weren't expected to survive.	7 8 9 10		be constantly aware of things that may or may not be going wrong. My lungs are extremely damaged because of the bronchiectasis and, as a consequence of that, I had
9 10 11	Q. A.	that we had up you have provided us with, which is you in hospital in this time when you were in a coma. It's lovely. You weren't expected to survive. No, no. I was missing the Olympics as well at the	7 8 9 10 11		be constantly aware of things that may or may not be going wrong. My lungs are extremely damaged because of the bronchiectasis and, as a consequence of that, I had a couple of years ago a number of infections but
9 10 11 12	Q. A.	that we had up you have provided us with, which is you in hospital in this time when you were in a coma. It's lovely. You weren't expected to survive. No, no. I was missing the Olympics as well at the same time.	7 8 9 10 11 12		be constantly aware of things that may or may not be going wrong. My lungs are extremely damaged because of the bronchiectasis and, as a consequence of that, I had a couple of years ago a number of infections but particularly on two occasions the infection was in and
9 10 11 12 13	Q. A. Q.	that we had up you have provided us with, which is you in hospital in this time when you were in a coma. It's lovely. You weren't expected to survive. No, no. I was missing the Olympics as well at the same time. I think you spent quite a few weeks in hospital. Yeah.	7 8 9 10 11 12 13		be constantly aware of things that may or may not be going wrong. My lungs are extremely damaged because of the bronchiectasis and, as a consequence of that, I had a couple of years ago a number of infections but particularly on two occasions the infection was in and around where the scarring in my lungs was which then
9 10 11 12 13 14	Q. A. Q. A.	that we had up you have provided us with, which is you in hospital in this time when you were in a coma. It's lovely. You weren't expected to survive. No, no. I was missing the Olympics as well at the same time. I think you spent quite a few weeks in hospital. Yeah. And months of recovery.	7 8 9 10 11 12 13		be constantly aware of things that may or may not be going wrong. My lungs are extremely damaged because of the bronchiectasis and, as a consequence of that, I had a couple of years ago a number of infections but particularly on two occasions the infection was in and around where the scarring in my lungs was which then resulted in bleeding into my lungs which then meant
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9 10 11 12 13 14 15	Q. A. Q. A.	that we had up you have provided us with, which is you in hospital in this time when you were in a coma. It's lovely. You weren't expected to survive. No, no. I was missing the Olympics as well at the same time. I think you spent quite a few weeks in hospital. Yeah. And months of recovery. Yeah, and I cried when I came out because I didn't	7 8 9 10 11 12 13 14 15	Q.	be constantly aware of things that may or may not be going wrong. My lungs are extremely damaged because of the bronchiectasis and, as a consequence of that, I had a couple of years ago a number of infections but particularly on two occasions the infection was in and around where the scarring in my lungs was which then resulted in bleeding into my lungs which then meant that I was generating a lot of fresh blood, which is not a particularly good thing if you're a
9 10 11 12 13 14 15 16	Q. A. Q. A. Q.	that we had up you have provided us with, which is you in hospital in this time when you were in a coma. It's lovely. You weren't expected to survive. No, no. I was missing the Olympics as well at the same time. I think you spent quite a few weeks in hospital. Yeah. And months of recovery. Yeah, and I cried when I came out because I didn't think I would come out.	7 8 9 10 11 12 13 14 15 16	Q.	be constantly aware of things that may or may not be going wrong. My lungs are extremely damaged because of the bronchiectasis and, as a consequence of that, I had a couple of years ago a number of infections but particularly on two occasions the infection was in and around where the scarring in my lungs was which then resulted in bleeding into my lungs which then meant that I was generating a lot of fresh blood, which is not a particularly good thing if you're a haemophiliac.
9 10 11 12 13 14 15 16 17	Q. A. Q. A. Q. A.	that we had up you have provided us with, which is you in hospital in this time when you were in a coma. It's lovely. You weren't expected to survive. No, no. I was missing the Olympics as well at the same time. I think you spent quite a few weeks in hospital. Yeah. And months of recovery. Yeah, and I cried when I came out because I didn't think I would come out. You did manage to return to work I think in 2010.	7 8 9 10 11 12 13 14 15 16 17	Q.	be constantly aware of things that may or may not be going wrong. My lungs are extremely damaged because of the bronchiectasis and, as a consequence of that, I had a couple of years ago a number of infections but particularly on two occasions the infection was in and around where the scarring in my lungs was which then resulted in bleeding into my lungs which then meant that I was generating a lot of fresh blood, which is not a particularly good thing if you're a haemophiliac. You described all the side effects or some of the side
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9 10 11 12 13 14 15 16 17 18 19 20	Q. A. Q. A. Q. A.	that we had up you have provided us with, which is you in hospital in this time when you were in a coma. It's lovely. You weren't expected to survive. No, no. I was missing the Olympics as well at the same time. I think you spent quite a few weeks in hospital. Yeah. And months of recovery. Yeah, and I cried when I came out because I didn't think I would come out. You did manage to return to work I think in 2010. I did. You had a further course of treatment for the hep C in	7 8 9 10 11 12 13 14 15 16 17 18 19 20		be constantly aware of things that may or may not be going wrong. My lungs are extremely damaged because of the bronchiectasis and, as a consequence of that, I had a couple of years ago a number of infections but particularly on two occasions the infection was in and around where the scarring in my lungs was which then resulted in bleeding into my lungs which then meant that I was generating a lot of fresh blood, which is not a particularly good thing if you're a haemophiliac. You described all the side effects or some of the side effects of the many treatments and drugs you have had to have.
9 10 11 12 13 14 15 16 17 18 19 20 21	Q. A. Q. A. Q. A.	that we had up you have provided us with, which is you in hospital in this time when you were in a coma. It's lovely. You weren't expected to survive. No, no. I was missing the Olympics as well at the same time. I think you spent quite a few weeks in hospital. Yeah. And months of recovery. Yeah, and I cried when I came out because I didn't think I would come out. You did manage to return to work I think in 2010. I did. You had a further course of treatment for the hep C in 2015	7 8 9 10 11 12 13 14 15 16 17 18 19 20 21	A.	be constantly aware of things that may or may not be going wrong. My lungs are extremely damaged because of the bronchiectasis and, as a consequence of that, I had a couple of years ago a number of infections but particularly on two occasions the infection was in and around where the scarring in my lungs was which then resulted in bleeding into my lungs which then meant that I was generating a lot of fresh blood, which is not a particularly good thing if you're a haemophiliac. You described all the side effects or some of the side effects of the many treatments and drugs you have had to have. Yes.
9 10 11 12 13 14 15 16 17 18 19 20 21 22	Q. A. Q. A. Q. A. Q. A. Q.	that we had up you have provided us with, which is you in hospital in this time when you were in a coma. It's lovely. You weren't expected to survive. No, no. I was missing the Olympics as well at the same time. I think you spent quite a few weeks in hospital. Yeah. And months of recovery. Yeah, and I cried when I came out because I didn't think I would come out. You did manage to return to work I think in 2010. I did. You had a further course of treatment for the hep C in 2015 I did.	7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22	A. Q.	be constantly aware of things that may or may not be going wrong. My lungs are extremely damaged because of the bronchiectasis and, as a consequence of that, I had a couple of years ago a number of infections but particularly on two occasions the infection was in and around where the scarring in my lungs was which then resulted in bleeding into my lungs which then meant that I was generating a lot of fresh blood, which is not a particularly good thing if you're a haemophiliac. You described all the side effects or some of the side effects of the many treatments and drugs you have had to have. Yes. Vomiting, osteoporosis, anaemia, memory gaps,
9 10 11 12 13 14 15 16 17 18 19 20 21 22 23	Q. A. Q. A. Q. A. Q. A. Q.	that we had up you have provided us with, which is you in hospital in this time when you were in a coma. It's lovely. You weren't expected to survive. No, no. I was missing the Olympics as well at the same time. I think you spent quite a few weeks in hospital. Yeah. And months of recovery. Yeah, and I cried when I came out because I didn't think I would come out. You did manage to return to work I think in 2010. I did. You had a further course of treatment for the hep C in 2015 I did which resulted in the virus clearing?	7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23	A. Q.	be constantly aware of things that may or may not be going wrong. My lungs are extremely damaged because of the bronchiectasis and, as a consequence of that, I had a couple of years ago a number of infections but particularly on two occasions the infection was in and around where the scarring in my lungs was which then resulted in bleeding into my lungs which then meant that I was generating a lot of fresh blood, which is not a particularly good thing if you're a haemophiliac. You described all the side effects or some of the side effects of the many treatments and drugs you have had to have. Yes. Vomiting, osteoporosis, anaemia, memory gaps, tiredness, fatigue, dizziness.
9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24	Q. A. A. Q. A. Q. A. Q. A. Q. A. A. Q. A. A. Q. A. Q. A. Q. A. Q. A. A. A. Q.	that we had up you have provided us with, which is you in hospital in this time when you were in a coma. It's lovely. You weren't expected to survive. No, no. I was missing the Olympics as well at the same time. I think you spent quite a few weeks in hospital. Yeah. And months of recovery. Yeah, and I cried when I came out because I didn't think I would come out. You did manage to return to work I think in 2010. I did. You had a further course of treatment for the hep C in 2015 I did which resulted in the virus clearing? Absolutely, yes.	7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24	A. Q.	be constantly aware of things that may or may not be going wrong. My lungs are extremely damaged because of the bronchiectasis and, as a consequence of that, I had a couple of years ago a number of infections but particularly on two occasions the infection was in and around where the scarring in my lungs was which then resulted in bleeding into my lungs which then meant that I was generating a lot of fresh blood, which is not a particularly good thing if you're a haemophiliac. You described all the side effects or some of the side effects of the many treatments and drugs you have had to have. Yes. Vomiting, osteoporosis, anaemia, memory gaps, tiredness, fatigue, dizziness.

everything that you've been recounting to us?

A. Good question. Emotionally I think that what it's done is actually sharpened my sense for life and relationships. I tend and have tended for a while now to not worry about small talk so much and I have tried, although I'm not particularly great at this but tried to -- for those people that I have invested in and for those people that I get to meet, I will give them time because I think relationships is something that is worthwhile and life gets in the way of relationships sometimes.

When you go through near-death experiences, for me anyway, it kind of re-balances, it kind of puts things in a different perspective, so I don't -- I tend not to worry so much about things that I probably should worry about but I tend to worry more about people and whether I'm being honest and true to them.

The other thing about emotional impact is for a while at the beginning of all of my illnesses or my infections we didn't share the news with many people because we didn't want to be always the people who had HIV. We didn't want it to be the sole conversation that we had because that would be boring and that would be wearing and we hoped that we were a bit more

that.

Work has been extremely supportive in as much as they, yes, they've stood by me and they understand so... but it's slightly disappointing that I've missed out on certain career progression and also probably associated with that some financial remuneration as well but hey-ho, that's life.

- Q. On the question of travelling abroad you and your family went on holiday to the States to Disneyland in 2014?
- A. We did.
- 12 Q. So what happened?
 - A. I had previously with work gone to America and this was during the time you needed to declare your HIV status because it is a communicable disease, so before you went you needed to get a visa and then associated with that visa you needed to demonstrate you were going to come back and you weren't going to be a burden on the American state, et cetera. In of itself it's, you know, it's not an easy process but you can do it.

In 2014 the visa restriction had been removed and so we went to on holiday to Florida. We were fortunate to have that opportunity and I thought it would be fine. So didn't have a -- I didn't go for

interesting than that.

But there is a definite impact and cost to your friends when you share stuff and whilst I'm and many of you are the ones going through those illnesses, and also those who are no longer here, there is a huge impact on family because they carry you and -- but the focus is always on the patient, the person who's suffering. But I know that I wouldn't be here without friends and family.

- Q. Can I ask you about your work and career and how that's been affected by your diagnoses and your illnesses.
- A. Yes. So I had or have a fantastic job. I'm not there, I'm off sick at the moment. It's challenging, it's interesting, it's intellectually demanding and it's great. I loved it and I felt as though I was making a difference and, you know, I was doing well. But my illnesses have meant that I work for -- it's a global organisation and there are always opportunities to go overseas and, in fact, there's kind of some expectation that you will go overseas so that it's part of your career progression. But that's not -- that's never been a practical option for me, one, because of the medical treatment overseas and, two, because of my health not being sustainable to do

a visa because there was no need because it wasn't a communicable disease listed on their entry criteria but, because of my previous visas on their system, they pulled me to one side. Heather and the kids were left in luggage reclaim or Customs or somewhere and I was taken round into a room and held there for half-an-hour while they tried to see whether I was eligible to come in or not.

It wasn't until I told them to Google entry requirements into the United States that they believed what I was saying, so that was fun.

- Q. You have talked also in your statement about some of the practical consequences of the infections that you have, cost of travel insurance prohibitively high?
- A. Yes. I mean, I think it's -- I can understand why it is so high but I didn't ask to be in this situation and it just seems so -- it just seems so wrong that if you have got multiple illnesses that aren't your --you haven't asked for them, that you're actually then being penalised, you know. So essentially travel insurance, the quotes are family of four can go on holiday but it's actually a family of five, let's say, because your insurance will actually be at least equivalent to another individual adult going on 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 --
 - A. Yes.

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- 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.

Then more latterly, because of the variant CJD,

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actually ask you for some more information.

So it's -- what strikes me is that there tends to be a lack of transparency around the criteria and I don't know why that is but, you know, that's what it strikes me as and also like the level of fortitude that you need to get through the process is -- it wouldn't surprise me if people just gave up, to be honest.

- Q. In relation to the current scheme, the EIBSS funding --
- 11 A. Yes.
- 12 Q. -- what's been your experience in relation to that?
 - A. I think in the previous incarnations of the trust, the Macfarlane Trust and the Skipton Fund, because they had been there for such a long time or relatively long time, I did sense that there were people there who had understood the community a bit more and had a relationship.

With the new body, that isn't there. I guess that would make sense, given that they are all relatively new to the job and they're new to the community. So there's not that level of interaction certainly -- well, maybe others have had more interaction but I certainly haven't.

Q. You have expressed a concern in your statement about

I was not able to get dental care from the first dentist I went to and then had to kind of go to the health authority to actually find someone within the area to actually provide dental care.

5 Q. Can I then ask you, you mentioned the Macfarlane 6 Trust ---

7 A. Yes.

> Q. -- and you've said in your statement that you've had certain payments from the Macfarlane Trust, from the 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.

A. Yes. So I don't have a problem with people being means tested, I just think that sometimes people who are able to save will save because they want to save for their dependants. If you get to a point where you've saved too much, then that will then exclude you from something that you need because on the basis of that then you would need to use your savings because 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.

> I can understand I think that definitely, you know, if funding is available then it should go to the most needy for sure, you know. I don't have an issue with that, I just think means testing is very -- is again another huge hurdle to jump in terms of like you create your own budget for a week or for a month or whatever and demonstrate that you have no residual income at the end of it. Okay, where do I start?

- Q. Perry, those were my questions for you but do you have anything else you want to say, anything that's not 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 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19	and I wouldn't want to be in your or your shoes particularly because I think you have a mammoth task. I would love and my own desire would be that there is transparency around what's happened in the past so that people in the future can learn and so that some people will be able to get some closure. You can't you know, I think it's impossible to reach closure for those that you've lost when they shouldn't have been lost, so I think that was the only thing wanted to say. MS RICHARDS: I'm just going to turn my back, Perry, and ask Mr Snowdon if he has any questions. No, nothing further. A. Thank you. SIR BRIAN LANGSTAFF: Perry, thank you very much. It's been a privilege listening to you. A. Thank you. SIR BRIAN LANGSTAFF: And thank you, Isaac. What we will now do is we shall take a break.	1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19	MS RICHARDS: We will be hearing again from three witnesses Ms Challis, Mr Nicholls and Ms Ashton. SIR BRIAN LANGSTAFF: So I look forward to seeing many of you, those who can come tomorrow. (3.01 pm) (Adjourned until 10.00 am the following day)
20	I hope that there may be coffee and tea and	20	
21	biscuits already there. I hope I'm not disappointed	21	
22	in that as I was at lunch but some things the Inquiry	22	
23	can't do! We shall go on trying.	23	
24	We shall meet again tomorrow at 10.00.	24	
25	Ms Richards, who shall we hear from tomorrow?	25	
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