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1 Thursday, 23rd May 2019 2 (10.00 am) SIR BRIAN LANGSTAFF: Good morning, Ms Richards. This 3 morning we start with our first witness, who wishes to 4 5 be known as Nigel, does he? MS RICHARDS: Sir, that's right. Nigel Hamilton. 6 7 **NIGEL PETER HAMILTON (sworn)** 8 Questioned by MS RICHARDS MS RICHARDS: Nigel, you have a twin brother, Simon, whom 9 10 we heard from yesterday. A. Yes. 11 12 Q. And you too were diagnosed with haemophilia as a child? 13 14 Α. Correct. Q. You have haemophilia A? 15 16 A. Yes. And until I think relatively recently you have 17 understood your haemophilia to be classified as mild? 18 19 A. Yes, that's correct. 20 But you now understand it may be more correctly 21 classified as moderate in terms of its severity? A. Yes. I can explain that. I have referenced in my 22 23 medical records. That in itself, getting those 24 records, was a bit of a battle, but with the support 25 of both my twin brother and my solicitors' firm we 1 hospitalisation and you were given Factor VIII on that 2 occasion as well? 3 A. Yes. For even mild haemophiliacs in those days it was 4 a scary exercise, both for the medical profession and 5 ourselves and our parents. It was suggested by the 6 school of dentistry that we would have spacing. So 7 perfectly good teeth had to be removed to allow us to 8 have a better grin, and as a result we were both of us

9 in hospital together. They decided to do it with the

> both of us so we had company to each other. On that occasion there was quite a lot of bleeding. I was actually released first and Simon

stayed a little longer than I did, because he had more severe bleeding than I had, but clearly we got Factor

VIII product to help us through that process. 15

16 Q. And then, as a child, you suffered an eye injury, and 17 that led to the development of a squint in one of your

18 A. Yes. That in itself was quite a turning point for me 19

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20 in my life. It had a number of severe impacts. It 21 kept me back from studying. I had to wear a patch.

22 At one stage my father had to remonstrate with the

23 specialist, because he wanted to remove the eye in

24 fear that this may actually cause severe damage to the

other eye in my vision, but with God's good grace we 3

were able to have a meeting with the Trust, and 2 documents which had initially been disposed of 3 reappeared.

> In those documents it identified in one of the correspondence that we were deemed to be mild, in that we were assessed to be mild when they checked our bloods, but in response to various bleeding episodes they identified that there was something that suggested that that wasn't right and we were more moderate.

So that suggestion was in the correspondence, something that we were not aware of, and the fact that the chief virologist had been asked to undertake a study of the wider family group, which also indicated those symptoms, suggested that we were moderate rather than mild.

17 Q. Now, as a young child, you had the kind of minor bumps 18 and bashes and minor problems that one might associate 19 with your condition?

20 A. Yes.

21 And you required Factor VIII products from time to time during your childhood? 22

23 A. Yes, we did.

Q. When you were about 11, I understand, you and indeed 24 25 your brother had to undergo dental work. You required

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1 came through. They retained the eye, and I went 2 through six to seven months of treatment, patching up, 3 and trying to improve the muscular development and 4 redevelopment of the eye itself. 5 It has left me with very sufficient peripheral

vision, but it has also left me with issues in relation to a change in colour, mild change in colour. Green is not green necessarily, you know.

9 Q. In the course of your teenage years in particular you 10 became very self-conscious about that. That 11 culminated in the middle of 1976 with you undergoing 12 some form of eye corrective surgery?

13 Yes. I remember the process very well. I remember the experience and the lead-up to it. [redacted] 14 facilitated that for us, in which she was very 15 16 diligent. My parents and myself met on a family haemophilia day in Craigavon Hospital, and we met with 18 the then Professor Archer, who was dealing with the 19 eye issue for me.

> In the records, quite clearly, there is correspondence between [redacted] and Professor Archer, identifying that he wanted to ensure that when I did go for the procedure, it would not interfere with the schooling that I was having. So I had the procedure on 13th July 1976. I was 14 years

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of age. Q. If we have up on screen, please, 2340008, we can see the Factor products that you were given around the time of that surgery. So we have got the date there of this letter, 6 August 1976. The first paragraph refers to the surgery which you had and then we can see in the second paragraph:

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"He was given Kryobulin cover pre-operatively and for ten days post operatively ..." and so on.

So you received Factor products to accompany that surgery in the way described there?

Yes. The medical experts determined that was an essential aspect of the procedure and they wanted, as they always did, diligently, to provide sufficient cover that if a bleed did occur, it could be controlled and it wouldn't cause further damage to the actual procedure itself.

SIR BRIAN LANGSTAFF: Could we just go back up to the top 18 19 of that? Yes, thank you very much.

20 MS RICHARDS: Nigel, bearing in mind you were still 21 a child, albeit in your mid-teens at that stage, were 22 you or your parents, as far as you are aware, ever 23 given any information or warning or advice about any 24 risks of blood-borne viruses associated with the use 25 of Factor products.

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1 and safe. Obviously, as you know, Nigel, those are 2 issues that the Inquiry will be exploring at later 3 stages.

4 A. Yes, I appreciate that.

- 5 Q. So as far as you were concerned, the operation was 6 a success. You got on with your life. You finished 7 your schooling and you went to university?
- 8 A. That's right. I did.

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- Q. Then, in or around 1984 or 1985, you were invited to 9 10 attend, along with a number of others, a meeting at the Royal Victoria Hospital. What can you recall 11 about that meeting? 12
 - A. Aspects of that meeting are indelibly imprinted on my mind. The issue itself was something that was coming to the fore through the press. It was on TV. It became evident that there was a virus, the source of which they weren't sure, but the impact of which was very serious. We were, as haemophiliacs in the community of haemophiliacs, with families throughout Northern Ireland, we were asked to attend one of a number of group meetings that were being held.

These were in a closed forum. I remember very well, we went into the room, which I believe in [redacted]'s statement indicates it was a lecture theatre. I would concur with that. I remember it was

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A. No, we weren't. Our initial desire, and my parents, as my guardians, made it clear to [redacted] that it was only to be a procedure if at that stage it would be safe. I was a young teenager. I was at Belfast Inst. We were going out and starting to go out with girls from sister schools, for want of a better phrase, and I didn't want to be the odd boy on the block. I didn't want to be the guy with a squint, "Cock-Eye". I wanted to be the guy that was the same as everybody else, just slip into the group. I felt it essential for me and for my self well-being that I was given the opportunity to do that. That's why we had the procedure.

In relation to the treatment and the pre-meeting, which I vaguely recall, it was made evident that the procedure would be provided and sufficient cover would be given, and it wouldn't be a major problem, and therefore, between the two consultants, it was determined, the date was set, and we took the procedure.

21 Q. It is right I should point out that [redacted], in her 22 witness statement in response, has said that: "Such 23 facts as were known about the treatment in 1976 were 24 given", she says, but she says that the use of 25 products at that time was considered to be effective

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a two-doored chamber. There were probably I would have thought from my recollections about 40 to 50 people, maybe slightly more. We were comfortably in the room.

[redacted] came in with Frank Jones, the then registrar, and Kaye Farrell, the then out-patient sister. She conferred with us on concerns that she had and checks that she wanted to make to be sure that we were aware, or she was certainly aware and the medical staff who looked after us, that if this virus was contaminating any of us, that they would have a record of that.

There were several elements of that meeting that I found strange, given the fact that there was a considerable amount of hype as to who may have been sources in the press in relation to the contamination of individuals with the AIDS virus, as it was then known. One of those was that [redacted] gave us the choice, and that has been referenced in previous witness statements and in evidence given, and there are medical records, that she wanted to know, and medical staff would take our bloods and test us, but it was up to us to decide whether we wanted individually, or as families, to be told.

(2) Pages 5 - 8

- 1 a strange exercise in itself. It seemed to me, as 2 a young man starting out in life, and I was in my days 3 in university, I felt such a critical issue would be 4 something that we would definitely individually and as 5 families need to know about. We would need to be 6 aware if we were infected with something that had 7 potentially catastrophic impacts.
- 8 Just pausing there, Nigel, is this right, and it is 9 what you suggest in your statement: the reason you thought it was strange to have the choice left was 10 11 because of the wider public health implications, if 12 somebody who was, in fact, infected with HIV did not 13 know about that?
- 14 If somebody chose not to be told, they were 15 a potential time bomb or hand grenade. They could 16 have infected a number of other people. And we have 17 seen situations in previous years, past years, where 18 individuals who have made a decision not to inform 19 potential partners from a social event and intimacy 20 have found themselves, when identified as carrying, 21 but not informing, have found themselves under the 22 duress of the legal system. That makes sense to me. 23 It would have made sense to me at the time. Why would 24 I want to walk round infecting people? If I had 25 something, I would want to know.

reason why that was done was to ensure nobody else came in, because this was quite a sensitive issue, a potentially very sensitive issue, and that in order to allow us to deliberate this matter before she returned and no-one would interfere by coming in and catching maybe someone talking and saying something or being aware of what that issue may have been, because there was a fairly high degree of secrecy outside the community. It was important that we were given the opportunity to do that in peace, without any distractions.

She did come back in, and then, from my recollections, we were individually taken and blood tested, and then the opportunity had been given to us to come back, if we wanted to know, or not come back if we didn't.

17 Q. And your choice was to be informed?

- 18 A. I thought that was the most responsible thing for me 19 to do, as an individual and also as a member of 20 a wider society.
- Q. Your HIV test was negative? 21

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- A. Yes, it was, bearing in mind I think that the HIV 22 testing only really was effective from 1984. 23
- 24 Q. Now, you have also explained in your witness 25 statement, and I don't propose to go to the detail of

Q. So you have a memory of the meeting and physically

2 where it was, and that there were lots of people

3 there. [redacted] came in and spoke in the way you

4 have described. What, if anything, can you recall of

- 5 what then happened.
- 6 A. You mean post-meeting?
- 7 No. Do you remember anything else about that meeting itself?
- 9 A. Yes. One other element that I found strange, but that
- 10 added concern to me, was that [redacted] decided to
- 11 retire from the room, as she had stated. She
- 12 indicated she wanted us to talk about this as a group
- 13 of people, and share our thoughts and decide, because
- 14 we were invariably going to be the potential positives
- 15 and negatives. She retired from the room with Frank
- 16 Jones and with Kaye Farrell. I remember the two doors
- 17 being closed. Now, it is in my mind that the doors
- 18 were locked.
- 19 Q. And it is right to say [redacted] says in her
- 20 statement that that's not the case. They were not
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- 22 In [redacted]'s statement she does not recollect that. Α.
- 23 In my statement I do.
- 24 Q. Yes.

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Now, I could be mistaken, but it has stuck with me the 25

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- 1 it, because it is there in writing, but you have
- 2 identified a range of other Factor products that you
- 3 understand that you received over the years, in
- 4 addition to the Kryobulin that we have seen from 1976?
- 5 A. Can I say the directorate that [redacted] ran, as
 - a haemophilia director, sought product within the
- 7 means of her budget, and there were a number of
- 8 competing pharmaceutical companies who were very keen
- 9 to ensure that their product was listed. As a result,
- 10 I, along with others, would have tolerated some
- 11 aspects of the side-effects of some of those, because
- 12 there were side-effects in the early days. It was
- 13 probably deemed necessary to ensure that there were
- a variety of products, so that they would be more 14
- 15 sympathetic to the victim or the individual who was,
- 16 as a patient, taking those products, and they would
- 17 have a minimum effect as side-effects. That would be
- 18 my understanding of why.
- 19 You began work in 1987 --Q.
- 20 A. Yes.
- Q. -- or thereabouts? 21
- 22 A. Yes.

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- Q. 23 Obviously, at this point, you understood that you did
 - not have HIV, and you were unaware of any other
- 25 infection that you might have received?

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- Yes, that's correct. That's correct.
- 2 Q. You married, you started a family?
- 3 A.
- Q. But you became aware, without realising their 4
- 5 significance, of certain physical symptoms over these
- 6 years. What kind of symptoms were they?
- 7 A. I started work with a company that required me to be
- 8 based in the UK mainland. I went into the sales arm
- 9 of that company. Needless to say, England is a much
- bigger place than Northern Ireland, which is probably 10
- 11 the size of Yorkshire. So I was given quite a large
- 12 area to cover, and it became increasingly larger, as
- certain staff were paid off and certain staff 13
- 14 retained.
- 15 So I was covering a vast area from Lowestoft and 16
 - Norfolk, up to the Watford Gap, and from the Watford
- Gap up to Birmingham. I had a young lady, as 17 18 an aside, who was my inside sales rep. She would, as
- 19 they did, set my appointments based on the maps. So
- 20 we would have three or four cluster appointments in
- 21 the same area. It is not so easy when industry is
- 22 spread over a larger area. I may have had one
- 23 appointment in Oxford, I may have then gone to
- 24 Lowestoft, I may have headed up to Cambridge and then
- 25 headed home. I was usually setting off about 5 or
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- 1 and tired, and bound by colds and lethargy. I was,
- 2 though, working hard and assumed I was getting run
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- 4 A. I can give you an anecdote on that. There was a chap
- 5 who was a good runner. I had rode a lot when I was in
 - Northern Ireland, before I had gone to work, and I had
- 7 been very fit. As a young man, I was very fit.
- 8 My brother and I were oarsmen. We competed at
 - a fairly high level. I gave that up when I went to
- work in England. 10
 - I wanted to keep myself fit, because I was
- 12 eating chocolates, travelling distances, sitting in
- 13 a car in traffic jams, etc, and had to have my wits
- about me. The natural form of relaxation would have 14
- 15 been to run. I lived in Derbyshire. I lived in
- 16 a nice area in the Peak District. I had a neighbour
- 17 who was a good runner, and he made me compete with
- 18 him. That stopped after a short time, because I just
- 19 didn't have the energy to even put my shoes on.
- 20 **Q.** Now, there came a point at which you were violently

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- 21 sick, violently unwell. That led to you seeing
- 22 a consultant in Newcastle, and you were given
- 23 information then about your health?
- 24 A. Yes.
- 25 Q. What can you tell us about that meeting?

- 6 o'clock in the morning. The average week for me was
- 2 about 2,000 miles.
- 3 Q. So you were working very hard and you had a young
- 4 family?
- 5 A. Yes.
- Q. And you were travelling a lot? 6
- 7 A.

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- 8 You put down the fatigue and the lethargy to those
 - life events. Is that fair?
- A. Yes. Bringing up a young family, at this stage we had 10
- 11 one and then two children, it was difficult for both
- 12 of us. We had to set our schedule, my wife looked
- 13 after the kids when I was working, obviously, and at
- 14 weekends she expected, quite rightly, as I did, to
- 15 spend time with her and with the kids. I was climbing
- 16 literally out of the car seat and on to the sofa.
- 17 I was butchered. I thought it was because of the
- 18 mileage and I always thought, "Yes, okay, but you are
- 19 holding your job down. Just keep it up. You are not
- 20 used to big miles. Northern Ireland is not a big
- 21 place". A large travel in Northern Ireland might be
- 22 from Belfast to Enniskillen. That would have been
- 23 half the journey to the first appointment.
- 24 Q. The way you put it in your statement was this:
- "I was aware of becoming more easily fatigued 25

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- A. Just to set the scene, I had progressed from sales rep 1
- 2 to regional manager for the company, looking after
- 3 Scotland, Northern Ireland and the south of Ireland
- 4 and the north-east of England. I was travelling
- 5 a lot. I had gone from Newcastle up to the Loch Ryan
- 6
 - area, where we had an office and we were closing that.
 - I found myself taking staff out for a meal.
- 8 I developed that evening, and had to get the hotel
- 9 doctor to come, a severe sickness of the stomach.
- 10 I think it was food poisoning. I will not say which
- 11 restaurant I was in. Suffice to say, I was violently
- 12 ill and I was really quite concerned. It was
- 13 an experience I had never had before. Being
- a haemophiliac, I was quite concerned. Some blood was 14
- 15 brought up. I was then travelling over to Northern
- 16 Ireland and down to the south on business, and I found
- 17 myself quite, quite unwell, light-headed, in a lot of
- 18 pain, but I didn't let that stop me.
- 19 When I was over, I went to [redacted] and
- 20 I called in to say "Hi", see some of the staff and 21 just say this was happening in my life. I took the
- 22 opportunity to say to her, "I have had a problem.
- 23 I was violently ill. Can you check it out?" and she
- 24 did. She had an inspection done for me, on
 - oesophageal inspection, and they identified that I had

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She gave me the choice of having it resolved there or having it resolved in the UK mainland, where I lived, and I elected to do that, because that's where my family were. So I cut my journey short and went back. She had already contacted Dr Jones, and I went in and there was a bed for me in the Royal Infirmary in Newcastle.

Following the procedure to resolve what was a minor tear, but for a haemophiliac continual seeping bleed, I found myself being called into what was more or less a broom cupboard, a small meeting area, which was part of the original Victorian ward. So I sat down. I wondered what this was about. This medical doctor came in with a big pile of records and introduced herself as a [redacted] who was a hepatologist in the Freeman Hospital. All news to me. I didn't know the Freeman Hospital existed, but it became evident that it was quite a serious issue that she wanted to discuss.

She led me through, by asking me if I had heard of hepatitis, and I said I had. Had I heard of hepatitis A and B? I said "Yes". "Have you heard of non-A non-B?" I said "No". She said, "I regret to tell you you have been infected with hepatitis C". My

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- Q. -- did you know that your medical records had been 1 2 shared between Belfast and Newcastle and passed over 3 in that way?
- A. No, I wasn't aware of that. I hadn't been involved in 4 5 that process.
- 6 Q. The first that you knew that you had hepatitis C was 7 this diagnosis being given to you by the consultant in 8 Newcastle?
- A. Correct. 9

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- 10 Q. You think about 1990?
- 11 Yes. I believe it was around 1990.
- Can you recall whether you were given any further 12 13 information about the condition or the risk of passing it on, or the prognosis, or anything like that? 14
 - A. Yes, I did chat with her about the situation. Her reasoning for meeting with me was to recruit me to a study she was carrying out with newly being tested treatments. I felt it was necessary to sign up to this. I wanted rid of this virus. She made me aware of some elements of what it would have done if it was allowed to pertain in my system.

I then was recruited by her to attend on Mondays, over a protracted period of months. The objective was to take treatment, which I was giving myself -- in fact, at that stage they were giving

first response was, "No, I haven't". She said, "Yes, you have". I said, "Have you evidence?" She said, "Yes, I have". I asked her when that had begun.

She produced from this batch of files blood tests, and she was able to show me when I received and from what batch I received, and when I was infected, and that was on 13th July 1976, the day I had had my procedure. I realised then that they were my medical records, and I questioned her on why she had my medical records and I had not seen any of this. She said that she had sought those from my consultant haematologist, [redacted]. They were both conferring about my health. At that stage they were obviously aware that there was an issue that had begun back in 1976, bearing in mind I believe that that was now 1990.

This was news to me and, as you can imagine, the very first experience of hearing this left me in total shock. My first anxiety was to my family. If I have had this for that length of time, and I now have four sons and a wife, are they infected as well? And I had to break the news to my wife.

- 23 Just sticking for a moment with the consultation with 24 the doctor in Newcastle --
- 25 A. Yes.

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1 it -- and then to go, while I was working in Morecambe 2 area, to travel in to the Freeman Hospital, give my 3 bloods, and they could then assess whether the 4 treatments were having the right impact or whether 5 they weren't.

Q. Now having been told this, you say in your statement: "To say I was devastated could not describe my

feelings in that instant."

You made contact with [redacted], and went back to see her again in Northern Ireland. What, if anything, can you recall about that meeting?

Well, I decided it was essential. I could travel back 12 13 and forward on business, but I took time to go myself. I contacted [redacted] to say that I was coming over, 14 that I had some questions for her that I needed 15 16 answers to, and we agreed to have a meeting. 17 I sensed, and I recall sensing when I met with 18 [redacted], we had a cordial meeting at the beginning, 19 but at one stage, when I had to repeat my insistence 20 that I wanted to see where exactly and when exactly 21 I was infected, she was reluctant initially, stalling 22 initially, I think is probably fairer, and she 23 produced the files. We had them on top of -- in the

24 area where we were, we were quite private, and there

25 was a panel, like a desk this size, and my records

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would have probably gone to about there at that stage.
They are a lot bigger now, and about that height. She
went through one of the piles, and she knew where it
was and when it was. She pulled it out and said
"There it is". I said "Thank you, thank you for
showing me", and it corroborated the information I had
already seen when I was in Newcastle.

Q. Could we just have up on screen, Paul, a further

Q. Could we just have up on screen, Paul, a further document. It is in exhibit 2340013. If you can go to what is about page 19, please, Paul. No, next one. That's it, thank you.

Nigel, this is from your records and you have exhibited this to your statement. It is a letter from [redacted]. It is written for the purposes of insurance, it would seem. It is dated November 22, 1993. I just wanted to ask you to look at what's said in the second paragraph, where it says:

"He is positive for hepatitis C, which was previously designated non-A non-B hepatitis. A positive result was found in this centre in 1990, and confirmed in Newcastle in 1991."

So that record suggests that the diagnosis was first discovered in Belfast and then confirmed in Newcastle?

A. I would concur with that.

is 2340012. If we go to the next page. So if we just have the first paragraph highlighted, please, under the heading "Diagnosis". This is a much later document, Nigel, that you have exhibited to your statement, but we can see here, if we pick it up from the end of the first line:

"... Interferon monotherapy 1995 with no response."

So this looks as though you underwent an initial trial, and then a course of treatment in 1995 with the side-effects you have described.

12 A. Yes

- 13 Q. And not successful?
- 14 A. Yes.
- 15 Q. Then, in 1998, you underwent dual therapy, Interferonplus Ribavirin, but relapsed post-treatment.

Just pausing there, your statement explains one of the many side-effects you experienced involved mood swings and personality alterations?

A. Yes, it certainly did. You are never prepared for this sort of thing when it comes. You are living through the middle of it. You don't necessarily realise it is happening to you, but changes were certainly taking place. Issues that were insignificant became critical. I became opinionated.

Q. But you were only told by the consultant in Newcastle?

2 A. Correct.

Q. Thank you. Now, in addition to that initial trial of
 Interferon, which you started in the circumstances you
 have described, you then went on to undertake four
 separate courses of treatment for your hepatitis C?

Yes, I did. I had what I was told was parent group 3, which was common to the European location that I was in. They said it could be specific to certain treatments to reissue. My first experience on the treatment with [redacted] was I'd probably say difficult. I was holding my job down. I had cooperation from my firm to take the Monday morning, but, of course, I had to make it up before the end of the week. As a manager you have responsibilities. I didn't want to be looked at as being different than anyone else, and that I could hold my corner up. So the treatment was difficult. I had headaches, 'flu like symptoms the whole way through that process, shakes, temperature rises, temperature falls, nausea,

which could be difficult and embarrassing, I also had

diarrhoea. Not easy when you are travelling distancesin a car.

Q. If we look at another document, which summarises thevarious courses of treatment you underwent, Nigel, it

I became defensive. I became offensive. I felt the need to state my case more rigorously than I should have done on many occasions. While it was a daily occurrence, it wasn't constant. In the first episode, it had very serious detrimental impacts on my career, and I was not getting any support to deal with the side-effects. I was modestly told about them, and told that they were different for everyone, but I went through a process of hell.

In the second, I had months of renal problems. I was through seven or eight different types of antibiotics to resolve the problems, and they never did. So I lost a lot of time not working during that period.

On the third, I took anti-depressants, because it would make me quite depressed. It would make me I suppose feel sorry for myself.

On the final one I had less issues in relation to my mental state and emotional state, but it completely floored me in relation to white blood cells, energy, sleep. One of the big issues that was becoming evident to me, and it was explained to me that the hormonal management within the liver was not as it should have been with a normal patient, and as my liver continued to deteriorate and degradate,

24 (6) Pages 21 - 24

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I found myself getting maybe 3 or 4 hours sleep. I might get to sleep at 5 o'clock in the morning.

All of that had a direct impact on my personality, needless to say, on my patience, and on my ability to carry out a normal life.

Q. Having undergone that second course of treatment, in 1998, ultimately without clearing the virus, you relapsed post-treatment, you continued to experience the symptoms of hepatitis C.

Then, in 2004, you received a letter, which we will put up on screen. It is 2340010, please. This is the notification in relation to vCJD?

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- 14 Q. What, if anything, do you recall about receiving this 15 letter and the impact upon you?
- 16 A. Just before that, can I say at this stage I was living in Northern Ireland, after the break-up of my marriage 17 18 or the breakdown of my marriage, as a result of the 19 treatments that I was on, and the nature of my 20 personality under those treatments, and the concern 21 and anxiety of my wife that, while not infected at 22 that stage, her and the children were still 23 vulnerable, living with a virus-carrying individual.

So I looked then and found that in this correspondence that vCJD had become an issue. It was

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1 consultant that I would not go in in the morning, 2 I would go in last in the afternoon.

3 Q. Again, you describe it very vividly in your statement,

that you would have staff masked up, medical kit, once

5 used, discarded or sent for high power cleansing. You

6 recognised the need to follow protocol but it was both 7 soul destroying and embarrassing to have to sign

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documents and watch nurses, dentists and other medical

staff mask up and kit up to deal with me. You

10 explained it both humiliated and angered you. It was

very obvious why it was that people were taking these

precautions? 12

- 13 Yes. Can I say I adopted to the protocols
- reluctantly, but the best way for me to handle that 14
- emotionally and mentally was to say that, "I don't 15
- 16 know what you guys have got", and I used to say this.
- 17 "I don't know what you guys have got, but thank you
- 18 for protecting me from what you may have".
- Q. Now, in 2006, you underwent the third course of 19
- 20 treatment, and again you relapsed post-treatment, so
- 21 that third course was not successful in clearing the
- 22 virus?
- 23 A. Uh-huh.
- 24 Q. Then in 2007, towards the end of 2007, you had a CT
- 25 scan, which showed cirrhosis. Is that right?

shortly after this that I actually became a UK Trustee for the Haemophilia Society, and sat on a panel with consultants in London. We were debating an issue and treatments around vCJD and its impacts. So this was just the next nail in the coffin for me.

6 Q. You put it this way in your witness statement, Nigel:

7 "In 2004, I was advised that I was one of 8 a number of patients who had received Factor VIII 9 treatment from blood donated by people who later 10 developed vCJD, and was therefore hit emotionally and psychologically by another hammer blow."

11 12 A. Yes, very much so. Can I say -- it may not be 13 referenced later on in your questioning -- I have gone 14 through in excess of 30 OGDs, and every time I had to 15 do an OGD I had to sign a document to confirm that 16 I was aware that I could very well be carrying vCJD. 17 That had an impact not only on me -- I was unclean 18 potentially -- but I couldn't go in as a normal 19 patient. Those treatments, I had to go in last. Very 20 first time I had one of those treatments I sat for 21 four and a half to five hours, because they wouldn't 22 put me in on the date that the administration had

> hepatitis C. So I made the arrangements with the 26

given me, because I was designated as having that, and

1 A. Yes. that's correct. That again was just another nail 2 in the potential coffin. We were heading towards

also -- well, having the risk of that, and also

3 closing the lid pretty quickly after that. I found

4 myself having to face the trauma of another very

5 negative issue, something that was having a major and

detrimental impact on the condition of my health, and

6

7 it was very difficult to deal with emotionally. It

8 probably for me, as much as hepatitis C, was an issue,

9 and haemophilia in one sense as well, where you didn't

10 want to share. I couldn't go into a Council chamber

11 and talk to colleagues and say to them, before we had

12 the meeting, "No, I am not going to have a glass of

13 wine because I have got cirrhosis". They would

automatically assume that I had drunk myself into that 14

15 state. Very few people in society are aware of the

16 difficulties created to the liver by toxins. Alcohol

17 is not the only one. Hepatitis is a major one. For

18 me to have developed cirrhosis was a major concern.

19 I sat with a friend of mine, a very good friend of

20 mine, who is an MP at the moment. We sat in my house

21 with my second wife. We recounted the issue, and we

22 talked about it, and at that stage I wasn't sure

23 whether I should stay in politics or whether I should

24 leave.

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I didn't actually put this in my statement so

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1 maybe you don't want to hear this. 2 Q. No. That's fine, Nigel. 3 A. Okay. We talked about this, and with his 4 encouragement I stayed on. My wife at that stage was 5 pretty concerned about the issues, and I think she 6 also developed doubts in her mind as to whether or not 7 there was some other reason, and that marriage broke 8 9 Q. You have explained in your witness statement how, following the identification of the cirrhosis in 2007, 10 11 you experienced a number of physical health 12 complications, in addition to the ongoing lethargy and pain and so on. Then, in October 2015, you had 13 14 a bleed from the brain? 15 A. Yes. Some say that you can make connections between 16 the treatments that you have and the development of that experience. I was doing business in the south of 17 18 Ireland with a company. I had developed a working 19 relationship through one of the Government training 20 homes in the south, and also with the equivalent body 21 in Northern Ireland, with the company I was working 22 for. We specialised in the off-shore industry 23 petrochemical business.

> I would have done training and travelled to the United States and further afield. I was at a meeting

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I can't have this happening in meetings, or on planes or anywhere else".

He took me in. I made my way back home. As I was coming home, one of the sisters phoned me and said, "What are you going? Where are you?" I said, "I am driving home". She said, "No, you are not. Turn the car round and come back straightaway". The reasoning was that there was more than just a nosebleed. They had done an initial scan and they identified that there was an aneurysm, and also there had been what they suspected was a tumour bleed, and there was.

Q. As you have said, you were prevented from working again as a result. You were restricted to bed and home for a period of some four months, and you experienced a range of side-effects. Your health problems continued. You began to become bloated and generally feeling very ill indeed?

A. I had a protracted, long-term, chronic issue with my liver, which at this stage I was aware of. It was something that I had over the years had to accommodate and come to terms with, and I found myself, really as a result of the shock, I felt, of this experience with the tumour and the aneurysm, I think that almost triggered the virtual total debilitation of my liver,

with a contract colleague from Canada, and I had been taking her round Northern Ireland to see other training companies and introducing her company to them. I found myself suffering from what felt like the onslaught of the 'flu. I would move my head, and then it would happen. She was very aware of this. She could see that I wasn't myself and she could see I had what appeared to be difficulties driving. We stopped and had something to eat, and I wasn't feeling great.

We came back into a meeting and I sat with one of my directors with her, and we were chatting away. Everything seemed okay. I was sitting back thinking "Okay, I have had a decent week. We have got the contract," etc, etc. Then I leant forward and I looked at my director. So I looked, and then it happened, and I was feeling very rocky.

During this period I was experiencing minor nosebleeds, which became prevalent. I didn't think that I had ever had a nose issue or a bleeding issue before. Maybe it was blood pressure. I don't know. That's what I thought. I was in Cork, and it happened. I went straight up to Gary Benson, the consultant haematologist. I said, "Look, you have got to do something about this. It needs cauterised.

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1 and I went into a state of serious ill health, yes. 2

I went from wearing suits like this -- in fact, this was one of them -- to not being able to wear suits, and going in to work in tracksuit trousers and a fleece. My employer, who was very co-operative and very supportive, took me to the side. We sat in the Board room, myself and this other director who I referenced in the Canadian visitors' trip. They were very concerned about my health. They were afraid that they were pushing me to such an extent that I could die, and they didn't want to be responsible for that.

They said, "Look, your job's safe". Bear in mind, I had lost my family. I had lost my self-respect. I had regained it, false summit upon false summit, and then I got the kick again, just when I thought everything was okay. It was far from okay. They said to me, "Look, take time off. Your job is

was gone, and now we are just social but very good friends.

safe". As he and I still joke when we are out playing golf, it was the longest sabbatical he's ever awarded anyone, such a sabbatical that I never went back to work. My job that I had developed within the company

- Q. Now, by this time or around this time in 2015/2016,
 you had undergone the fourth course of treatment, with
 triple therapy, a combination of three drugs over a 24
 week period.
- 5 A. Yes, I had.
- Q. That did have a different outcome, in terms of thehepatitis C itself?
- One of the positive elements of taking treatments that didn't work into the long-term, rested, as was described to me by a hepatologist, it rested your liver. Your liver was not being bombarded and criminalised, damaged. So during the period, the damage would stop, or slow down, and you were given more life longevity to your liver. Then when the treatments had failed, or been unsuccessful, the bombardment started again. So it was respite for the liver, as he described it.

The final treatment that they gave me came a number of years after I wanted to continue to try and resolve, because I was conscious of the fact that my health was getting worse, and I didn't want to go to that final precipice of total liver failure. But the treatment came. It was a practical treatment from their perspective and worth applying funding for for me, because it would work they felt pretty

had life during the life of it, devastating impacts,
and froze me into a stupefaction of a couch potato,
I found myself recovering, and they then could look
seriously at giving me a liver transplant.

- 5 Q. In 2016 you were on the liver transplant list?
- 6 A. Yes.

- **Q.** You underwent a variety of tests over a prolonged period of months in that regard, but you didn't at that stage receive a transplant. Then, at the end of 2017, you were told you had liver cancer in the right lobe?
 - A. Yes. That was an interesting experience in itself. Emotionally for me, it was very interesting. I always felt when I heard someone had cancer, "Oh, my God! God help you! God help that poor person!" I was actually quite elated. The reason why, and that may sound very strange, it was a means to an end, a necessary evil. While I was on the transplant list and told that I was moving up, the treatment froze me, and I found myself then starting to get back into the potential to work. My boss said, "Look, I have got some work for you out in Antwerp. I need a guy that's going to go there and do the business." I said, "It gives me a chance to test myself, to see if I have still got the sharpness that I once had", and to see

successfully on the parent group 3A that I had. So we started that treatment.

I can only liken it to something like an extreme form of chemotherapy. Yes, there was a degree of hair loss. The only place I can grow hair now is just on the lower part of my lip. I went through a lot of nausea. I didn't sleep. Six months I never slept, never slept. I lay on the sofa. In fact, I invested in a large TV, because I said, "I am going to be here for a while". I wasn't allowed to drive. I wasn't allowed to drive because I was not fit to get up and get into the car. My judgment was bad on that treatment. My licence ceased for a period of weeks. I had to fight with Gary Benson and my local doctor afterwards to get it back. But it worked. It was worth of sacrifice.

The importance of that issue was my hepatologist had advised me that they were unwilling to proceed while I was on the list for a transplant, and I had maybe a 20% active liver, but heading downwards at some speed. They said to me that the opportunity to get the transplant rested really, because the cost of a transplant and the likelihood of getting an accurate liver at the time was always slim.

So I took the course of treatment, and while it

if I was up to the job. Could I stay, if I got back into employment, at that level? Could I bring back some self-respect and some self-confidence that obviously I had lost?

So I took on the challenge. We were having our Christmas do in Edinburgh. On the day of the Christmas do, I had to go and see my consultant hepatologist to get the results of a scan test that had been run, one of a number. They thought I had cancer before, with shadows on the liver. It was a monthly occurrence. You took these things. I had, I think, 35 OGDs. I got to a stage where I stopped taking the sedative, because I needed to drive. So they rammed them down, they pulled them out, and I got up, had a cup of tea and went home, or went to work, or did what I had to do.

I found myself then with that issue. Having to tell my colleagues, who waited for me to come and join them straight from the airport, that I had good news and bad news. They wanted the good news. I said, "We are all going to have a cracking Christmas". They said, "Okay. What is the bad news?" I said, "I have got liver cancer".

One man, sitting opposite eating -- because it was a bijou restaurant, a nice Thai restaurant -- it

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- 1 was like something out of one of those comedy 2 scenes -- the fork sort of fell as his food came out 3 of his mouth. He looked me straight in the eye, and 4 thought, "How dare you come into this restaurant and 5 tell us a story like that?" But my colleagues were 6 personal friends, and they wanted to hear the truth, 7 and I had nothing to hide.
- 8 On 12th February 2018 you received an important 9 telephone call to tell you that there was a donor liver available for you? 10

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A. Yes. At this stage I had developed a stable relationship -- at last, thank God -- with a very good woman. Ironically her brother had also had a transplant and she lived in the south of Ireland. She and I were going to take some time and go down over the February 14th period down to a place called Clifton in the south of Ireland and have some time to ourselves.

I was sitting with my dog beside me, my lifelong partner, and the cat on the sofa, draped over it, and I got a phone call at 1.30 in the morning. Having previously been in politics, when you get a private phone call at that time of the morning, it is either the police or it is the hospital. So I answered, and it was a lady from King's College, who said to me that

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a transplant if you are less than 20% of actually staying alive. So you were caught between the devil and the deep blue sea. I found myself a willing accomplice in the process. It was an opportunity to try and restore some sense of normality to my life and give me a fresh start, and I was very grateful that after 19 months this had finally come, and only through the courtesy of liver cancer.

So I went across. After a nine-hour procedure I came out of it in the intensive care unit, which looked like something out of a space movie, fantastic technology that they have developed, and I'm here today to tell the story, and I didn't think I would be. I thought I would lose the opportunity to see the end and get some conclusion to the experiences of the life path that I have had to have, courtesy of the virus.

- Q. You have said this in your statement, Nigel, that after undergoing the transplant and the recovery from it, you returned home to begin the rest of your life.
- I did, yes, and I have pursued that diligently ever 21 22 since, respecting the quality of life that I have, 23 respecting the sacrifice that was made by the person 24 who gave me that liver, and trying to help other 25 people.

they had a liver. I said, "That's fantastic".

- 2 I didn't assume that it was for me, because I had been
- 3 told on several occasions, by my consultant
- 4 hepatologist, that because I had had two treatments to
- 5 resolve or contain the cancer in my right lobe of my
- 6 liver, that I would not find myself in a situation
- 7 where transplant would be practical for another three
- 8 to four months. So I had put that out of my head.
- 9 I said, "When do you need me to come over? Some time
- 10 this week". She said to me, "No, you will be getting
- 11 a phone call from the Air Ambulance", which came
- 12 during the conversation. I said, "Yes, I am getting
- 13 a call now". "That's X from the Air Ambulance. He
- 14 will phone you back. You need to be over here for
- 15 your procedure early in the morning. Have you got
- 16
- your bag packed?" I said, "I have packed a bag. It
- 17 is in the car. I have one in the house. Yes, I am 18 ready to go". She said, "Right".

19 Knocked my neighbour up, told him to look after 20 my dog and feed my cat. He was very generous and said 21 he would. I headed, with a very good friend, and met 22 my brother, Simon, at the Air Ambulance. We got 23 a quality picture, courtesy of the pilot, just in case 24 I wasn't coming home. You have a 20% chance of not

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surviving the transplant. And you really only get

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- 1 Q. Nigel, you have touched on already and you have set
- 2 out in some detail in your witness statement some of
- 3 the many broader impacts that your infection and
- 4 treatment had on your life?
- 5 A. Yes.
- 6 Q. It caused the breakdown of your first marriage, and
- 7 you told us today about your second marriage?
- 8 A. Yes.
- 9 Q. It impacted upon the time that you were able to spend 10 with your children growing up?
- 11 A. Yes.
- 12 And it impacted upon your work, employment and career
- 13 over a number of years?
- A. It certainly did. 14
- Q. Rebuilding a new job and finding a new role in 15
- 16 politics in the way you have described in your
- 17 statement?
- 18 A. Yes, yes.

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- In terms of the broader impacts, is there anything 19
- 20 that you would like to add to what you have already
- 21 told us and what you have set out in the statement?
- 22 A. I have several observations that I would like to make,
- 23 if that's okay with you, Sir Brian. Thank you.
 - I have written them down, because I have been advised
- 25 I do go on a bit, as you are probably aware, but

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40 (10) Pages 37 - 40

23 May 2019

I want to be as succinct as possible, and I want to get the points across. They are important points for me, given the path that I have had and the experience that I have received.

So, first of all, Sir Brian, I'd like to thank you for taking the opportunity to treat us equally in Northern Ireland, and bring here to us the Inquiry. It is a case of Rome not going to Caesar; Caesar coming to Rome, and Rome is very grateful.

In my case, yes, you have referenced it, Jenni, I lost my family, I lost my career, I lost my health and I lost my self-respect. In the early days I saw no hope and no prospect, as the sense of normality wasn't within my grasp.

Upon reflection, I questioned my mortality and recognised it was not within my control. And then the new liver, and with it came hope and expectation. It was a real reprieve, a new life and a future.

While I believe I will never get justice, how can you bring back that which has been ripped from my life, I will through you, sir, and your good judgment, get closure.

To my fellow witnesses, who we have heard so far this week and we will hear tomorrow and this afternoon, I would like to pay tribute for the sharing

If I lived in England, the recognition of my victimhood would be different, but in Northern Ireland, like those in Scotland and Wales, all victims of this same National Health Service disaster appear not worthy of equal financial support during the lifetime of this Inquiry. That's a sad reflection on a government which has now created a hierarchy of victims under the pretence of it being a devolved matter. That to me, as an act, is reprehensible.

If I lived 50 miles down the road, in the south of Ireland, the treatment and respect and recognition would be different again.

So while we still have the Inquiry here, sir, I believe we must press home our case. We are the same as every other victim in every region of the United Kingdom. I am very pleased that our infected and affected community in England have received further recognition, and that the uplift they have received will ease some of the hardship they, like us, experience.

Lastly, while I recognise that the forensic elements and aspects of the Inquiry will take place in the New Year, I for the life of me can't understand why a government seems to me to allow itself to be scapegoated for the sole responsibility of this

of their harrowing and emotional experiences, and they have done this in open forum, as have I, to provide an insight into what this national disaster has done to the lives of its victims and the infected and affected community, and the legacy of trauma and pain it has left all of us to cope with.

So for me it's legacy can best be summed up by firstly, in my case, and I know in the case of many, a legacy of institutional, medical dependency. The paths of lives, like mine, irreversibly altered and influenced by infections introduced outside our control and influence, and in so many cases the apparent unwillingness to share information until years after the damage had begun its assault on its victims.

I call it "the mantra of a mushroom": kept in the dark and only fed with information when absolutely necessary.

Secondly, and just as damning, the legacy and hierarchy of victimhood and, shamefully, a government willing to allow financial support of those very victims, people like me, sons, daughters, fathers, mothers, brothers and sisters, equally infected across the regions, equally affected across the regions, but unequally supported.

disaster, when I believe the corporate pharmaceuticals
have a key role in this tragedy, and are themselves to
degree complicit.
That's all I have to say. Thank you.

MS RICHARDS: Sir Brian, I am not quite finished yet, sir. Before I ask Mr Williams if there is anything further to add, I have been asked by Mr Robinson, who represents the Belfast Health and Social Care Trust and [redacted], to clarify that [redacted]'s witness statement says, in relation to the meeting in the 1980s, to discuss HIV, she says:

"I certainly remember that the room was not locked."

14 I make that clarification.

SIR BRIAN LANGSTAFF: I thought you made that clear during the course of questioning.

MS RICHARDS: I thought I had, but I have been asked to
 repeat it.

SIR BRIAN LANGSTAFF: There is a difference of
 recollection between Nigel and [redacted] on that.

MS RICHARDS: Precisely so, sir. I am just going to ask
 Mr Williams, who, as you know, Nigel, represents you,
 if there is anything further. No.

24 A. Thank you very much.

MR ROBINSON: I wonder, sir, if I could just clarify

44 (11) Pages 41 - 44

1 the point and why I raised it and it's only to -one thing I wanted to ask was this. Going back to the 2 SIR BRIAN LANGSTAFF: Just a moment. 2 meeting which was held between [redacted], two others MR ROBINSON: Yes. 3 and a number of those who had haemophilia and had had 3 SIR BRIAN LANGSTAFF: We have a process for raising 4 Factor product in 1984/85, thereabouts, as you 4 5 points. What we shall do for a moment is we will just 5 remember it in the hospital. 6 6 take a short break so you can go into the witness room A. Yes, sir. 7 here. Mr Robinson can explore with counsel for the 7 SIR BRIAN LANGSTAFF: She left you there to discuss and 8 Inquiry what points he might wish to raise, and we 8 consider what you wanted to do. 9 9 will take it from there. It may mean that you will A. Yes. come back in a moment or two. I have a question of my SIR BRIAN LANGSTAFF: You have told us how they felt 10 10 own to ask you in any event. So you can wait for 11 11 strongly -- at least you feel strongly now that you 12 that. 12 should not have been given that choice, but you would 13 be, as you described, a ticking time bomb. 13 A. Thank you, sir. 14 (Witness withdrew) 14 A. Correct. SIR BRIAN LANGSTAFF: You must have felt that at the time, (11.11 am) 15 15 (A short break) because you say you took the decision to be told, 16 16 17 because you felt that was the responsible thing to do. 17 (11.17 am) MS RICHARDS: Sir, nothing further that I am going to ask. 18 18 A. My attitude has not wavered over the years. 19 Obviously, sir, you indicated you had a question for 19 SIR BRIAN LANGSTAFF: You've indicated you thought it was 20 the witness. 20 the wrong choice to be left with you and it should not 21 SIR BRIAN LANGSTAFF: Yes. We will bring Mr Hamilton 21 have been offered? 22 22 back -- sorry -- Nigel back. A. In my circumstances, if I had elected --23 (Witness returned to hearing room) 23 SIR BRIAN LANGSTAFF: I am not really concerned so much 24 Questioned by SIR BRIAN LANGSTAFF 24 with your view, as this. How many of you were there SIR BRIAN LANGSTAFF: Sorry for keeping you, Nigel. The 25 25 discussing, roughly? 45 46 A. From my recollections, I believe, affected and 1 A. Yes. 1 SIR BRIAN LANGSTAFF: -- just to recall. It seems to me, 2 infected family members as well, I believe in the 2 3 region of 40 to 50 people. It was a lecture theatre, 3 I think, that you probably can't quite remember it 4 as [redacted] has said. 4 now. 5 SIR BRIAN LANGSTAFF: Did anyone say, "How dare you leave 5 A. No, sir, I can't. 6 that choice us with us!" or words to that effect? 6 SIR BRIAN LANGSTAFF: You can. 7 7 A. I know after the deliberations there were views held A. I can't. 8 by both sides, quite strongly. Whether we were 8 SIR BRIAN LANGSTAFF: You can't. So if, on reflection, 9 9 holding those views ill-informed or well-informed at you do recall anything that was said to her to 10 the time I cannot recall, but the feeling that it was 10 challenge her view, and what she may have said in response, could you please put that in writing? It is 11 a potential time bomb indicated to me and others that 11 12 we would need to know. If I had something operating 12 only fair she should have a chance to consider it 13 on my system and I was not aware of it, I would like 13 herself. to know. If the government put a bug into my head, A. I agree, totally. 14 14 I would like to know that bug was there. SIR BRIAN LANGSTAFF: And let us have that in due course. 15 15 SIR BRIAN LANGSTAFF: Did anyone challenge the doctor 16 A. I will, sir. I will give some deliberation to that. 16 17 about leaving you with the choice? 17 SIR BRIAN LANGSTAFF: That's all I wanted to ask. Do any 18 A. I do recollect that I made observations to her at the 18 other questions arise out of that? 19 meeting, and I know others did as well, and it became 19 MS RICHARDS: Nothing else, sir. 20 a little bit of a free-for-all. There were people who 20 SIR BRIAN LANGSTAFF: Thank you once again, Nigel, for 21 were totally against it and others who were totally in 21 coming, and I am sorry for keeping you waiting for 22 favour of it. The reality of it was those personal 22 a few minutes. 23 exchanges would have taken place, I would imagine, 23 A. Thank you. 24 after the meeting was over. 24 SIR BRIAN LANGSTAFF: Well, we will take a break now until SIR BRIAN LANGSTAFF: I am not asking you to imagine --25 11.50.

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1	(11	.22 am)	1		identification, because he wishes to be known as
2	,	(A short break)	2		"Mr I", and nobody publishes anything which might show
3	(11	.54 am)	3		his image. For that purpose I have made a legal
4	•	R BRIAN LANGSTAFF: Now, Ms Fraser Butlin, our next	4		order, a breach of which is treated as a contempt of
5		witness is Mr I, is it?	5		court, and so a breach of which is really quite
6	MS	FRASER BUTLIN: That is correct.	6		serious.
7		R BRIAN LANGSTAFF: Let me remind those of you who have	7		Let me just read it out to you, because that's
8		been here this week and tell those of you who have	8		what I have to do. The press are already aware of its
9		not, as yet, the Inquiry takes seriously the	9		exact terms:
10		difficulty which many people have in talking to the	10		"It is ordered that the name and address of
11		world about experiences which are often deeply	11		witness W1383" to you and I that's Mr I "and any
12		personal. It is important for us to get the best	12		other identifying information, such as the witness'
13		evidence which they can give. That often may involve	13		image or a description of their appearance, cannot be
14		ensuring that when they give evidence, they don't have	14		disclosed or published in any form, unless express
15		the sense that they are speaking to people outside the	15		permission is given by me or by the solicitor to the
16		room in a way which is visible. That applies to the	16		Inquiry acting on my behalf. Witness 1383 must be
17		next two witnesses, the first Mr I, today, whose	17		referred to only as 'Mr I'.
18		evidence will not be live streamed visually, so nobody	18		"This order remains in force for the duration of
19		will see his face. It will be live streamed on audio	19		the Inquiry, and at all times thereafter, unless
20		feed, so that anyone who wishes can see what is being	20		otherwise ordered. I may vary or revoke the order by
21		said by him to you. You will have the benefit of both	21		making a further order during the course of the
22		seeing and hearing what he has said. He is happy with	22		Inquiry."
23		that.	23		Mr I.
24		What it means is that I have to make sure that	24		MR I (affirmed)
25		nobody publishes anything which might lead to his	25		,
		49			50
1		Questioned by MS FRASER BUTLIN	1		products I was
2	MS	FRASER BUTLIN: Mr I, you have severe haemophilia A?	2	O.	In relation to the question that you were being heat
3		Yes, that's right.	3	٠.	treated products or Scottish products
4	Q.		4	Α.	Yes.
5	Α.		5		can you tell us what your mum's understanding was
6		If fact, you had your first bleed when you were just	6	٠	about what was going on?
7	٠.	six weeks old?	7	Α	Mum herself had been diagnosed with hepatitis non-A
8	Α.	Yes, that's correct.	8		non-B after a successful tonsillectomy. She got very
9	Q.	You initially received cryoprecipitate?	9		ill after the procedure and so was aware of the
10	Α.	No, not initially. Within Northern Ireland I have	10		dangers with American Factor VIII. At a young age,
11		always had Factor products. The only time I ever	11		she had talked to [redacted] or the treating
12		received cryoprecipitate was in England, whenever we	12		consultant at the time and they had assured her that
13		were on a family holiday. It was later in life than	13		I would be on either National Health derived products
14		that. Apologies.	14		or heat treated products. So she put the faith in
15	O	No, that's fine. Your parents have recalled that it	15		that that would be what I would be given.
16	٠.,	was in the early '80s that the treatment was changed	16	Q.	
17		over to Factor concentrate?	17	⊸.	why that was?
18	Α.	Okay.	18	A.	Not so much why it was. More so just because of what
19	Q.	•	19		had happened to mum in the past, with her experience

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22 A. Yes, that's correct.

heat treated products, and when they were not

A. Yes, I have, not long after a conversation around it.

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Q. Have you talked to your mum about this?

available you were being given Scottish products?

There may be a mix-up, but it was definitely Factor 25 parents say they were told were as pure as possible"? 52 (13) Pages 49 - 52

of the American products.

21 Q. You have said in your statement you understand that in

around 1983/84 they were trying out heat tested

products, and when they didn't use these, they were

trying to use Scottish products on children, "which my

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- A. Yes, that's correct.
- 2 Q. Was that your understanding of what you were being
- 3 told?
- 4 A. Yes.
- 5 Q. Again, your mum recalls she was told by Dr Dempsey
- 6 that you would never be given American products. You
- 7 would only be given Scottish or heat treated Factor
- 8 VIII.
- 9 A. That's what she was led to believe, yes.
- 10 Q. So you would receive the purest products possible?
- 11 A. Yes, that's right.
- 12 Q. Could we have document 1383006, please. The main
- 13 paragraph -- this is a letter in 1995, where it seems
- 14 that you were a particularly high user of Factor VIII?
- 15 A. Okay.

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16 Q. It says at the start:

"I have been having fun and games trying to procure supplies of Factor VIII from Scotland. It appears there is some difficulty in meeting demands by production. Therefore I have been looking at the usage during the past few months for all the patients."

Your treating doctor is asked to give an indication of whether there is anything special or peculiar going on with you. Were you aware of any of

53

- 1 had hepatitis C?
- 2 A. Yes. That's right.
- 3 Q. And she shouldn't be concerned about it, as you would
- 4 live a long and happy life?
- A. Yes.
- 6 Q. Is that your recollection --
- 7 A. That's my recollection.
- 8 Q. -- or your understanding of what your mum --
- 9 A. My understanding of what it was, yes.
- 10 **Q.** Then, when you were about 6 or 7, your parents were
- 11 called back into the hospital, and what were they told
- 12 about your hepatitis?
- 13 A. I wasn't 100% sure it was that age, but that I had
- 14 cleared the virus, or I had cleared the virus
- 15 naturally. That I think was from [redacted]. And
- then, whenever they went and had a conversation with
- my paediatric consultant, Dr Dempsey, he was furious,
- and furious that they had been told that, and was
- 19 actually very insulted, and said, "You know, this
- 20 virus, nobody has proved this virus goes away. This
- 21 virus has the potential to hide and may be
- 22 undetectable in tests", and not to consider that I had
- 23 cleared it.

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I think then, going forward after that, I was tested very regularly, into my mid to late teens, and

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- 1 these difficulties in relation to Scottish Factor?
- 2 A. No, no.
- 3 Q. Your parents' understanding is that you were given
- 4 infected blood products some time between 1982 and
- 5 1984?
- 6 A. Okay.
- 7 Q. Which is when they were first told you had contracted
- 8 hepatitis?
- 9 A. Yes.
- 10 Q. When your parents were told you had contracted
- 11 hepatitis, you were about 2 or 3 years old?
- 12 A. Yes, that's ...
- 13 Q. What were they told?
- 14 A. I am not totally au fait with the conversation. Just
- sort of going on experience, that yes, I had it. It
- 16 was obviously a concern. Nobody really knew what the
- 17 next stage was going to be, whether it would develop,
- whether it was going to be any further than that, but
- they were told I had it, and that was about the height
- 20 of it I think.
- 21 Q. You have said in your statement that she does not
- 22 recall being given any information about what the
- 23 infection meant for you?
- 24 A. No.
- 25 Q. And she remembers being told that all haemophiliacs

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- 1 a decision was made somewhere along then that, you
- 2 know, yes, it has been undetectable for a number of
- 3 years and that I had cleared the virus.
- 4 Q. You requested a copy of your medical records in autumn
- 5 2018.
- 6 **A.** Yes.
- 7 Q. To try to understand and confirm that chronology?
- 8 A. That's correct.
- 9 Q. Because, as you have said, you were working off your
- 10 mum and your parents' memories?
- 11 A. Yes.
- 12 Q. What in terms of documentation have you been able to
- 13 obtain?
- 14 A. The medical records that I have had made available,
- 15 going through them myself, I found very limited detail
- on why, where or when I did contract the virus, a very
- 17 similar amount of detail for why, where, when the
- 18 virus become undetectable, and any conversations that
- 19 was had around that.
- 20 Q. The details of your treatment in the '80s is simply
- 21 missing at this stage?
- 22 A. Yes, that's correct.
- 23 Q. You were always treated at the same hospital?
- 24~ A. Yes, bar a few occasions maybe whenever we were on
- a family holiday or such like.

- Q. But the bulk of your haemophilia records would be
 with --
- 3 A. Would be with the Royal Victoria Hospital at this4 time.
- 5 $\,$ Q. You said that you have had a recent conversation with
- 6 Dr Benson about records?
- 7 A. Yes, that is correct.
- 8 Q. What was that conversation?
- 9 A. He made it quite clear that a lot of this
- 10 information -- obviously they changed hospitals in the
- 11 late '90s, early 2000s over to the City. There may
- 12 have been documentation that got lost in the move, and
- that they are still turning up details here and there,
- and, you know, there is more details that may come up
- 15 going forward, but they obviously can't make any
- 16 promises on that. It was long before his time.
- 17 Q. But at this stage you don't have those early records?
- 18 A. No, I do not.
- 19 Q. As far as you are aware, you have not contracted any
- 20 other infections, but you are worried about it?
- 21 A. That's correct. On every correspondence you may see
- 22 between my consultant and any other consultant, the
- 23 first paragraph nearly always sets out that I am
- 24 a public health risk, due to the potential of
- 25 contraction of vCJD. That's something you have to try

- 1 concerned that you may have been used for research 2 purposes?
- 3 A. Yes.
- 4 Q. Why do you think that may have been?
- 5 A. Probably because I supposedly cleared the virus
- 6 naturally. I would imagine that there was tests done
- 7 to find out how I had done it. I don't think it was
- 8 a common occurrence that the virus just did go away.
- 9 So I imagine there was research done to find out why.
- 10 If it was for the greater good, that's fair enough to
- me. I have no issue with it at all. I just do recall
- 12 a number of years in my sort of mid teens, there was
- 13 more blood taken than just your regular tests.
- 14 Q. As you said, your hepatitis C was cleared naturally,
- 15 without any treatment?
- 16 A. Yes.
- 17 Q. Could we have document 1383004, and the first
- 18 paragraph of that letter, please. It is a letter from
- 19 1995, dealing with the point that you are anti-HCV
- 20 positive but have normal serum ALTs, but are not
- 21 positive for PCR RNA. It is the medical terminology
- for saying you have cleared the hepatitis C?
- 23 A. Yes
- 24 Q. The next sentence is what I wanted to draw your

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25 attention to:

- 1 to live with at the same time, you know, and it is
- 2 maybe not the nicest thing to see in your opening
- 3 paragraph of an e-mail or a letter about you, you
- 4 know.
- 5 Q. And you have received the correspondence indicating
- 6 that because you had Factor concentrates between 1980
- 7 and 2001, you shouldn't donate blood, organs or semen.
- 8 A. That's correct.
- 9 Q. And you should inform all health care professionals?
- 10 A. That's correct.
- 11 Q. And that concerns you?
- 12 A. It's something you have to live with. It is
- something, you know, the potential is that nothing
- 14 will come of it, but there is always that doubt in the
- back of your mind, or should you start feeling unwell,
- 16 is this something new? Is this something that's
- 17 coming? There is the stigma of having had hepatitis C
- in the past. The conversations that were passed over
- 19 to my parents at the time, you know, that this virus
- 20 doesn't go away. It may hide. It may do this. You
- 21 know, it is something to live with.
- 22 Q. You said that you were tested throughout your teens
- 23 and early 20s --
- 24 A. Yes.
- 25 Q. -- in relation to the hepatitis C, and you are

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- 1 "No-one is entirely certain as to the future for
- 2 such patients, but clearly they do not require Alpha
 - Interferon."
- 4 A. Yes.

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- 5 Q. And you haven't had treatment?
- 6 A. No
- 7 Q. But your understanding is that the future is somewhat
- 8 unclear for you?
- 9 A. That's right. I think hopefully it is clear that the
- 10 virus has gone. I have seen other documents and have
- 11 seen, you know, correspondence that says that
- 12 [redacted] has ...
- 13 Q. Could we stop? There is a three minute delay so we
- 14 should be fine.
- 15 SIR BRIAN LANGSTAFF: Just to remove your name.
- 16 A. It had to be me.
- 17 MS FRASER BUTLIN: I will just go and ask
- 18 What I will do, Mr I, is the tape I think will
- 19 restart now and I will ask the same question.
- 20 A. Yes
- 21 Q. So we should pick up where we were. Okay?
- 22 A. Okay.

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- 23 Q. We were looking at the document on the screen.
 - I asked you: "Your understanding is that the future is
- 25 somewhat unclear for you?"

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(15) Pages 57 - 60

- 1 A. Correct. Again, it is something that you have to deal
- with, but hopefully the future is clear enough that
- 3 there's going to be no repercussions. I have seen
- 4 myself referred to, "A patient who has occasional
- 5 elevated ALTs, but is hepatitis C negative", I believe
- 6 is the medical description that would be in some
- 7 correspondence.
- 8 Q. But you have described being quite unwell because of
- 9 the hepatitis C, or at least because of what you think
- 10 is because of the hepatitis C --
- 11 A. Potentially.
- 12 Q. -- since you were young?
- 13 A. Yes.
- 14 Q. Can you tell us what the physical symptoms have been?
- 15 A. Well, I have always had issues with my stomach, mild
- 16 irritable bowel syndrome, reflux. I would feel more
- 17 fatigued than peers of my own age or sometimes people
- that I work with. It may just be me or it may be down
- 19 to the virus. Again, that's questions that sort of go
- 20 unanswered. Nobody seems to be able to give you
- 21 an answer to it. I have asked, on occasion, have they
- 22 been related, and the best guess is "possibly".
- 23 Q. You have described in your statement that the lack of
- 24 get up and go --
- 25 A. Yes.

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- 1 A. It can do, yes, that's correct.
- 2 Q. Have you ever been offered any counselling or
- 3 therapeutic support in relation to the hepatitis C?
- 4 A. No, not until this Inquiry started, and then the ...
- 5 Q. You have said already your mum is also a haemophiliac?
- 6 A. That's correct, yes.
- 7 Q. I am going to ask you a few questions about her.
- A. Okay.
- 9 Q. Because I know you have already talked to her about
- 10 a lot of her story as well.
- 11 A. Yes.
- 12 Q. She has mild haemophilia A?
- 13 A. Yes.
- 14 Q. As you have said, she was also infected with hepatitis
- 15 C, which she believes was from treatment before and
- after a tonsillectomy in November 1980?
- 17 A. That's correct.
- 18 Q. She developed jaundice very shortly after that?
- 19 **A.** Yes
- 20 Q. And was very unwell for about six months?
- 21 A. Yes.
- 22 Q. She recalls a conversation between the doctors at the
- 23 time. Do you know anything about that?
- 24 A. I know she had a conversation with the surgeon, prior
- 25 to her tonsillectomy, which she did not have with the

- Q. -- has had a big impact on your friendships, and asyou care for your son?
- 3 A. Yes. Maybe -- obviously not as much as other people
 - have been affected that have sat on this seat, but
- 5 definitely there is an issue. There definitely is
- 6 an underlying issue of some description that I don't
- 7 have the same energy maybe as peers my age, and it is
- 8 noticeable at times, and it seems to come and go in
- 9 waves.
- 10 Q. You have also struggled mentally. What can you tell
- 11 us about that?
- 12 A. Again, I think a lot of that maybe relates to that
- 13 nobody knows going forward. So I would probably
- 14 describe myself at times as a bit of a hypochondriac.
- 15 You start feeling sick or something starts going
- wrong, you think "Is this in relation to something?
- 17 Is there something more coming?" Generally, it may
- 18 turn out to be the 'flu, it may turn out to be
- whatever, but there is always that underlying doubt.
- 20 Q. You said in your statement that not knowing the extent
- 21 of the infection and the potential long-lasting
- 22 effects is very daunting?
- 23 A. Yes.

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- 24 Q. And it has made you very paranoid and anxious about
- 25 your health?

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- 1 haematologist. The surgeon asked her if she was sure
- 2 that she wanted to go ahead with the procedure, due to
- 3 the unknown of the product she was going to be given.
- 4 She had not been fully aware of the risk but was
- 5 content that she needed to have the tonsillectomy, so
 - carried on with the procedure.
- 7 She then went on to develop jaundice, feel very
- 8 unwell, and was sent home I think quite shortly after
- 9 her treatment or her procedure. They tested her
- 10 regularly. Maybe a district nurse came out and took
- 11 blood tests and such like off her. I do know that in
- one conversation with her she mentioned that at one
- stage the nurse missed the vein and she started
- bleeding from the puncture wound. The district nurse
- 15 actually dropped the syringe and stepped back. So
- they knew themselves there was more to it than just
- 17 hepatitis or an illness, in her mind that is anyway.
- 18 And she was diagnosed with hepatitis non-A non-B, as
- 19 it was known then.
- 20 Q. Your mum recalls a conversation by her bedside, just
- 21 before she was discharged from the hospital, where one
- 22 of the doctors said "Maybe she's got ..." at which
- 23 point he wrote something on a piece of paper or on his
- 24 hand and showed it to one of his colleagues, and the

other one said, "It is just the junk we have been

(16) Pages 61 - 64

- 1 pumping into her, she is fit to go home."
- 2 A. Yes, I remember hearing about that conversation.
- 3 Q. And she has always wondered what that conversation was 4 really about?
- 5 A. Yes.
- In about 1984, your mum wanted to know about hepatitis 6
- 7 C --
- 8
- 9 Q. -- and whether she was infected. Can you tell us how she came to find out about her diagnosis? 10
- 11 A. I think the media were starting to pick up on some 12 reports of this virus that was hitting haemophiliacs
- and people who had been treated with blood products. 13
- 14 She then took action herself and went to see her GP.
- 15 On going to ask the GP he says, "what the hell do you
- 16 want a hepatitis C test for? You have no chance of
- 17 getting it". So she said that she felt she had, and
- 18 he said, "Okay, I will refer you".
- 19 My knowledge then was that she was contacted by
- 20 [redacted] in the hospital, and brought in, and
- 21 somehow the information had got fed to her that she
- 22 wanted a test for this, in which she was then told she
- 23 had it, and that was how she found out that she had
- 24 hepatitis C.
- 25 Q. It was quite striking for your mum, wasn't it, that

- 1 difficulty sleeping?
- A. 2
- 3 Q. How did that affect you and the rest of the family?
- 4 A. It is always a stress and always a worry. I knew
- 5 obviously from a child, basically, about the
- 6 haemophilia, hepatitis, how it was all related, and
- 7 pretty much how it went hand in hand almost. So
- 8 whenever you go into your teens and your later teens,
- 9 and you start to realise the actual severity and the
- 10 implications of these viruses and what they can do.
- 11 My parents were involved with the local group of the
- 12 Haemophilia Society at the time, whenever I was young.
- 13 A lot of the people you met, you know, older men who
- 14 had had haemophilia, most of them are very seriously
- 15 ill, and it wasn't the haemophilia. It was viruses,
- 16 should it have been hep C, HIV, and it was something
- 17 you learned to develop and grow up with, you know. So
- 18 it was something you were never really scared of, but
- 19 you are very aware.

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- So I suppose going into my later teens and and a lot of them have passed away actually, it is a stress, you know. You always wonder, is there going to be something, is this going to happen to my mum?
- having seen that in my younger days, all of these men, Is she going to get worse. Is she going to develop

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- when she went to the GP to ask about it, the GP
- 2 laughed at her?
- 3 A. Yes.
- 4 Q. When she was requesting the test?
- A. That's right. 5
- Q. And when she was told she had hepatitis C, she was 6
- 7 also told she will probably have a long and normal
- 8 life, and it was just a risk of having Factor VIII?
- 9 A. That's right.
- Q. Your mum has been unwell for a number of years. What 10
- 11 have her symptoms been?
- 12 Similar. She would fatigue a lot easier than others.
- 13 She would have maybe bouts of times where she would
- 14 feel 'flu-like symptoms, just feel generally unwell.
- 15 I believe that a lot of it has been a direct effect
- 16 from carrying hepatitis C for the length of time. It
- 17 definitely has had a negative impact on her health
- 18 and, you know, whatever going forward, I don't know.
- 19 Q. She has had significant lethargy?
- 20 A. Yes.
- 21 Q. She used to think she was just being lazy?
- 22 A. That's right.
- 23 Q. She has also had a lot of stomach and gastro problems?
- A. 24 Correct.
- She suffered from depression and had significant 25

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- 1 more illness? There is always an underlying worry
- 2 there, yes, of course. That spreads to the wider
- 3 family as well. My father would be affected as well,
- 4 I am sure.
- 5 Q. And very practically, it meant that your mum couldn't
- 6 work full-time?
- 7 Yes.
- 8 Q. So she did a number of part-time jobs around what she
- 9 could do and around child care?
- 10 A. That's right, yes.
- Q. So financially it impacted the family as well? 11
- Of course it did, yes. 12
- 13 Q. Your mum only recently underwent treatment for the
- hepatitis C? 14
- Yes. 15 A.
- Do you know why she resisted it for so long? 16
- 17 A. I think there had always been an underlying worry
- 18 about what potentially could come from the Interferon
- 19 treatment. Again, with their involvement in the
- 20 Haemophilia Society and such like, they knew people,
- 21 they knew people who had been through it. They have
- 22 seen the side-effects. They have seen how it could
- 23 affect you in general. I don't think she just didn't
- 24 want to put herself through that.
 - The treatment she received recently was promised

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1 it would be a very simple treatment, there is very 2 limited side-effects. I must admit I pushed her 3 myself to try, or tried to guide her to take it. 4 I had been assured that the treatment was a lot 5 better, and it wouldn't have any negative impact on 6 her, other than hopefully clear the virus and reduce 7 her chance of liver issues going forward.

Q. Your mum has described in her statement:

"Over the years, my haematologist, Dr Benson, has offered me an array of treatment to help clear my hepatitis C virus."

A. That's right. 12

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"I have always shied away from treatment, probably 13 14 having a silly mindset that if I tampered with the 15 virus, it may just turn nasty towards me. I suppose 16 I have lived with the infection in my body for so long it has become part of who I am. After avoiding 17 treatment for many years I was told that I would 18 19 eventually need it."

20 So she did start the treatment?

21 A. That's right, yes.

22 How is your mum now post-treatment?

A. Well, she has been through her treatment and has been 23 told that the virus is non-detectable. Again another 24 25 concern: does that mean it is cleared or it is just

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Q. She recalls that when she was wheeled into theatre, two nurses came forward. One of them grabbed her left arm and looked at it.

> "She said to her colleague, 'Look! Is that a needle stick mark?' while looking at the mark from my blood test. They were very abrasive and I couldn't understand why."

Then when she came to, the nurses were cleaning down all of the equipment, and one of them said, "This is all for you", gruffly. It was only then that it dawned on her that they probably knew of her hepatitis C status and thought that she was a drug addict.

Yes, and I think that is the stigma that's attached to a lot of it, you know. You didn't get it. We were given this. We didn't get it through any foul play or action of our own, you know. It was nothing that we wanted or put -- a risk that we put ourselves through to get. I think that has to be very clear, that, you know, there's a stigma.

I think I said in some of my own statements, but prior to the mid/the early '80s, if you told anybody you had haemophilia, they would have said, "What's that?" Afterwards you told somebody you had haemophilia and the feeling you always got was they may have taken a step back and says, "Oh! Have you

non-detectable and it may come back? As far as how

2 she feels, I think she has actually felt possibly

3 worse since taking the treatment and from after the

treatment as far as aches, pains, feeling lethargic 4

5 and such like goes. She doesn't feel great.

6 Q. Your mum had a particularly terrible -- what she's

7 described as a terrible experience of the stigma

8 associated with hepatitis C when she went in to be

treated for a serious abscess and she was at the

10 School of Dentistry.

11 A. Yes.

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12 Q. Do you know anything about that?

A. I just remember her coming out and being disgusted 13

with the set-up, that she was left to the very last.

15 There was going to be no other procedures after it,

that -- I think everything was covered up. There was

16 17 surgical bags over everything to make sure that, you

18 know, everything was kept uncontaminated. Whenever

19 she recovered or woke up in the recovery, they were

20 basically scrubbing the place around her. You know,

21 it was -- and they had not moved her into a recovery

22 ward. Just the general feeling -- and there is a lot

23 of people sitting in this seat have said -- there is

24 a distinct notion you are unclean, you know, and that

25 is the main stigma.

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1 got HIV or have you got hepatitis?" I think that's

2 a critical point that needs to be sort of put across,

3 that for what was quite an unknown disease, a

4 bleeders' disease, you know, it got a lot of attention

5 in the '80s, '90s and it was all for the wrong

6 reasons.

7 Q. Moving back to you, you've received money from the

8 Skipton Fund?

9 A. Yes.

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10 Q. And continue to receive money from the Northern

Ireland Blood Payment Scheme?

That's correct. 12

13 Q. How have you found dealing with that new scheme?

The new scheme not so good. Previously it was within 14

the -- it was different trusts. So it would have been 15

16 Caxton I would have dealt with in the past, and prior

17 to the regular payments and such starting very rarely

18 ever contacted them. Again you always feel if you

19 have to contact, if you have to ask, you're begging

20 for help and that's a notion that -- you don't like

21 feeling like that either.

> However, with Caxton I went through a bit of a break-up. I found myself on the lower end of having a good bank balance and I did ask for some help. They were very helpful. There was no issue whatsoever.

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(18) Pages 69 - 72

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The same can't be said for the BSO. Now I am not going to criticise the person that you deal with. Very pleasant interaction with them, but -- and I could show you the form -- the initial form.

I used to have a mobility car sort of is the background of it. In the benefit changes I lost it moving on to PIP. So I found myself again in a situation where I was going to have to outlay a significant amount of money to keep myself on the road and I went to them and asked for help.

On the initial form it says that these one-off grants are for to help people with mobility issues, with this, with that. Whenever I went through everything, went through the whole process of filling in your bank details, your incomings, your outgoings, which feels very intrusive as well, I got a letter back saying, "This has to go to the Health Trust for discussion and you should know within the next few days".

My return came back that no, they felt I was not eligible for any aid, because my earnings were too high and that I didn't fit that criteria, and that these benefits were -- this was not to cover mobility, even though it clearly says on their form to start with. By that stage I just replied. I thanked them

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1 A. That's right.

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- 2 Q. -- because she's been much shyer about asking?
- 3 A. Correct.
- Q. You have said in your statement you don't feel that
 financial assistance should be means tested. Why is
 that?
 - A. Why should it be? That's more the question. Whether you work, whether you don't work -- I am quite lucky with the role I am in. My employer is very, very understanding. I can take time. I can work from home. I can, you know, have flexible working hours should I feel ... I have a sick benefit scheme. So if I need to take time off, I know I'm not going to have loss of earnings and such like. There are others who may not be in that position and can't get themselves in that position and can't work, but that's not my fault. I have been lucky enough that I can work.

I think we were all afflicted with the same infections, viruses. So why should we be treated any differently? I think that's very important.

And a point that was made by the last person in the seat too: the devolution of power in Northern Ireland should make no difference whatsoever. The fact that our politicians can't get on with each other doesn't mean that we should be treated any different.

for their time and says, "That's fine. I disagree
with your decision, but I am not going to take it any
further".

So that has been my experience with the BSO other than the regular payment side of things and I won't personally be going back and asking for any more.

- 8 Q. It wasn't just intrusive; it was also illogical from9 your perspective?
- A. Illogical and derogatory nearly, you know, and it made
 you feel like again you're begging for help. These
 things are supposed to be there for people affected,
 and whenever you have to go and ask for it and be told
 "No", you sort of wonder to yourself, "Well, what's
 the point in it?"

16 I also find them to be very — I think if you
17 are pushier with them, I think if you have the
18 backbone to stand up to them, or maybe just not feel
19 as if you are begging, and be quite willing to shout
20 and scream, you will get more. So it's a very unfair
21 process.

- Q. And that's why you think that your mum hasn't receivedas much --
- 24 A. That's right, yes.
- 25 Q. -- financial assistance as you --

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- 1 Q. You also had difficulty obtaining life insurance.
- A. That's right, yes.

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- 3 Q. And what have you been told?
- 4 A. I can't get it, and that's the long and short of it.
- 5 I've tried in the past. Whenever I started buying my
 - house I tried. I was told then I couldn't get it, and
- 7 more recently I took up a will writing service through
- 8 work, and obviously they advise you on what you should
- 9 be doing to protect yourself financially and protect
- your family going forward, should anything happen.
- 11 Their main piece of advice is "life insurance". The
- 12 guy came back to me about twenty minutes later and
- says, "I have tried everyone that provides us cover.
- 14 I'm sorry. No-one will touch you".
- 15 Q. Those are the questions I have for you.
- 16 A. Okay.
- 17 Q. Is there anything else you'd like to say at this18 stage?
- 19 A. No. I would like to thank the Inquiry again, as
- 20 everyone else has, for coming around and doing their
- 21 tour of the country. I actually have personally felt
- 22 it a bit liberating. I had this conversation with my
- 23 mum last night, that I found it a lot easier to tell
- 24 people and to tell people even in work. I would
- 25 always have kept it very close, kept it very personal,

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76 (19) Pages 73 - 76

1 even the fact I had haemophilia, due to the stigma live streaming which will show her as she gives 2 related with it. Over the last year maybe since this 2 evidence. She is giving evidence anonymously. So the 3 has come on I've quite openly told colleagues and more 3 same ruling applies in her case as did in Mr l's. You 4 people than just my direct management, you know, what 4 will forgive me I hope for reading it through so that 5 afflictions I've had and I have found it easier. So 5 everyone can hear it again, as I have to do: 6 6 thank you. Thank you. "It is ordered that the name and address of 7 Q. I am just going to ask Mr Snowden if there's anything 7 witness W0481", that's Ms J to you and me, "and any 8 8 he would like me to raise. other identifying information, such as the witness' 9 9 A. No problem. image or any description of their appearance cannot be Q. There is nothing from him. 10 disclosed or published in any form, unless express 10 permission is given by me or by the solicitor to the SIR BRIAN LANGSTAFF: There is nothing from me except to 11 11 12 thank you for your openness and for being prepared to 12 Inquiry, acting on my behalf. Witness W0481 must be 13 referred to only as 'Ms J'. 13 be and being here. 14 A. Thank you. 14 "This order remains in force for the duration of SIR BRIAN LANGSTAFF: Thank you. Well, we will take 15 the Inquiry and at all times thereafter, unless 15 16 a break now, shall we, until 1.45? That's when we 16 otherwise ordered, and I have the power to vary or will hear, shall we, from Mrs J? 17 revoke that order by making a further order during the 17 MS FRASER BUTLIN: Mrs J. That's correct. 18 course of the Inquiry." 18 19 (12.30 pm) 19 It is so ordered. Ms J. 20 (Luncheon adjournment) 20 MS J (sworn) 21 (1.52 pm) 21 Questioned by MS FRASER BUTLIN SIR BRIAN LANGSTAFF: Our next witness is Ms J. 22 MS FRASER BUTLIN: Ms J, you are a symptomatic carrier of 22 23 MS FRASER BUTLIN: That is correct, sir. 23 haemophilia B. SIR BRIAN LANGSTAFF: In her case, as I mentioned this 24 24 A. Yes. 25 morning, as in the case of Mr I, there will not be any 25 Q. Can you tell us what that means? 78 77 A. It means that I would be known as a carrier of 1 I had further teeth. But after my daughter was born, 1 2 haemophilia. I wouldn't be made out to have 2 I had another very major haemorrhage. 3 full-blown haemophilia, it would be mild haemophilia, 3 Q. About 1984? A. Yes. I know at that time I needed a very large blood 4 but over the years I have had several serious 4 5 haemorrhages and required a lot of treatment before 5 transfusion, plus being on cryoprecipitate and stuff 6 and after procedures. 6 at the time, but in between times I had had -- then 7 7 Q. You have had five major haemorrhages --I had a hysterectomy and I had a major haemorrhage 8 A. Yes. 8 following that as well. 9 Q. Your second daughter was born in 1988? 9 Q. -- in your life. What can you tell us about them, or 10 would you prefer me to set them out? 10 A. A. Well, most of them I do remember quite clearly, the And you had also been given cryoprecipitate then to 11 11 Q. 12 first one really being when I was about 11 years of 12 prevent any haemorrhage? 13 age, getting my appendix out. I took a haemorrhage 13 after that and I needed a large blood transfusion. You were also given Factor IX throughout whenever you 14 14 Q. That was about 1969? 15 had particular surgeries, as well as cryoprecipitate? 15 A. 1969. And then, following that, I had quite a serious 16 Different times I would have been given either Factor 16 17 bleed after getting some teeth out. A few other 17 or it would have been bloods or Cyklokapron. It just 18 times, it would mostly have been due to dental work. 18 depended on what procedure I was getting. To be 19 Even when I would be in my early 20s, I had further 19 truthful, sometimes I was not fully aware of exactly 20 teeth out, and I wasn't long married, and guite 20 what I was being given at the particular time. You 21 a major bleed even then. At that time I was 21 just knew you went up to have pre or post treatment. 22 identified as a bleeder, but I had never been 22 Q. All of that treatment or the majority of your 23 23 treatment was here in Belfast? identified as a haemophiliac or a carrier of anything. 24 Then there was further investigations done and 24 A. Yes. 25 then I was told that is what it was. Following that, Q. But you weren't invited to attend the meeting in 1984

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- about infections that we heard about early this morning?
- 3 A. This morning was actually the first time I had ever4 heard of any meeting even ever having taken place.
- 5 Q. And that troubled you?

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- A. Yes, because at the time I was never told probably
 until the early '90s that I was infected, but it is
 obvious now to me that in 1985 it was known that I was
 an infected person, and I should have been included in
 that meeting.
- Q. You recall that at some point in the 1990s you were
 told that the hospitals were changing their blood
 supplies. What can you remember of that?
- 14 What I do remember was it was a short time after I had 15 actually been told I had hepatitis C, and I was still 16 actually trying to come to terms with actually having the diagnosis. It is in my statement that I had been 17 18 told when I had been attending a clinic and asked how 19 I was coping with my hepatitis. It was following 20 this, it was part of a conversation in a consultation 21 a lot of weeks or months later, I asked about how the 22 infection had taken place. I had been told at that 23 time that unfortunately some of the products had been 24 brought in from America, and it is now public

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knowledge that some of the products had actually been

"What I don't understand is that the hospitals knew which blood products had been given to which patients. So why didn't they know that I was infected earlier? Didn't they use the batch numbers to work out who was given infected blood? I find it frustrating that I don't know when I was infected."

- A. Exactly, because every unit of blood that is given to anyone, any treatment, there is a label comes attached to everything. So there should be a follow-up. And once a batch has been identified as being contaminated, then they should be able to recall exactly who has been given what contaminated blood.
- 13 Q. You have referred to it a little bit already, but how14 did you then find out that you had hepatitis C?
- A. I was attending the Haemophilia Centre, which at that time was based in the Royal, for a routine check-up.
 I went in for my usual check-up, and in the middle of it I was asked, "How are you coping with your hepatitis C?"

Well, truthfully, at that stage I nearly fell off the seat. There and then I just thought, "I have been handed a death sentence". I was imagining nearly I was going to walk out the door and never come back in again. My head was just -- my whole world just collapsed. Fortunately, my husband actually was with

bought and used, and I was reassured that that wasn't

2 going to happen again, and that they were actually

3 looking into buying products from a Parisian company,

4 so it would eradicate any further infections taking

5 place.

6 Q. We have talked about sort of the five major

7 haemorrhages you have had and the dental treatment

8 that you have had. You know, obviously, at some point

9 you were infected with hepatitis C, but you aren't

10 sure when that occurred?

A. To this day I don't know. I was never actually toldhow, when or where. I was just told "you have it".

13 **Q.** And how do you feel about that?

A. I feel very let down. "Let down" is actually quite
an easy word to say, but I feel that I was just part
of a statistic. I think people forget when they are
making diagnosis of things or if they are aware if
people have a condition that they are actually dealing
with a human being, and they don't realise the impact
a diagnosis has on anyone.

21 I think once people were made aware -- I am 22 talking about government and medical teams were 23 aware -- I think anybody who was at risk should have 24 been informed immediately, not years later.

25 Q. What you have said in your statement is:

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me that day. We walked out on to the corridor. He knew there was something wrong, because I had went in myself and actually I explained to him. We turned and actually came back in again. That day it was a registrar I had spoke to. I asked to speak to the consultant that day, in the middle of the clinic, but unfortunately it was a busy clinic.

8 Feeling dismissed sounds wrong, but I felt 9 partly dismissed. I was told, "Oh, yes. Yes". I was 10 handed a leaflet, more or less, and told "It will be 11 all be sorted out. Don't worry, there will be 12 treatments", but I just felt there wasn't a support 13 network even opened up to me at that time. You were just left to your own. I walked out of that place 14 15 absolutely devastated. My world had just collapsed.

abbotatory deviations. My front had just composed.

16 Q. Were you ever told you were being tested for hepatitis

17 C --

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18 A. No.

19 Q. -- prior to that appointment?

20 A. No.

21 Q. You were a nurse at that time?

22 A. Yes

23 Q. Was hepatitis C ever raised in connection with your 24 work?

25 A. No. Most nursing professionals would have had

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- 1 a vaccine for hepatitis B as part of their medicals,
- 2 but it was never -- as I say, my knowledge of
- 3 hepatitis C was very limited until I ended up being
- 4 told I had it myself.
- Q. And you were in quite a state for a few weeks afteryour diagnosis?
- 7 A. I think I felt as if I was in a parallel universe.
- 8 That might sound ridiculous, but the world was going
- 9 on without me. I became probably more insular in
- 10 myself. I would hold things quite a bit to myself and
- 11 I found even I became more insular. I was frightened
- who I could talk to, who I could share things with.
- 13 I became absolutely paranoid round my children.
- 14 I worried about if I was going to infect my children,
- 15 how I was going to even -- would I live to see them
- growing up, would I see the next month, the next year?
- 17 The unknowns were -- I think you just go into
- an absolute mental turmoil, because it's just the
- 19 unknown entity of what's in front of you.
- 20 Q. You have described you were scared to touch your
- 21 children?
- 22 A. Yes.
- 23 Q. You were anxious when it came to hugging them?
- 24 A. Yes.

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25 Q. And you would be frantic if one of the children used

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- 1 a journey that we both have unfortunately had to go
- 2 on, which a lot of other marriages probably wouldn't
 - have held together on.
- 4 Q. It was both you have said in your statement the fear
- 5 of infecting him, but also because you were becoming
- 6 more insular, as you described earlier?
- 7 A. Yes. Because it is like everyone who has
 - an infection, an illness or anything, it is actually
- 9 quite hard to share your own intimate feelings about
- 10 it. Also, sometimes you are actually scared to
- 11 actually share them, because you don't want someone
- 12 thinking little of you, even though it is your
- husband, partner, brother, sister, whoever it is, but
- 14 I think it just seriously affects your relationships
- 15 with other people, because truthfully you actually
- 16 can't be yourself. You are yourself, but you are
- 17 living an unknown, and you are walking, should I say,
- an unknown path, and I think you are scared to
- 19 actually probably let your whole true feelings come
- 20 out, and I think again that's what affects your
- 21 relationships.
- 22 Q. You only told members of your close family about the

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- 23 hepatitis C?
- 24 A. Yes.
- 25 Q. Why was that?

- 1 your toothbrush or touched a drinking glass that you'd
- 2 used?
- 3 A. Yes. And it was very hard to explain to a young
- 4 family why you were doing that, and to this day it is
- 5 quite emotional thinking about it, that you lost that
- 6 personal touch that you should be able to just
- 7 automatically go up and hug your children. It is just
- 8 that fear. They are too young at that time to
 - understand why. I feel probably long-term that
- 10 fortunately my relationship is very good with my
- 11 children, but when I look back now, I realise that
- they didn't get that probably warmth that they should
- 13 have got from me at the time.
- 14 Q. It also impacted on your marriage?
- 15 A. Yes.

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- 16 Q. Can you tell us how?
- 17 A. Well, fortunately I have a very good husband, but our
- intimate relationships would have been out the window,
- put it that way. That's the easiest expression I can
- 20 use. Because I was scared of infecting him. Even
- 21 trying to even share my affections with him, I was
- 22 finding it even hard, because part of me was still in
- 23 a mental turmoil most of the time. But fortunately we
- 24 have battled our way through it together, and I am
- 25 very, very thankful for that. But I realise it's

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- 1 A. Well, truthfully, the stigma was the main thing,
- because people's perception, and even today it's still
- 3 the same, that hepatitis -- I heard someone else speak
- 4 about it earlier. I was waiting on someone thinking
- 5 I had been standing mainlining up the street. You
- 6 know, it's the perceptions that people have of it.
- 7 It's a hard thing to actually share with anybody else,
- 8 outside your own family, and I think you have to feel
- 9 very secure in that. But the main thing really is
- other people's perceptions of the disease. As I say,
- 11 I shared it with my immediate family. My colleagues
- 12 I worked with for a long time were aware I had
- haemophilia, but they never knew I had hepatitis.
- 14 **Q**. And that meant you felt you said that you were living
- 15 a double life?
- 16 A. Exactly, because I had a work life hat and I had
- a home life hat, and that probably affected probably
- 18 a lot of relationships with people I worked with,
- 19 because they only actually saw part of me, and
- 20 probably it is like everyone wears a mask. I probably
- 21 had my mask on in my working life and I could only
- 22 pull my mask off when I came home.
- 23 **Q.** Now, you were working in the hospital where you also
- 24 received treatment?
- 25 A. Yes.

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1 Q. And what was that like?

A. It was actually quite difficult, but I was fortunate
 that the colleagues that I worked with in the area

that the colleagues that I worked with in the area that I had the treatment in, I had the respect of

5 them, even as a person and I trusted in their

6 confidentiality, because I was fully aware that they

were reading my notes, giving me treatment. It is

8 quite intimidating. I know it is intimidating for any

patient to go and have treatment, but it is quite hard

for colleagues sitting reading your notes, and knowing

your intimate details about your life.

12 Q. You have described one occasion when you went in for13 surgery and knew the surgeon?

14 A. Yes.

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15 Q. And you found that difficult?

16 A. I found it difficult, but because of his

professionalism I have to say, and he reassured me at

18 the time that my diagnosis to him had no impact on his

treatment to me, and that reassured me, very much so.

20 I think a lot of times it is down to individuals'

21 response to you. His reassurance actually I think got

22 me through that particular journey.

Q. Unfortunately, that wasn't the case every time, and
 you have described in your statement one particular
 occasion when you had a shoulder injection?

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straight over into the Haemophilia Centre, and asked to speak to somebody, because I said, "If I have been treated like that, someone else is going to be".

I said, "Look, someone here, will they make sure they speak to the infection control people in this area so that this doesn't happen to anybody else again".

7 Q. You had another occasion when you needed8 a gastroscopy?

9 A. Uh-huh.

10 Q. And you faced difficulties then as well?

A. I unfortunately was diagnosed with a tumour in my
stomach. I had to have a few gastroscopes done.
Especially, on one occasion, I went in, and there's
quite a discussion round what part of the list I would
go on to start off with. I thought, "Well, fair
enough". Then it was, "Oh, how are we going to
disinfect this equipment?" I could hear all this

conversation going on as if I wasn't even in the room.

"Oh, maybe we could use an old scope".

I was slowly but surely sinking further into the floor, because I thought, "Here I am sitting here with the mange, never mind a stomach tumour". Then the discussion was also made, "Well, if we can't use old equipment, then we'll maybe have to destroy the rest",

A. That day I can recall very clearly. I am not being derogatory to people with this condition, but I actually felt like a leper sitting there. I went in to get my shoulder injection. The surgeon arrived to give it to me, and he was in a discussion with me, and all of a sudden the nurse that was in the room realised that I had hepatitis. Well, the next thing, truthfully, she nearly went off the wall. "Oh", you know, you can imagine the whole hullabaloo. "Oh, such an infection risk, you are going to contaminate everyone else. What are we going to do with this equipment once we have finished?" I am sitting there with a painful shoulder, about to get steroids put in, thinking, "Oh, my God!" I actually turned round and

said, "If you follow the correct infection control procedures, I am no more risk than anybody else sitting here or anybody that walks in off the street"

sitting here or anybody that walks in off the street".

Fortunately, the consultant spoke up as well,

and I did get the procedure done. But I never seen antics like it. People running about putting gloves on here, there and everywhere, and you just felt like -- truthfully, I was so disgusted when I actually came out of it. I was very sore, after getting the treatment and everything done. It was the Belfast

25 City Hospital at the time. I walked from there

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tens of thousands of pounds of equipment going to be absolutely scrapped just because it's been down my throat".

I heard actually a similar comment made earlier, so it seems to be a common theme. Eventually, I did get the procedure done, and I had a surgery for my tumour, which fortunately was removed, but it resulted in me being in hospital for nine days. If I hadn't had the scope done, put it this way, my diagnosis wouldn't have been done and I wouldn't have been sitting here today. But it is just the fact again that I was such an infection risk, and again, were they going to dump the equipment out after they used it on me, which I think is deplorable.

it on me, which I think is deplorable.
Q. In your statement you said that, as a nurse yourself for so long, you feel that the perception of hepatitis

17 C among health care professionals was atrocious?

18 A. As I said, truthfully, I do, because I think that
 19 people's knowledge -- I have to say initially myself,
 20 before I had my diagnosis, I had limited knowledge of
 21 it, but because there has been more in the last

22 20 years, I think all across the board of medical

professionals really need to be re-educated in what hepatitis is, about the infection risks of it, and

25 actually be up-to-date with the knowledge of it, but

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and I was sitting thinking, "Heavens above! There is 91

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actually remember to treat patients as human beings. They are not just a factory line coming in.

I would always like to have thought that people who looked after you had compassion for, but not always did I find that, and I think it is very important that people are more aware of what the infection, no matter what infection it is, that patients are treated appropriately.

- 9 Q. You underwent a first course of treatment in about 10 1999 or 2000?
- 11 Α. Yes

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- 12 Q. And that was with Interferon?
- 13 A. Uh-huh.
- 14 Q. How did you fare with that?
- 15 When I started the first course of treatment, I really 16 went into it blind, in the sense that I wasn't fully 17 aware of what side-effects actually was going to 18 impact on me. I knew it was the treatment that I was 19 hoping that would clear the virus, but I wasn't 20 expecting to end up with constant nausea. The fatigue 21 was unreal, and the lethargy you had, and then even 22 the impact of actually having to self-administer your 23 own treatment at home. Again, the paranoia even came 24 in at home with that, because all of a sudden again

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I was having syringes and needles present in my home,

1 your estimate in your statement?

2 A. I can't remember truthfully exactly the time zone,

3 because a lot of it truthfully I have tried to block

4 out. But it was at least a year nearly in between it.

5 If my medical notes were in front of me, I could

probably find it very clearly, but I know there was

a good gap in between the two treatments.

8 Q. And once you started the second round of treatment, 9

what were the side-effects that you faced?

10 A. I thought the side-effects from the first type of

Interferon were bad, but I didn't realise how I was

- going to be affected further, because unfortunately 12
- 13 even -- I felt as if I was going through
- a chemotherapy regime, because I was absolutely and 14
- utterly exhausted all the time. I would be nauseous. 15
 - I ended up actually starting to get quite paranoid.
- 17 The impact of it was actually ten times worse than the
- 18 first one. I became clinically depressed, and I have
 - never been depressed ever in my life. I became even
- 20 further insular. Just my whole life completely

21 changed again.

> In one of the consultations when I was up at the hospital, the registrar spoke to me and persuaded me to actually go on to anti-depressants so that

I could -- I had actually thought of stopping the 95

with young children. Again, the infection risk

against my children came back into it again, because

3 I realised that there was treatment there. But

4 unfortunately, despite going through the whole

5 treatment, I was still positive at the end of it.

6 Q. Initially your viral load dropped, but by the end it

7 was obvious that it hadn't been successful?

8 A. I think -- I can't be 100% accurate, but I know at

9 some stage I produced a couple of false negatives in

10 my viral load, and then I was told that I would need

11 to go on the different type of Interferon, which was

12 the pegylated one at the time, but unfortunately it

wasn't available here. 13

14 Q. Why was that? What are your feelings about that?

Well, to my knowledge, what I was told was it was 15

16 available in other parts of UK, but it hadn't been

17 cleared by NICE guidelines to be given here, and also

18 that with different health regions there is different

funding, and that I would have to wait a wee while.

20 I can't remember exactly how long I waited

21 between one treatment and the other, but eventually

22 I was told that the second type of treatment was

23 available for me.

24 Q. You think it was about 18 months later that you were 25

able to start the second treatment. At least that's

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1 treatment, because the impact on me was so much. She

2 said to me at the time, "It is important for you to

3 try and continue" and persuaded me to actually go on

4 anti-depressants so I could actually finish the rest

5 of the course.

6 Q. Around that time, you were studying for a further

7 qualification, and you couldn't complete that?

8 A. No. I had actually registered with the university

9 because as part of everyone's life you want to keep

10 upgrading your certificates and stuff, and I had

11 actually completed a certificate in health and social

12 services management, and I was going on to do the

13 diploma. I had actually started the first couple of

weeks of it, but this was when I was doing my second 14

15 lot of treatment, and it got to the stage the fatigue

16 and the running back and forth to hospital even,

17 I just knew that I wasn't even going to make it, and

18 I had to pull out of the course, and that was

19 devastating to me, because I had built my way up to

20 actually getting to further advance myself. So that

21 was a big loss for me.

22 **Q.** And you struggled to be in work during the treatment?

23 A. I would have finished my work, came home, injected

24 myself and truthfully lay and perspired -- this is the

25 delicate way of putting it -- all night. I took two

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- 1 paracetamol and then had to get up maybe at 6 o'clock
- 2 in the morning to go back to work. With hindsight
- 3 looking back, I actually don't know how I kept myself
- 4 going, but I had two young children, I had a husband
- 5 who had just started actually a degree course himself.
- 6 So I was the main earner at home. So I don't know,
- 7 I had to push up from my feet and try and keep going.
- 8 When you did need to phone in sick, you said you 9 couldn't tell your colleagues what was wrong?
- A. I think I must have had more 'flu than anybody else 10
- 11 has ever had, but truthfully it wasn't a lie, in the
- 12 sense that I was having constant 'flu symptoms anyway.
- So, I mean, it wasn't a lie, because the symptoms that 13
- 14 you get from your treatment is headaches, shivers,
- nausea, vomiting. That was the simplest answer, was 15
- 16 to phone in and say I had the 'flu.
- Q. That second treatment cleared the virus? 17
- 18 A. As far as I'm concerned I'm clear, but I don't know
- 19 whether I'll be clear forever. I have come up with
- 20 a negative result, but I can never honestly say that
- 21 I'm 100% clear.
- Q. You've had a number of scans and you don't have 22
- 23 cirrhosis of the liver, but since the treatment you
- 24 have continued to feel really quite unwell. Can you
- 25 tell us how you felt?

- that? 1
- 2 Well, to be truthful, over the last four or five years
- 3 prior to that, because of the multiple times, as you
- 4 said there, that I have had palsy, I had the tumour,
- 5 I was finding that, actually, when I went back to
- 6 work, I was finding that the fatigue, the tiredness,
- 7 the multiple times I was having to attend clinics,
- 8 I was just truthfully finding that I couldn't
- 9 physically carry on.
- 10 Q. You said you would finish a 12-hour shift and would be
- flat out asleep until dinner time the next day? 11
- If I worked a week-end shift, my family all knew that 12
- 13 they needn't even dream of phoning me until 4 o'clock
- even the next day, because I would have been 14
- 15 absolutely physically exhausted. I know people can be
- 16 exhausted doing shifts, but I found that it really had
- 17 got too much.
- 18 Q. You had worked shifts all your life?
- Yes. 19 A.
- 20 So you were used to how that felt?
- 21 A.
- Q. But this felt very different? 22
- 23 A. I would say truthfully, over the latter part of -- but
- 24 then I am only talking about maybe five years post
- 25 treatment. After the second lot of treatment, then

- A. As the years have gone on, I would have a general
- 2 fatigue all the time. I would be a lot easier tired
- 3 than I really should be. Part of it I would have put
- 4 down a few years ago to, at my age, the menopause or
- 5 something, but I know it wasn't, because the symptoms
- 6 kept repeating themselves. Even my memory probably
- 7 wouldn't be as sharp as it would have been, and
- 8 I would be more susceptible to infections, colds and
- 9 'flus, and I found even recovery time from a lot of
- 10 the surgeries I have had is a lot slower than
- 11 a regular person should expect.
- 12 As you have said, in 2015, you had a gastrointestinal
- 13 stromal tumour removed?
- 14 A.
- 15 You have had five attacks of Bell's Palsy?
- 16 A. I have had five attacks of Bell's Palsy, and I feel
- a lot of that -- I think my immune system is weakened 17
- 18 from the hepatitis C, but also from the treatment that
- 19 I was given for hepatitis, because I feel really that
- 20 it was nearly like a double course of chemotherapy,
- 21 which long-term I feel has affected my immune system.
- 22 I feel I have been more susceptible. Unfortunately,
- 23 I feel it has just been like a catalogue of illnesses
- 24 have occurred more so since then.
- Q. You ultimately took early retirement at 59. Why was

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- 1 I would have found more and more symptoms actually
- 2 were getting worse. What you put down to general
- 3 tiredness was turning into exhaustion.
- 4 **Q**. Do you now have any follow-up with the liver clinic?
- 5 A. I haven't heard a word from the liver clinic now for
 - several years. One minute I was attending quite
- 7 regularly, having bloods done. I had had a few scans
- 8 done, and then all of a sudden no further
- 9 appointments. So I don't know whether I will have
- 10 a further review. I had always taken it even that if
- 11 I was clear, that because of my history, that I would
- 12 have been seen even every couple of years, but I feel
- 13 like one of those people that's sort of "Oh, no, you
- 14 were okay", and so you have been pushed to one side
- 15 now. So ...

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- 16 Q. The question you say you have been left with is about
- 17 the impact of hepatitis C on your future health and
- 18 things going forward?
- A. Exactly. That's what I have been saying there, is 19
- 20 I have noticed as the years have gone on that my
- 21 health is further deteriorating. I seem to be more
- 22 open to things. I do wonder -- I never had had
- 23 stomach issues most of my life, and then all of
- 25 nowhere. Most people would get Bell's Palsy, maybe

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a sudden a few years ago this tumour has come out from

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- 1 would get it once or twice and recover, where mine has 2 never recovered, and I have been left permanently with 3 disability. I just still think that has been an 4 impact of the disease on me.
- 5 Q. You spoke earlier about being diagnosed with clinical 6 depression during the treatment, and being offered 7 anti-depressants and taking them, but were you ever 8 offered any counselling or psychological support?
- 9 A. No. The only support I ever had was at one stage when 10 I was attending for treatment, I was told that -- I am 11 nearly sure it was the Red Cross was available for 12 a massage, and I got two massages, because they were 13 attached to the cancer centre, and that was the 14 counselling and the psychological support I got.
- 15 Do you think if you had been offered counselling or 16 psychological support, you would have taken it up?
- Most definitely, because I think it is a very lonely 17 journey to make on your own. I think if you have 18 19 always someone -- family is important, paramount, but 20 I also think it is important that someone else can be 21 actually there that can be an ear to lean on. I think 22 that would have actually made a lot of people's 23 journey right through this whole thing an awful lot 24
- Q. You also received a letter about vCJD in the mid 25

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- 1 actually able to sit here and actually bring them out 2 now
- 3 Q. I want to move on to the Skipton Fund. You have 4 received payments from them, and you remember signing 5 a form before you received the payments. What did 6 that form say, as far as you remember?
- 7 A. It was such a long time ago, but from what I do 8 remember, if you signed it, you agreed that whatever 9 the outcome of the payment was, that was the totality 10 of it, and that you wouldn't have been eligible to 11 make a further claim into it.
- The payments you receive have shifted over to the 12 13 Northern Ireland scheme?
- 14 A. Yes.
- Q. Do you have any particular points you want to raise 15 about the processes?
- 16 17 A. The only thing I do want to say, yes, I feel it is 18 good that it's been recognised that people need help 19 with benefits, or whatever. But I feel that --20 I heard someone else also mention it -- there 21 shouldn't be any difference made from tier 1 to tier 4 22 in the payments of the benefits. I feel that everyone 23 who has been affected by hepatitis C, HIV, regardless, 24 should all be treated exactly the same. Also, again,
- 25 that it shouldn't affect people's general benefits,

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1990s. What can you tell us about that?

- 2 A. That was like another -- truthfully, it dropped
- 3 through the door. I opened it and sort of put it back
- 4 in the envelope and sort of then reopened it again.
- 5 My first reaction was, "What next?" because I just
- 6 thought, "You can't actually tell me anymore,
 - because ..." But when you tried to talk about it,
- 8 I felt it was sort of brushed to one side. It was
- 9 just either part of being a haemophiliac or part of
- 10 anybody who has had a blood transfusion.
- 11 Even to this day, I don't actually think there 12 is actually very much -- the letters were put out, but 13 there wasn't actually much follow-up afterwards. Most 14 of what was said to you was, "well, we had to put 15 those out. Don't worry about it. It might not ~..." 16 You know, I felt the whole thing was actually played 17 down.
- 18 Q. You have said you were left trying to just blank that 19 out?
- 20 A. I think so. I think that's probably been my own 21 coping mechanism, that you mentally can only take so
- 22 much on board, but it is always back there. But
- 23 I think the like of this Inquiry has made me probably
- 24 bring forward things that I have buried in my mind for
- 25 quite a while, and it's probably good that I am

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- 1 because if it is given to people, it is counted as
- 2 their income, and then again it will stop people
- 3 actually getting some general benefits, which
- 4 unfortunately some people, because of their disability
- 5 or because of their infection, has had to leave their
- 6 employment or whatever. People need support, not
- 7 things pulled away from them.
- 8 Q. You have also said that it would have helped if you
- 9 had had access to discretionary payments when you were 10 ill?
- Yes. 11 A.
- 12 Because that would have put less pressure on you to
- 13 keep working when perhaps you were too ill to?
- A. I didn't know about a lot of the stuff. The longer it 14
- 15 went on, you find out about things. They have not
- 16 actually been put to the forefront. I don't think,
- 17 even amongst sufferers of the disease, or the
- 18 infection, should I say, were actually informed of how
- 19 to access a lot of things. It is only if you enquired
- 20 into them or someone actually told you. The things
- 21 were never actually put in front of you clearly to
- 22 know about.
- 23 Q. You are also anxious about how many databases you are 24
 - now sitting on, with your personal medical
- 25 information?

1 A. Well, obviously, prior to my knowledge of my profession does as well, and also that people realise 2 diagnosis, I obviously was tested, without my 2 that this is about people. This is a human story. 3 knowledge. So that's on a database. When the Skipton 3 This is not about stats. This is a human story. Fund got in touch with me initially, I am obviously on 4 4 Thank you very much. 5 their database. Now I am on some other government 5 SIR BRIAN LANGSTAFF: Well, thank you for sharing your 6 database. It's got to the stage I don't know where it 6 part of the human journey with us. 7 has been shared. I think it is important that people 7 A. Okay. Thank you. 8 actually know where their information is. 8 SIR BRIAN LANGSTAFF: We will take a break, shall we, till 9 9 Q. Those are the questions I have for you. Is there 3.10? anything else you would like to say? MS FRASER BUTLIN: Thank you, sir. 10 10 A. No. I think I've covered it. But there's just 11 (2.20 pm) 11 12 a couple of wee things I would like to just finish on. 12 (A short break) I would really like to thank Sir Brian and all 13 13 (3.12 pm) 14 the team. I have to say from the people who phoned 14 SIR BRIAN LANGSTAFF: Ms Fraser Butlin. 15 me, the people who regularly e-mail me, I think the MS FRASER BUTLIN: Sir, if we may, I would like to recall 15 Mr I, in light of some evidence that was provided 16 support that all the victims have been given is 16 absolutely fabulous. Thank you for giving myself and 17 about an hour ago. I think it would be useful to the 17 18 18 others a chance to share our journey, and that's what Inquiry --19 I am calling it, a journey. I hope and pray, as 19 SIR BRIAN LANGSTAFF: About an hour ago? 20 a victim and a survivor, that answers are forthcoming 20 MS FRASER BUTLIN: -- to see it. 21 on how, why, where patients like myself contracted the 21 SIR BRIAN LANGSTAFF: Very well. 22 22 virus, and I hope in future that this situation never MR I (recalled) 23 arises again, and the stigma of hepatitis C is 23 Further questioned by MS FRASER BUTLIN 24 understood by people generally, and I mean the general 24 MS FRASER BUTLIN: Mr I, thank you for continuing to give 25 public have a clear understanding and the medical 25 some further evidence. 105 106 A. Thank you. 1 this scandal. It is a tragedy that should never have 1 Q. You are still under oath. 2 2 taken place, and I can only imagine the pain it has 3 A. Yes. 3 caused families throughout the UK. Q. Could we have document 1383007, please? If we just 4 4 "I am aware of the issues you raise regarding 5 look at the very first part of it, it is a letter from 5 the potential disparity in financial support between 6 the Right Honourable Karen Bradley, Secretary of State 6 victims in Northern Ireland and those in England. As 7 7 for Northern Ireland, written on 22 May. It says: you know, the Infected Blood Inquiry is UK-wide, and 8 8 the Inquiry terms of reference include consideration "Thank you for your e-mail of 14th May 9 9 concerning the Infected Blood Inquiry." of financial assistance across all the nations of the 10 That's an e-mail you wrote? 10 UK. The announcement made on 30th April increasing 11 A. It is. 11 funding for recipients in England is to be welcomed, Can you tell us what you put in that e-mail to the 12 as are the efforts made by the Department of Health 12 13 Secretary of State? 13 and Social Care to reach out to the devolved A. Yes. Within light of the Inquiry coming up, I had to 14 14 administrations with a view to working together to e-mail the Secretary of State asking that, on the back 15 support recipients in all four nations. 15 16 16 of Theresa May's benefits, the scheme uplift which she "Indeed, my colleague and Health Minister, 17 has shown in England, could Northern Ireland follow 17 Jacqui Doyle-Price, has explicitly stated that she 18 suit and just mirror what England has done. Due to 18 would like to see greater parity of support. 19 the fact we don't have a fully functional Stormont 19 "Please be assured that I am keeping a close eye 20 Parliament here, I was worried once again we would be 20 on developments in the Inquiry. It is only right that left behind and we would be treated differently again. 21 those whose lives have been blighted should receive 21 22 Q. This is the reply you got? the care and assistance they need. Of course, the 22 23 23 best means of supporting victims in Northern Ireland A. Yes. 24 Q. You just got it about an hour ago. It says this: 24 is via a functioning assembly, in which locally 25 "I empathise with all victims at the heart of 25 elected ministers can speak up and act on their

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1 behalf. That is why securing a successful outcome to CHRISTINA MCLAUGHLIN (sworn) 2 2 the talks process is my absolute priority." JOHN PATRICK CONWAY (sworn) 3 3 What is your response to that letter? PATRICIA MARTINA KELLY (sworn) 4 A. I think I have heard it echoed in the crowd that it 4 Questioned by MS RICHARDS 5 has just been stalled again, and we will be held back 5 SIR BRIAN LANGSTAFF: Now, John, you have a naturally and used as a political football to try to get 6 6 quiet voice. So you may need to move your chair just 7 politicians with no relevance to this Inquiry back 7 a little bit closer to the microphone so we can all 8 around the table. I don't think that Stormont has got 8 hear what you have to say. Thank you. 9 9 anything to do with this. I think that the fact that MS RICHARDS: Sir, just before I start asking the 10 witnesses questions, it is right that I point out that 10 the scheme is already in place, it just takes a civil they were relatively late additions to the witness 11 servant or herself to sign a page and say uplift it to 11 12 mirror England. I don't think there is any reason for 12 schedule. As a result, the Belfast Health and Social 13 Care Trust and some of the doctors who are mentioned 13 this at all. 14 MS FRASER BUTLIN: I have no further matters I want to 14 in their witness statements have not had 21 days to 15 raise with you. 15 respond to certain criticisms raised in the 16 SIR BRIAN LANGSTAFF: No. I have no questions to arise 16 statements. That's not the fault of the Trust or the out of this. Thank you very much. 17 doctors. So those listening to the evidence or 17 18 reading the evidence should bear in mind that there A. Thank you. 18 19 SIR BRIAN LANGSTAFF: Do we now have Tina, John and 19 may well be aspects of the evidence which would not be 20 Patricia --20 accepted by the Trust or doctors, and responses in 21 MS RICHARDS: We do, sir. 21 writing from the Trust and the doctors are expected in 22 SIR BRIAN LANGSTAFF: -- as they would wish to be known? due course. 22 23 MS RICHARDS: Yes, please. So if the three of you would 23 SIR BRIAN LANGSTAFF: They should read nothing adverse like to come up. Thank you. 24 into the fact that there has been no response as yet, 24 25 /// 25 because the simple fact is the Trust has not had time 109 110 as yet. 1 PATRICIA: That is correct. 1 2 MS RICHARDS: You are also going to talk a little about 2 MS RICHARDS: That's right, sir. So that no adverse 3 inference should be drawn, but as a result there may 3 Eddie, who has given a statement to the Inquiry but 4 be matters that they would have otherwise wanted to 4 will not be giving oral evidence? 5 draw to the Inquiry's attention that I would not be 5 TINA: That is correct. 6 able to explore with these witnesses, but these 6 MS RICHARDS: Shea was born, I think, in 1973? 7 7 witnesses will be giving their recollection, setting TINA: Yes. 8 out their views, and you, sir, will receive the 8 MS RICHARDS: He had severe haemophilia A? 9 Trust's and doctors' evidence as part of the Inquiry 9 TINA. Yes MS RICHARDS: He was under the care of either the Belfast 10 record in due course. 10 SIR BRIAN LANGSTAFF: Yes. Haemophilia Centre at the Royal Victoria Hospital or 11 11 MS RICHARDS: So you are Tina, John and Patricia. 12 Belfast City Hospital for much of his life? 12 13 TINA: Yes. 13 TINA: That's correct, yes. JOHN: Yes. MS RICHARDS: But also one of the local hospitals? 14 14 PATRICIA: That's right. TINA: Altnagelvin Hospital, that's our local hospital, 15 15 MS RICHARDS: You are siblings. You have other brothers 16 16 yes. 17 and sisters. Can I go through them in order of their 17 MS RICHARDS: In terms of medical records, you have 18 age to see if I have it right. Eddie is eldest. Then 18 received, as I understand it, Shea's records or that 19 there is you, John, you Patricia, Paula, Ann, Rosie 19 would have been records at the Royal Victoria Hospital 20 and you, Tina, and the baby of your family was Seamus, 20 or the City Hospital? known as Shea? 21 TINA: Yes, they were all received. We did apply for 21 22 TINA: Yes. Altnagelvin's records just prior to the Royal's, but 22 MS RICHARDS: I will refer to him as Shea. You are here 23 I only realised the other day we haven't received 23 24 to talk primarily about what happened to Shea and 24 those yet. 25 speak on his behalf? MS RICHARDS: Now, can I ask first of all you, John, as

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1 the eldest of the siblings giving evidence today, can of you described him as "the golden child"? 2 you tell us how Shea's haemophilia affected him as 2 TINA: Yes, he was. 3 3 MS RICHARDS: He was ruined by you all, spoilt rotten by a child and growing up? 4 JOHN: Well, basically Seamus was very much into soccer, 4 you all. 5 but mother and father had us all warned that he wasn't 5 JOHN: He described himself as the golden child. MS RICHARDS: You have been able to establish I think from 6 to play any sort of contact sports. So he was kind of 6 7 pushed down the road of being a snooker player, and he 7 your own knowledge of Shea growing up, and indeed 8 turned out quite good at it. In those days my 8 what's in his records that he was given 9 9 recollection of Seamus is he had a very poor quality cryoprecipitate and then Factor products? of life, very little schooling. We are going back 10 10 TINA: That's right. 11 quite a while. So when Seamus got a bleed or 11 MS RICHARDS: In the mid 1980s, he moved on to receiving 12 a haemorrhage, in those days there, probably the drugs 12 Factor products through a Home Treatment Programme, so available might not have been as good as they are it was administered at home? 13 13 14 today. So I do recall Seamus lying on the sofa at 14 TINA: That's right. 15 home in real plain. 15 MS RICHARDS: You don't have details of precisely what 16 MS RICHARDS: I think the way you put it, Tina, in your 16 batches or what products he was given? statement, he didn't have a normal childhood? TINA: We can only guess at them. He did receive 17 17 18 cryoprecipitate and Kryobulin. He has received those TINA: 18 Nο 19 MS RICHARDS: As you have said, John, he was not able to 19 but the when, we don't know. 20 attend school regularly? 20 MS RICHARDS: In your statement you said that in about 21 JOHN: No. 21 1985, when Shea would have been 11, 12 years old, you MS RICHARDS: Your parents were devoted to him and he was 22 understand that he was tested for HIV and found to be 22 23 the baby of the family? 23 negative? JOHN: He was the baby, yes, definitely. 24 TINA: Yes. 24 MS RICHARDS: You have all said in your statement -- one 25 MS RICHARDS: Do you have any recollection, any of you, of 25 113 114 1 that process going on at the time? 1 MS RICHARDS: Patricia, can you recall what Shea's TINA: 2 2 One of my other siblings does, yes, very much so. attitude to his infection to the hepatitis C was? 3 I don't remember that. I just remember him being 3 PATRICIA: I can indeed. Seamus had a broken femur, and 4 tested for what was in the news and stuff at the time. 4 was in the Royal Victoria Hospital, four years prior 5 MS RICHARDS: And you have seen from his records that he 5 to him dying, and he came to stay with me, because at 6 had a number of subsequent HIV tests, all negative, 6 this stage then I was fighting to get him a ground 7 7 but over the years you are not sure whether he would floor accommodation to suit his needs. He made me 8 8 have understood and agreed that he would be tested on quite clear that he wanted his own towels, that nobody 9 9 those regular bases? else in the house was to use those towels, and that 10 TINA: I honestly don't even know if he was aware of the 10 they were to be threw out and destroyed after. He first test. I wasn't even aware that he had been would have done his own Factor VIII, always did. 11 11 tested until I seen his notes for the subsequent ones. 12 Seamus was an expert at it. But I was not under no 12 13 MS RICHARDS: Now, at some point Shea was diagnosed with 13 circumstances allowed to handle needles or anything. hepatitis C, and your parents were informed of that They had to be in a yellow bucket. I had always baby 14 14 diagnosis and, John, you have said that Shea was aware 15 wipes in the room, so he could clean his hands and 15 16 16 of it from a young age. stuff. I was not allowed to touch anything 17 JOHN: Yes. Well, I remember, vaguely I remember 17 whatsoever. 18 obviously -- it is a long time ago -- but I remember 18 MS RICHARDS: One of you in your statements talked about 19 he was made aware of it, and I remember my mother 19 Shea having been embarrassed about the infection, the 20 saying to me that it's important that this doesn't get 20 condition that he had --21 out. She says "Be careful with your own friends that 21 PATRICIA: When the girl from the housing executive did 22 you don't happen to let this drop, because he is 22 come to my home to visit Shea, his words to me was:

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"You better not tell her I have hepatitis C". I said:

"Sure, Seamus, this isn't your fault". He said:

"I don't care. I don't want you to tell her". I said

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really worried about it and he will just never put his

foot in the street again if it gets out", you know,

I do remember that.

1 "Right, okay. I won't". doctor saying to him: "You know, best keep this to 2 MS RICHARDS: Do you know what information your parents 2 yourself. You don't really want anybody to know 3 3 were given or Shea was given about the nature of the this." 4 condition and its prognosis, or risks of infecting 4 So what was said to him, even as a child, and 5 others? 5 obviously my parents would have been there, has PATRICIA: To be fair, both of them were very private 6 probably resulted in why they didn't want it to be 6 7 about it as well. They didn't speak about it. Like 7 8 MS RICHARDS: One of the criticisms, Tina, you have made 8 John says, everybody was warned at the time when 9 9 Seamus had it, that was old enough to know. It didn't in your witness statement, in terms of the advice that go outside of the house. There was nobody to talk 10 was or wasn't given, is you say he wasn't given advice 10 about it and it wasn't talked about. 11 11 about how best to manage the infection, in terms of MS RICHARDS: And, Tina, you have said in your statement 12 healthy lifestyle and healthy eating? 12 that their understanding, at least at an early stage, 13 TINA: Yes, absolutely, so much so that it was actually 13 14 was that it was if you are going to get a virus, you 14 when he was diagnosed -- I don't want to jump forward, 15 put it this way, the best you could get, that it was 15 but it is important to point out that he wasn't 16 no big deal and that it shouldn't be problem. 16 aware -- in fact I was not aware, none of us were. We TINA: Yes. That was the way it was sold to us, if you 17 are not medically trained people, so you don't look 17 like. So we didn't worry about it. We didn't think 18 into something unless it is necessary. He went into 18 19 it was -- it was just another label that Seamus had, 19 Altnagelvin very sick, just this time last year. When 20 you know. We were so obviously engrossed with the 20 he went in, he asked for the dietician, because I had 21 haemophilia, because that keeps a lot of people busy, 21 brought leaflets in that were outside about keeping 22 you know, for pretty much all the time. So we didn't 22 a healthy liver and what to do. Seamus didn't eat 23 think anything of it. But just to point out that the 23 healthily. He lived on his own. He wasn't a big 24 shame that Seamus had from the hepatitis C initially 24 fella. We called him "the takeaway king". If he was 25 arose from what I would be 100% sure came from the 25 going to eat anything, it would have been fish and 117 118 1 chips. I mean fatty foods aren't good for the liver, 1 would have been aware of symptoms, things to look out 2 and red meat and stuff. We have learned a lot this 2 for. He wouldn't have been aware of it. Seamus would 3 last few days. Seamus wouldn't have been aware of 3 have been frail looking, you know. Well, at times 4 that. He immediately asked for a dietician in the 4 through his life he would have put a bit of weight on, 5 hopes of giving him a few extra months of life, which 5 and he would have looked a bit healthier, and maybe 6 was quite sad. 6 his joints wouldn't have been as impacted. But there 7 7 MS RICHARDS: In 1995, Shea started a course of Interferon was times that he was very frail, very depressed. 8 8 treatment, which involved him having to inject into I didn't realise until the last week of actually the 9 the stomach. How did he cope with that. John, can 9 London hearings that depression comes along with 10 you recall? 10 hepatitis C. So yes, there was lots of symptoms in JOHN: I just remember vaguely that it made him very ill. 11 11 hindsight now fit. He just couldn't cope with the treatment at all. 12 MS RICHARDS: You have mentioned in your statements, in 12 13 MS RICHARDS: Was he able to finish the course? 13 2004, Shea received a letter about a possible risk of TINA: No. vCJD? 14 14 JOHN: No. 15 15 TINA: That's right. 16 MS RICHARDS: Now, if we come forward from the 1990s MS RICHARDS: Do any of you recall whether that was 16 17 through into the early 2000s, and obviously you 17 something that impacted upon Shea? 18 explained how the haemophilia that Shea suffered from 18 PATRICIA: To be honest with you, he would have hid 19 was very much at the forefront of your minds and his 19 letters from you and he wouldn't tell you. He would 20 mind. Looking back now, can you see the extent to 20 never have said "I have appointments" or "I have 21 which the hepatitis C affected him? 21 this". He hid everything. He hated hospitals. TINA: He was terrified of HIV and AIDS. He was 22 Certainly. 22 TINA: MS RICHARDS: How was that? 23 terrified of that. I would have said when this letter 23 24 Well, I mean, we are only realising in the last 24 came in, he would have been pretty much kept to 25 year, right up until Seamus was diagnosed, we never 25 himself.

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1 MS RICHARDS: Now, Tina, in November 2008, you accompanied and I distinctly remember Dr Benson met us when we 2 Shea to a liver ultrasound scan in Belfast? 2 went into -- I am sure we went into the haematology 3 TINA: 3 part. He actually says: "Thank you for bringing I did. MS RICHARDS: That was only a few weeks after your mother 4 Seamus up", and took Seamus away then for the scan. 4 5 had died? 5 So, no, I wasn't in at the actual scan. MS RICHARDS: You described in your witness statement, 6 TINA: Yes. 6 7 MS RICHARDS: She had extracted a promise from you, 7 Tina, a conversation you had with Shea when he came 8 I think? 8 out of the scan? 9 TINA: 9 TINA: Yes. Yes. MS RICHARDS: What was the promise she extracted? MS RICHARDS: What can you recall about that conversation? 10 10 It was a curious conversation. I have always Every day of our life before she even died, but 11 11 12 certainly when she was very, very ill -- she didn't 12 remembered it. We were coming down in the car know she was going to die. She was very, very ill and afterwards. He was a bit quiet. He says to me, 13 13 14 must have known that things weren't great. Her 14 "That's the strangest thing". And I said, "What is it?" He says, "Do you remember we got the money?" I 15 express wish was that we would care for Seamus, keep 15 16 16 an eye out on him, make sure he was okay. It didn't said, "The money because of the hepatitis", or the matter about the rest of us like, but as long as he 17 contaminated blood, as he knew it. I says, "That's 17 was okay, which we would have done anyway of course, right". He says, "This hepatitis thing must be more 18 18 19 because Seamus was a high priority for us all, but we 19 serious". I says, "What makes you think that?" He 20 were fulfilling her wishes. 20 says, "Because it can cause cirrhosis of the liver". 21 MS RICHARDS: So you accompanied him when he went to 21 So I think maybe that was when he realised "this could hospital for the scan? 22 be trouble, but I am okay", and he was quite confident 22 TINA: I drove, yes. 23 that he was okay, and maybe confident that it would 23 MS RICHARDS: Did you go in with him for the scan? 24 never impact him. He says, "Because they give you 24 No, not to the scan, but I remember walking in, 25 more money whenever it comes to cirrhosis, but I don't 25 121 122 want that", he says, "because you are a dead man". 1 "Although his blood tests are rechecked every 1 MS RICHARDS: And he called it "dead man's money"? 2 three months, the condition of his liver continues to 2 3 TINA: Yes. 3 give cause for concern and would need to be closely 4 MS RICHARDS: And that is the stage 2 Skipton payment? 4 observed over the coming years." 5 **TINA:** That is what I believe it to be, yes. 5 Is it your view that the condition of Seamus' MS RICHARDS: Is what you think he was referring to? 6 liver was closely observed over the following years? 7 7 TINA: That's right. Absolutely. I believe that Seamus was very TINA: 8 MS RICHARDS: Nothing further was said. You understood 8 closely monitored. However, that wasn't shared with 9 9 that Shea was okay at that time? Seamus, and anything arising from that, any worries 10 TINA: He told me that. I didn't know any of it. That 10 arising from that was never shared with Seamus or us, 11 has always stuck with me. 11 because he was terrified that, you know, as I said MS RICHARDS: Now, one of the main concerns you express in 12 this stage of cirrhosis of the liver and leading on --12 13 your statement and, of course, conscious as I am that 13 because obviously cancer is a very real risk. So he the doctors and Trust have not had a chance to respond was very concerned about that. So whenever he left 14 14 to it, but one of your concerns is what you regard as 15 that first scan, in 2008, he was very confident that 15 16 16 a failure to undertake regular screening or scanning he was safe. We were confident that he was safe. To 17 of Shea in the years after 2008. Is that right? 17 be quite honest, we never gave it any second thought. 18 TINA: Well, that was the only scan he ever had until he 18 We thought if there was any issue, the doctors would 19 was diagnosed. 19 send for him. 20 MS RICHARDS: I am just going to ask to have up on 20 MS RICHARDS: So you are critical of the fact there wasn't screen -- in fact, it is in your statement, Tina. 21 a scan over the following years after 2008? 21

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Perhaps I will just read it out. You have referred to

a letter at the end of your statement in a summary,

a chronology at the end, from 10th September, 1997,

from Dr McNulty. It says this about Shea: 123 124 (31) Pages 121 - 124

TINA:

Yes.

liver function tests?

MS RICHARDS: Do you understand there to have been some

form of ongoing monitoring, in terms of blood tests or

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1 **TINA:** Absolutely, at his Haematology clinic, yes. alone, because you know when I am in pain I can't be 2 MS RICHARDS: But you don't know what emerged from those 2 bothered with anybody, and then I will see you in tests or whether they were shared with Shea? 3 three days time again." That was Seamus' attitude. 3 TINA: No. I did look through his notes, albeit it was 4 MS RICHARDS: Tina, you have observed in your statement 4 5 very difficult to look through his notes when he has 5 that Seamus wasn't the same again after that. In what 6 literally just passed a year coming this week, so it 6 7 was too emotional to look through at some of the 7 TINA: Hindsight, I know, is a wonderful thing, but a lot 8 stuff. Just as a haemophiliac going to clinic, your 8 of his friends were sending messages to me, you know, 9 9 bloods are checked. We were aware that his liver via Facebook and whatever, to say they were a wee bit 10 function would have been one of those checks that 10 concerned. He had a very, very close group of friends 11 would have been being looked at, as well as virus 11 equally like family. They were very concerned about 12 levels and stuff like that. 12 changes going on with him and things, maybe wee MS RICHARDS: Now, in September 2014, you have already 13 comments he was making about sore tummy and different 13 14 referred to this, Patricia, Shea broke a bone, a femur 14 things that were going on with him. Of course I would 15 bone? 15 have probed him, but as soon as you probed him: "Who were you talking to?" You were caught out 16 PATRICIA: Yes. 16 17 immediately. MS RICHARDS: He spent about three and a half weeks in 17 18 18 hospital? I did try and encourage him to go and make sure 19 PATRICIA: He did. 19 he was okay. He said "No, I am feeling okay. I am 20 MS RICHARDS: How did that impact upon him? 20 coming round now", that type of thing. There was 21 PATRICIA: Well, the way Seamus was, because he was in 21 that. I have lost my ... 22 MS RICHARDS: That answers the question, thank you. 22 Belfast, "It would be taking you out of your way. So 23 what you have to do is bring me up this and this and 23 TINA: Thank you. 24 this and this for the next three days. Go down then 24 MS RICHARDS: Then a time came in October 2017, when Shea 25 and put so much money on my TV. Then just leave me 25 did go and see his GP. What can you recall about 125 126 that, John? 1 which was in the stem of the liver, which meant that 1 2 2 JOHN: Well, basically I remember him landing at the he couldn't have any treatment, and pretty much you 3 house and telling me that he had cirrhosis of the 3 have three to six months to live. 4 liver, and he had cancer in the liver, he says: 4 MS RICHARDS: And that was perhaps November 2017? 5 "I have got three to six months to live, and I have 5 TINA: Yes, by the time he got --6 organised my funeral, but I need you to organise a few 6 MS RICHARDS: He told you, John, in the way you described. 7 7 other things for me and take care of a few things", He phoned you, Tina. 8 and he just sat down. He had his dinner and he left. 8 TINA: Yes. 9 9 MS RICHARDS: And I think you Patricia? I just couldn't believe the conversation. It was so 10 surreal. I was like did that just take place? He 10 PATRICIA: Yes. 11 just walked in and says "I'm dying in six months' 11 MS RICHARDS: And told you essentially what John has just time". It was a shock, like, you know, a total shock. 12 relayed? 12 13 MS RICHARDS: And that was triggered by -- he had gone to 13 TINA: I got quite cross with him. I have never ever the GP first of all because he was experiencing very fell out with Seamus. Seamus and me were very close 14 14 bad stomach pains, and then he was referred to the 15 15 growing up. There was only a year and a few months 16 hospital. You said that was quick, immediately 16 difference. Albeit he would have drove you crazy 17 referred to the hospital? 17 mostly growing up. He was just so funny. He had 18 TINA: He went to the GP with tummy pains, as you said. 18 a humour and he had a dry humour. Sometimes he would 19 There was nothing before that. What she seen in him, 19 have said stuff and you didn't know "Is he serious?" 20 she was horrified. So much so that she sent him for 20 So he phoned me and he says, "You're not going to 21 a scan, which resulted in it being done on the 21 believe this". I hadn't obviously been chatting to 22 Saturday. I didn't even know you could get a scan on 22 John or anybody. I said, "Why, what's wrong?" He 23 23 a Saturday. Anyway, he was sent up for a scan. says, "They have told me", because I knew he was 24 Unfortunately, as the events rolled out, the scan had 24 running for the test, I knew there was something going 25 showed that he had actually got advanced liver cancer, 25 on. He said, "there is nothing they can do". He

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says, "They were hopeful that maybe the tumours were small enough that there could be some treatment, but there is nothing they can do. I have three to six months to live". I said, "I don't believe you. No way. We'll not be accepting that. Not at all. That can't be right. It can't be that final".

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I will be honest with you. I was thinking look at all the years that maybe -- you know, this cancer, or that type of cancer doesn't appear overnight or certainly over a few weeks. It has to gather for years to get to this stage. That was my own feeling on it. And as he told me that, what horrified me more, because at this stage, obviously I was aware with the conversation I had had with him that hepatitis can cause cirrhosis and leading on to cancer, and he says to me, you know, "The doctor was lovely." He was absolutely delighted with this. It was Dr McCrory. He says, "He was very kind, but he was saying to me, you know, it was probably my lifestyle that caused this." I went, "Absolutely not. Absolutely not. Don't you dare let that be said to you". He says, "But, he is lovely". I says, "I am sure he is lovely, but this is a direct result of hepatitis C. Don't you dare accept that".

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You know, he fought the corner of the doctor.

Seamus couldn't go down the town to the bars because they were too rough. So these were his two local bars and all his friends went into it. That made me angry, because there is a stigma getting put on him, and I don't really like that.

MS RICHARDS: John, you have made some observations about the times you used to occasionally go out with Shea?

JOHN: As I say, he didn't play football but he loved football. Me and him would have went out and watched 10 a game of football and had a couple of pints. I would say I probably consumed more alcohol than Seamus. He 11 12 couldn't afford it, to be honest with you. I just 13 don't know where that came out of. It's just crazy

for them to suggest that. MS RICHARDS: There's also some suggestions -- again, 15 I know you are aware of this in the medical records, that over the years he missed appointments or didn't attend. Whichever one of you wants to answer that, please do.

19 20 Can I answer that? Patricia, sorry, go ahead.

PATRICIA: I was just going to say no doubt about it. It was like you would have needed a crane to get him there. No doubt about it. I would say aye, he did, and he had loads of appointments from us, because he

mortally hated hospital. He really, really did. At

That is how much respect he had for the medical 2 profession and how my mother and father brought him

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PATRICIA: Brought us all up. 4

5 He wouldn't have questioned that. However, I was TINA. 6 adamant that's what it was.

7 MS RICHARDS: You three know, I think, that there are some 8 medical records that refer to Seamus having an alcohol 9 problem?

10 TINA: Uh-huh.

MS RICHARDS: What's your response to that? 11

12 PATRICIA: Can I answer that?

MS RICHARDS: Of course you can. 13

14 PATRICIA: I am telling you now, I am so, so angry, 15 because that's not Seamus' lifestyle. Don't you get

16 me wrong. Seamus would have done anything to get out

17 of the house, did not rest, did not put his leg up and 18 rest the way the other brother would have did it.

19 Seamus could not stay in the house. He had to be out,

20 out, out, all the time, but if they had been there and

21 seen Seamus, Seamus sat at the bar a lot of the times

22 with a cup of tea, just for conversation to his best

23 friend that worked in the bar, just for somewhere to

24 go and somebody to talk to, because he couldn't do the

25 things that other people wanted to do.

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1 one stage my mother was coming home from the hospital 2

from visiting, and he was running down Spencer Road in 3 his pyjamas. He was getting there before her. He ran

4 out of the hospital. That was just Seamus' nature.

TINA: It was painful, what he was going through in the hospital. It was painful when he was a child. But if you are chatting more about when he was an adult --

8 MS RICHARDS: Yes.

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9 TINA: I know that Seamus went to doctors. I mean.

10 I have had comments -- I attend clinic for other

11 reasons with other family members, and we also share

12 the same consultant. Lovely, lovely man, very jovial,

13 very likeable. But there was comments made to me,

"That boy doesn't turn up". But Seamus went, in 14

15 particular, on a few occasions -- I don't want to

16 criticise, because maybe that's too strong and I am

17 being unfair and the last thing I want to be is unfair

18 to anybody, but Seamus would have been criticised for

19 maybe just not attending the clinic, you know.

20 I don't think anybody would understand, other than

21 maybe the people in this room, haemophilia is so

22 debilitating. Seamus probably was one of the worst

23 haemophiliacs you will ever meet. He had chronic

24 joints. Getting out of bed -- I will give you -- if

25 he got out of the car to come to your house, you

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1 ignored him for a couple of minutes. I am saying 2 ten minutes maybe. Because he would have stood at the 3 door of the car to adjust. He would let on he was 4 looking for something. You just ignored that. Then 5 he would have come into your house and he would have 6 sat on the arm of the chair. He could never sit down 7 in the chair. 8 If you said, "Are you sore today, mucker?" "No, 9 I am grand". 10 It was embarrassing -- he was embarrassed by his 11 condition. Instead of maybe the clinics realising 12 that he was not coming because he just couldn't come, it was criticised that he was -- sorry, maybe not 13 14 taking care of his health, and that couldn't be 15 further from the truth. Seamus managed his own 16 health, albeit maybe in an amateur way, because he was

19 MS RICHARDS: Now, over the months that followed from Shea

not medically trained. He had to become that. So

20 having been given this diagnosis in about

21 November 2017, Shea's family, yourselves, the wider

I really have to fight his corner in that sense.

22 family and friends, tried to support him and watch out

23 for him?

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Absolutely, yes. 24 TINA:

JOHN: Yes. 25

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Anyway, Rosemary did get in. She says, you know, we need to contact your GP and maybe get her to come out and take a look at you. "We will do it tomorrow." So she says, "All right, we will give it to tomorrow." Then she phoned me and she says, "This has to stop. This can't go on".

He phoned me that particular night, just a wee conversation. I said: "How are you feeling?" "Aye, grand." I said, "Rosemary was saying that you might need a wee bit of the GP out." "Aye, I will go tomorrow." "I said, "Right, sure, I will come up and we will get it arranged. We'll take you over and get it arranged. We will take you over and we'll get the GP to look you over, sure, do no harm".

As it turned out, it wasn't the next day, because he got us to the following day, which was the Tuesday. He phoned the GP, or the GP phoned him, and she said, "Seamus, I am not coming out, because if I come out, I am putting you straight into hospital. I am sending an ambulance for you now." Unfortunately, the ambulance came and away it went. MS RICHARDS: You have described again in your statements that in the weeks before he died he was in pain?

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24 JOHN: Yes. 25 TINA: Much pain.

MS RICHARDS: You have said in your statement, Tina, that 2 Shea was aware he was dying, and he became a little 3 reclusive?

4 TINA: He did. Sorry. This part is quite funny, because 5 he was so crafty at manipulating who he wanted to get 6 in and who was going to see him. And again, phone 7 calls, we could have had a phone call conversation for 8 an hour, and everything was grand, and he sounded 9 grand. Particularly, I think it was around 20th 10 April, Rosemary had rung me. She says to me, "That boy has the key in the back of the door". So 11 12 obviously the key is in the back of the door, you 13 can't get the key in. She had a key to go in. She 14 would have made him dinner and left stuff over, and Patricia was the same. But he had the key in the back 15 16 of the door so that he could decide who was getting in 17 and when.

> So for maybe three days we weren't getting in to see him. Now, I had again one of his friends who would have messaged, and she was very, very concerned, because he was talking to her in the middle of the night, and he was quite fear -- he was terrified, I will be honest with you. The bravery was there, but he was terrified, and night-time was very troublesome for him.

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MS RICHARDS: Couldn't find a comfortable way even of 2 lying. He told you that he had received the dead 3 man's payment?

4 **TINA:** Yes. The particular day that the comment about 5 his lifestyle, he told me it on the same day it 6 seemed, the same day he was told he had three to six 7 months to live, that it was probably his lifestyle 8 that had done it and he was handed the dead man's 9 payment. He says: "What do I do with that?" 10

MS RICHARDS: Before I ask you to talk about the very last part of Shea's life, can you tell us a little more 11 about what he was like?

12 13 TINA: As a child -- I have to tell you -- this is the character of him, even from a child. Rosemary, myself 14 and him would have shared a room when we were 15 16 children, although he slept really with my mother, 17 because he was always ill. But you would have got 18 spurts of Seamus being at himself. We still had to go 19 to school. We had built -- not built-in wardrobes, 20 wardrobes that were kind of in the wall of the 21 bedroom, with a sliding door or a push door. Seamus 22 would have went into that wardrobe and hid for maybe 23 fifteen minutes. We would have went to bed. You 24 would have been just drifting off into a nice sleep, 25 and he would have jumped out of the wardrobe with

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1 a sheet over his head screaming. It took you about 2 a month to come round. Then he would have done it 3 again. So in that way he was just a nightmare. He 4 was so funny growing up with, he was just lovely to 5 grow up with. You remember him with the snooker, 6 going down --7 JOHN: As I say, we pushed him towards snooker, because 8 he was quite good, and we didn't want him doing any 9 contact sports. I hate snooker, but I agreed to play him, because it was what we needed to do to get him --10 like it wasn't much of a match. It was usually 11 12 a humiliation. He used to just destroy me in front of everybody. But, you know, as I say, he did love 13 14 soccer. He loved it so much. Me and him were 15 Liverpool supporters. We always tried to go out and watch an odd match there, have a beer. That was it. 16 17 TINA: As regards the snooker --JOHN: The snooker, he had me tortured. As you know, 18 19 I work for local newspapers. Seamus was always 20 looking for some photograph in or snooker results in. 21 Of course they always left it to the last minute, 22 where you nearly had to stop a press just to get it 23 done for him. He never changed. No matter how many 24 times you told him, "I need these results earlier", it 25 just didn't wash with him at all.

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me -- it is actually his friend that owns the bar. He says, "He phoned me and the bouncers are going to take me up the back stairs. Two of them will get the back wheels and two get the front". I didn't even lift on it. I says, "That's perfect".

I don't think I have ever seen anything more horrible than to see him being carried up, such a frail state, and these big burly men in tears. He didn't see them in tears. They were very good at keeping it. But that will stay with me forever, you know. He was taken up the fire escape outside, because he didn't want people to see him being wheeled through the restaurant or the bar, whatever was downstairs.

MS RICHARDS: In the last few weeks of his life, there
 were three things he particularly wanted. One was the
 snooker?

18 TINA: That is right.

19 MS RICHARDS: One was to be with -- he had a daughter, to

20 be at his daughter's 16th birthday party.

21 TINA: Yes.

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 $22\,$ $\,$ MS RICHARDS: $\,$ And the other was to go on a family cruise,

take his daughter and go on a cruise with all of you.

24 TINA: He did.

25 MS RICHARDS: He played snooker and he made it to his

TINA: When he was 14 -- he was learning to drive when he 2 was 16, but when he was 14, he obviously couldn't 3 drive and he asked Sid, my husband now -- he wasn't my 4 husband then -- and myself to take him to Omagh, 5 because he was going to play Jimmy White in Omagh. He 6 was, as I say, 14. He went up and he beat him. The 7 atmosphere was just amazing. I know you have a photo 8 of him. 9 MS RICHARDS: We have a photo of Shea as an adult. It is 10 2778002. If we go to the third page, please, Paul. 11 Keep going. Next one. There's Shea. 12 TINA: That's him. That was ten days before he died. He had helped arrange that. Jimmy White was very fond of 13 14 him, very emotional that night. It was a tough night. My husband and my son and that took him down. John, 15 16 myself -- a few days before that I had said, "We will 17 come up". He had all his gear on him. We were laughing about him. He never carried a bag. He had 18 19 this bag on him and he was ready to go for the big 20 night. He says to me -- I said, "We will come up and 21 I will bring up -- we will put the chair out". "What 22 chair?" "The wheelchair". I was assuming that he 23 would be going in a wheelchair. "I am not going in

The night I came up, in the afternoon he said to

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a wheelchair". Right. Okay, no problem.

1 daughter's birthday?

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TINA: He made it to the snooker that night, albeit he literally just sat there. He wasn't fit to play. He would have loved to have played Jimmy White again, maybe to see if he could beat him again, you know.

The day of his daughter's birthday, he actually wanted to just be alive for the day of his daughter's birthday. I went over. That was the day he was coming out the hospital. I don't know why, he didn't want to come out of hospital that day. We never could pick up on why he wanted to stay to the Monday, for whatever reason. For somebody that hated hospitals and would never have dared be wanting -- he didn't want to come out.

On the way home -- and I know it is my statement -- we had ordered balloons and all-sorts. He says, "I will go in, maybe I will just get her another wee present", because he absolutely idolised her. He adored her. I said, "Sure, we will do that."

I wheeled him out into the car, got him settled, got down to the shopping centre. I said, "We will go in and pick up the balloons now". There is like a wee jewellery store. He says, "You just go on in and get them". He was completely wiped out. Literally, to get him from the wheelchair, from the bed into my car,

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and he was not fit to go in, obviously. So we got him home, and a couple of photographs with Jennifer, showing her 16th birthday, and that was it. He was wiped out for the rest of the night. He wasn't fit. But he got to be there at the 16th birthday. MS RICHARDS: He didn't manage to take her on the cruise? JOHN: No, he didn't, no. We were doing our best to try to arrange a family cruise, like. TINA: Talks about helicopters and everything. JOHN: He just went so far downhill after that that it was impossible. TINA: He went very quickly. MS RICHARDS: The last few days and weeks of his life you have described in your statement, as have your brothers and sisters. So I won't ask you to say anything more about it than you want to, but he was in a lot of pain? JOHN: Very much. PATRICIA: Horrendous. JOHN: Horrendous. PATRICIA: Horrendous. **JOHN**: Especially the last three or four days there where he was totally in his bed and, you know, he had to toilet and such, and obviously the other brother, being haemophiliac as well, wasn't fit to do anything

like that. So I was doing it, because the girls can't do it. It was just impossible to move him without causing pain, you know.

TINA: This day last year -- and I can talk about it now, but this morning I probably couldn't have -- we can obviously all point out where we exactly were at this minute in time, which was beside his bed, but this particular morning I went into the room. What I didn't know -- he wouldn't let us stay at night. He was a nightmare. John had slept on the sofa and he wasn't even allowed. "Who's out there?" You know, he caught you, like, but he needed somebody there night and day. You couldn't have left him.

So I came up in the morning with the buns for the tea, but when I went into the room there was black bodily fluid on the floor and he was annoyed. I will be honest. He probably was going in and out of some kind of consciousness. He wouldn't take Oramorph, because he wanted to keep his liver -- because Dr McCrory says, "Don't be taking paracetamol. Don't be ..." Whatever that doctor had told him, it was gospel. He really did take it on board. I think he then tried to not take anything, which was -- you know, and the pain that he was in was horrendous. When I went in that morning, and we called

She got him sorted and got him into the bed.
I actually don't know what I cleaned up, whether it
was blood, whether -- I don't know what it was. It
was just liquid. I was a wee bit horrified. We felt
very, very alone, very isolated and not helped in any
way from -- I would have thought -- as haematology and
hepatology clinics, I thought maybe, you know,
somebody should have been there, some expert help in
that sense. Like we would have went to the ends of

Rosemary over and we cleaned up -- I cleaned it up.

the earth to help him, as you would do for anybody, but I think a wee bit of extra help or expert help would have absolutely been perfect at that time.

MS RICHARDS: And, John, you have described in your statement how the two of you had made plans to watch -- I'm sure I'm going to get the name of the football tournament wrong -- the European Cup finals?

JOHN: The Champions League final last year. I would like to add to what Tina was saying that on one occasion I entered the room to get him a drink and that fluid was there. I don't know. I am wrong maybe, but I thought it was something to do with the radiation treatment he got previous, because it didn't look like blood. It's hard to describe what it looked like. He actually nearly came out of the bed shouting

at me not to touch that. "Don't you touch that. Whatever you do, do not touch that". I remember that well.

Then, yes, on the Saturday night we had plans to go across to a pub across the street from where Seamus lived to watch the Champions League final. We spoke about it most of that week, and then on the Tuesday or Wednesday night he says to me -- he says, "You know, if you're going to take me across to that match, you're going to have to push me in the wheelchair. How do you feel about that? Ha-ha!" I says, "I feel okay about that, because I can get drunk and you can push me back", and he says, "Right. You're on. I will definitely go across in the wheelchair". I says, "Right", but obviously he just got -- he just went downhill all week.

The Champions League final on that Saturday night for me was sitting at Seamus' bedside showing it on an iPad. He was dropping in and out of sleep, you know, and when he heard a cheer coming from actually the pub across the street, believe it or not, he just sat up once and says to me, "I take it Liverpool scored", which wasn't the case, but I says, "Yes, they have", and he just went back down again and he never spoke to me after that again. That was Saturday night

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1 and Seamus passed away in the early hours of Monday TINA: Yes. 2 morning. 2 MS RICHARDS: Is there anything in particular you would 3 MS RICHARDS: That was 28th May 2018, so almost a year 3 like to say about that? 4 JOHN: You know, he was the baby of the house. I mean, 4 ago? 5 JOHN: Yes. 5 I gave him fifteen years. I would be expecting Seamus MS RICHARDS: How old was Shea? to be organising my funeral, you know, not the other 6 6 7 JOHN: 45. 7 way about like. So ... I think it's more the shock 8 TINA: But he was only six weeks 45. 8 of the speed in which -- you know, that's where I am 9 9 JOHN: Yes. disappointed with the medical side of things, that MS RICHARDS: You mentioned earlier he had organised his 10 they could have afforded us maybe a bit more notice, 10 11 11 own funeral. I think it was a Liverpool funeral. Is if not -- I am not saying they could have saved his 12 that right? 12 life. I think he would have succumbed to the cancer JOHN: Yes, yes. It was all Liverpool-themed, yes. 13 eventually anyway, because by the sounds of things, 13 PATRICIA: He bought a Liverpool top. 14 you know, hepatitis is a very serious thing, despite JOHN: He bought a Liverpool top for the top of his 15 15 what we thought. 16 coffin. 16 If they had just afforded us with scans or PATRICIA: He told the undertaker, "Nobody's getting that. 17 picking anything up, even symptoms. Seamus' symptoms 17 18 18 That's going down along with me". were so severe, looking back, that we maybe would have 19 JOHN: He says, "Don't let anybody take it off the 19 had some warning. Maybe that sounds selfish, because 20 coffin. It's to go down with me". 20 that's what I would love for myself, a bit of 21 MS RICHARDS: All of you described in your statements the 21 preparation for this, you know. You know, I have to devastation that his death brought upon the family --22 22 say Seamus says to me two weeks before he died, "I'm 23 JOHN: Yes. 23 not affeared to die". I say, "Nor should you be. My MS RICHARDS: -- and the hole, the gap that's left in your 24 mummy will be there with you. You know, she's getting 24 25 lives. 25 her boy, but you're going nowhere yet". I says, "I've 145 146 1 been studying this thing. You've five years in you". 1 hope going, because he was gauging, he was asking 2 2 these questions to see, "What time have I got?" He He looked at me as if I was crazy like, but anyway 3 I get away with that. I says -- you know, we would 3 kept saying to every doctor, because we could hear 4 have had a wee conversation. I says, "Know what you 4 from outside. "I think there's two months in me left 5 should do? You should open a snooker school. We'll 5 yet, you know". She says, "Well, you're going nowhere 6 help you run it", you know, just silly chat, anything, 6 today" and I thought, "Thank you". So that encouraged 7 7 but he says, "I want more time, Tina". I says, him a wee bit and gave him a wee bit of hope. 8 8 "I know. You'll get that time". Like that was But the morning of the liquid he cried out and 9 9 literally two -- it wasn't even two weeks before he he's never asked for the pain relief in such a way. 10 died. You're sitting there and my heart was breaking, 10 He says, "Tina, please give me my Factor VIII" and I says, "No problem" and I mixed it up, and I went to 11 but you couldn't show the emotion, because it wasn't 11 12 fair on him. 12 inject it and the needle just -- obviously his veins 13 The particular morning of the -- I mean, the 13 had collapsed, because it just would not go in. He pain must have got horrendously, you know, to cope says, "Is it in there now?" It was like, you know --14 14 with for him. He wouldn't accept the driver, because 15 I says, "It's in there now", but it wasn't like. 15 16 There was nothing -- it wasn't going to do anything 16

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pain must have got horrendously, you know, to cope with for him. He wouldn't accept the driver, because in his eyes -- my mother and father both had a driver before they died and it's the most amazing thing, because it's a very gentle way of helping you across, if you like. It's the most amazing tool, but he wouldn't accept that.

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The hospice nurse came in, and she nearly didn't get in, because she was from the hospice, a lovely girl. He says to her he was looking to go on holidays. She says, "Well, we'll not be just going today". I thanked her so much, because she kept the

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However, you couldn't have passed the bed.

That's the sad thing, because the professionals that were coming in and dealing with Seamus were very, very skilled in dealing with cancer pains and tumour pains

anyway. It wouldn't touch it. He says, "I'll take

some of that Oramorph stuff". I says, "No problem.

I'll get you that now", and we measured it out now.

As John says, he was just going in and out of some

kind of coma I think, which was a blessing.

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1 or whatever they see on a daily basis. They were TINA: She has, yes. 2 excellent. They were excellent people, GPs, 2 MS RICHARDS: -- to voice that Michael himself died in his 3 excellent, but none of them knew about haemophilia 3 late 50s, I think? 4 4 TINA: He was ten days off his 60th birthday, because he pain, and haemophilia pain is horrendous, horrendous, 5 especially in its rawest form when you have no Factor 5 -- again, I don't know if it's a haemophilia thing --6 6 he had it all planned for a party and he was having VIII to even try and, you know, resolve bleeds. His 7 legs were that thin, but his ankles were like that. 7 this, you know -- and just a gentleman, just a lovely, 8 8 His knees were like that, which they always were, but, lovely guy. 9 9 MS RICHARDS: He had haemophilia? I mean, I could see -- you know, I am very aware of 10 TINA: Severe haemophilia. 10 haemophilia. So I knew that he had severe bleeds MS RICHARDS: He was infected with hepatitis C --11 right up and down his body. He hadn't got any 11 12 bruising, which is not necessarily the best thing, 12 TINA: He was. because if it comes up into the bruise, it's not MS RICHARDS: -- through infected blood products. 13 13 14 bleeding inside; it's coming to the surface. He just 14 TINA: Yes. MS RICHARDS: And he too died of liver cancer in March 15 had the most horrendous few days, and then eventually 15 2018? 16 we did get the driver. He agreed to the driver, 16 albeit we had a couple of choice words from him, and TINA: 17 17 He did, and Seamus was aware of his death. he did agree to it, but it took a lot for the driver 18 18 JOHN: Yes. 19 to just even touch the pain. 19 MS RICHARDS: I'm just going to ask you, last of all, just 20 MS RICHARDS: Two months before Seamus' death your cousin 20 a little bit about your eldest brother, Eddie. I'm 21 Michael died. 21 not going to ask you so much, as you know, because TINA: Uh-huh, Michael Perkins. 22 22 we've got Eddie's written statement. MS RICHARDS: Michael's daughter Laura has given 23 23 JOHN: Yes. 24 a statement to the Inquiry and she is content for 24 MS RICHARDS: Eddie also has haemophilia? 25 vou --TINA: He has, yes. 149 150 JOHN: Yes. 1 you know, "Could you make sure that Eddie's getting 1 2 referred for a scan?", thinking that that would happen 2 MS RICHARDS: He also spent a lot of his childhood in 3 3 very easily. That wasn't the case. hospital?

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4 JOHN: Uh-huh. 5 MS RICHARDS: And he also received Factor VIII products? 6 JOHN: Yes. 7 TINA: He did. 8 MS RICHARDS: And had a similar experience after his 9 diagnosis with hepatitis C on Interferon as Shea did? 10 PATRICIA: Yes. MS RICHARDS: Now you've accompanied Eddie to some recent 11 12 consultations. There was a scan he was due to have in 13 May of last year --Yes. 14 TINA: MS RICHARDS: -- that didn't happen. Can you recall what 15 16 happened? 17 TINA: I had asked -- obviously when Seamus was diagnosed 18 quite shockingly, what seemingly to us -- well, it was 19 totally out of the blue for us, but anyway after that

I expected, knowing that Eddie had hepatitis C, that

certainly the doctors would be knocking down the door

to get to Eddie and give him a check over, you know,

after Michael and then Seamus. So we expected that.

So on a few occasions when I would have been, you

know, in contact with the doctor, I would have said,

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6 occasions at that stage, but he did get the scan 7 appointment out, 22nd May. Hence Seamus was extremely 8 ill at that stage, but there's enough of us that I was 9 going to take Eddie. Eddie trusts -- you know, he 10 relies very heavily on ourselves. So he had asked me to take him and I says, "Of course I'll take you up". 11 12 Seamus was very, very ill at that time. 13 Two days before the scan was due he got a phone call from Hepatology in Belfast to say that the 14 15 scanner was broke and they would send him out a new 16 appointment. My initial thought, "Well, that was --17 well, that was nice" -- you know, because I think --18 they were very aware -- everybody was very aware of 19 Seamus' imminent death. I thought, "Well, that was 20 nice of them, because, you know, we can take Eddie up 21 maybe in a few weeks". I don't think a few weeks 22 would have mattered. That wasn't the case quite 23 frankly. I do believe that they used Seamus' death as

By the time we got to May, when he eventually

did get an appointment -- and I had asked on two

a timing tool, and that's the only way I can say it,

that is as the year simmered on, we got to September, and again I had asked, you know -- because the scan didn't follow on, and I assumed it would, and I had asked Dr Benson, "Would you refer Eddie for the scan, because they haven't sent out a new one? The scanner was broke". He did look a bit confused, to be fair. He did think, "Was the scanner broke?", you know, or -- I gave him this information and he seemed surprised. So whether he thought Eddie had had the scan I don't know. So we went.

At that stage, I thought, "Well, we'll give it two weeks". The two weeks had passed. Still no scan. Eddie at this stage was anxious, as you would be yourself, putting very high reliance on the scan being, you know -- keeping him safe. He says to me, "I haven't had any word about that scan", and I says, "Well, look, I'll send an e-mail", and I sent an e-mail. I sent the e-mail to pretty much I would say maybe ten people: Hepatology; I sent it to Haematology; I sent it to social workers; I sent it to the head of the Trust. "Could you give my brother a scan?", because at this stage I was kind of thinking this isn't an accidental forgetting about him. I felt it was a deliberate avoidance to bring him in.

Now we had just such a horrible year, you know,

"Yes. 22nd May", and I says, "Absolutely not", and the reason being is Eddie writes everything down. He documents everything, and as soon as that call came to him he rung me. I sat at the doorstep of my house, because we had just left Seamus, and he says, "The scanner's broke. I don't have to go for the appointment" and I says, "Okay". Obviously we thought the appointment was coming out. I says, "So I know that appointment was cancelled".

What I didn't realise when Eddie was reading it out, he was reading it off his handwriting. She asked me on the phone did I have a letter to the effect. I says, "I'm sure he has, because he's just read -- he read it to me", but he didn't. It was my mistake. He had read it off his notes.

However, I went back into my O2 account and I found the timing of my phone call from Eddie, from Eddie's phone. Then we went into Eddie's O2 account and we found the call that came from Belfast. So the call did come in. She wasn't aware of it. I'm not saying she was trying to say that it didn't happen, but she was saying it didn't happen, but she wasn't aware of it. So I says, "Well, look, you know, going forward what are we doing? We need to get him scanned", because my concern was that we weren't going

I was thinking maybe our grief is turning into anger, but it certainly was for me. So the e-mail -- from the e-mail I got one phone call back and it was a lovely nurse by all accounts. She just says, you know, "Your brother was taken off the list or struck off", whatever it was. I says, "Why would you do that? He's got hepatitis. What would be the reason for that?" She says, "Well, our policy is if you don't turn up for a scan" -- I think it was two consecutive scans. I am not aware of any other appointment ever sent to Eddie, but apparently they said that there was one the previous year around Seamus' diagnosis. Eddie is not aware of it. My aunt, who at that time would have been Eddie's carer as well, wasn't aware of it. So anyway we've left it that this invisible scan appointment nobody knows about.

So this nurse went on to say that, "He was taken off the list because he didn't turn up for his scans", and I went, "Right. Okay. Could you give me the dates for them, because, like, I'm finding that shocking, because he's desperate for this scan". She said the date of the year before and I says, "Well, look, I'm not aware, so I can't comment on that. I don't know. Have you any other dates?" She says,

to lose another brother to the horrific death that
 we'd just lost Seamus. So the scan did happen.

3 MS RICHARDS: That was the end of November, 20th November.

TINA: That was round about the end of November, yes.

5 28th November actually I think it was.

6 MS RICHARDS: You went along with Eddie?

7 TINA: I did. I drove him up, yes.

 $\,$ MS RICHARDS: What you've said in your statement is that

9 you recall being told two different things about

10 Eddie's liver by two different doctors.

11 TINA: I did.

12 MS RICHARDS: What was that? What was the first thing

that you were told?

TINA: So in the morning -- he had two different
 appointments is the way it was presented. He had
 an appointment for an ultrasound scan in the morning
 and then he was going to have a consultation that
 would have explained what went on.

19 So we went in the morning to the ultrasound and then we came downstairs into the Hepatology clinic for

then we came downstairs into the Hepatology clinic for the consultation. Now the scan, Eddie went in and he came out. He's quite jovial as well. He says, "I have gallstones". I said, "I never knew that", just, you know -- I says, "Well, there you are there.

That's grand if they're not doing you any harm".

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1 So we went downstairs. We walked into the 2 Hepatology clinic and we met a doctor called Dr Cash. 3 He just says, "It's nice to meet you, Eddie. I've never met you before", which I found incredible quite 4 5 frankly, because I thought -- I wouldn't have been 6 aware -- I knew Seamus had never been, you know, 7 involved with the liver side of things for all those 8 years, but I did think maybe Eddie might have been. 9 I wasn't aware, but he hadn't met Eddie and Eddie had -- he just says, "You've had a scan there. Have you 10 11 ever had a scan before?" It was just a conversation. 12 He says, "No, I've never had a scan", and then they talked about other things, you know, that ... 13 14 MS RICHARDS: What you've said in your statement, and 15 obviously, as I said at the outset, we don't yet know 16 what the doctors or the Trust might say, but what you recall the consultant, Dr Cash, saying was that all 17 was looking good with Eddie's liver. You accepted 18 19 that and you were pleased with that? 20 TINA: We were very happy with that, yes, because -- yes. 21 MS RICHARDS: But then you then saw another doctor, Dr McDougall? 22 23 TINA: Uh-huh. MS RICHARDS: And what did Dr McDougall say to you as far 24 25 as you recall?

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what we're being told?" So he went, "But it's okay, because we have a great treatment", and I know there is a great treatment, and that's the sad thing about it, for hepatitis, and I says, "But, you know, cirrhosis of the liver, as far as my knowledge is, is not curable" and he says, "No, you're right, but this treatment will slow down any effect of the hepatitis attacking the liver".

There was a couple of mentions of alcohol as well, which I immediately -- Eddie had not touched alcohol in over ten years. So, you know, it had to be the hepatitis that was attacking the liver, which was very concerning to us.

As we were sitting, because Dr Cash had previously mentioned this brilliant treatment which we were -- you know, and I had asked him why Seamus wouldn't have got this treatment. He didn't clarify that for me, but Dr McDougall did clarify. So they must have had a conversation in between. His words to me were, "With your brother's", referring to Seamus, "larger tumours this treatment wouldn't have been appropriate or it wouldn't have been any good to him", and he immediately turned from me to Eddie and he says, "But, Eddie, with the smaller tumours it would".

I thought I was going to explode. I couldn't

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TINA: Well, as we were leaving Dr Cash, I had asked for 2 a copy of the scan just because we had already applied 3 for Eddie's notes, you know, as a process for the 4 Inquiry and stuff, and we didn't want to leave 5 anything outstanding. So we had asked for a copy of 6 the scan, which he gave us, and as we were walking 7 out, he just says, "Well, Eddie's going down for some 8 bloods. Eddie, I'll probably do another wee scan when 9 you're down there", which -- fine. We went 10 downstairs. Eddie went in, and about ten minutes 11 later the nurse came out and she says, "Mrs 12 McLaughlin, could you come in? Dr McDougall is in 13 explaining stuff to your brother". I just -- I'm not 14 sure what I'm allowed --15 MS RICHARDS: No. You --

16 **TINA**: Is it okay to say exactly what happened?

17 MS RICHARDS: Yes.

TINA: 18 Okay. So I went in, and as I went to sit down on 19 the chair, Dr McDougall just announced that he was 20 explaining to Eddie that there was advanced cirrhosis 21 of the liver, which nearly knocked me off my feet, 22 I'll be honest with you, because I had -- and 23 I actually says to him, "What do you mean? Sure we 24 were just literally upstairs told that the liver was 25 fine. How could -- you know, how could this be now

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1 believe it. I couldn't even -- I couldn't react, 2 because I was very aware of Eddie. I didn't want to 3 alert him, but my understanding that cirrhosis of the liver is not tumours. Tumours are to me another more 5 serious stage of liver issues. 6

The conversation just went on. Eddie had spoke to Dr McDougall about what was going to happen next. He was going to have some bloods and then we were going home, but when we left the clinic, I picked up my daughter. She is at Queen's. So we made a day out of it. Eddie was up with us. It was around Christmas. So we thought, "We'll go for our tea". So when my daughter got into the car, Eddie says, "I was at the clinic", and Carly says, "Aye, and how did you get on? Did you get on okay?" He says, "Aye. I was just told there was a wee bit of cancer there". I almost crashed the car.

Well, I didn't -- to be fair, I kind of thought he had misinterpreted cirrhosis, you know, and maybe picked up tumours. I says, "No, mucker, it's not cancer. Cirrhosis is bad, but, you know, it will be monitored and looked after. It can turn to cancer, but, you know, it's not cancer" and he went -- "No, no", he says. "Before you came into the room" -- no. He says -- "No, no", he says. "I've a wee bit of

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1 cancerous cells, but not to worry about it", and it. I says, "I'll bring Eddie to Belfast. That's not 2 I says, "But who told you that?" and he says -- he 2 a problem", but he was adamant that it will be the end 3 couldn't remember his name. I says, "Dr McDougall?" 3 of May and not before, and I couldn't understand that. MS RICHARDS: What you have said in your statement and 4 and he says "Yes", and I says, "But ..." -- he says, 4 5 "No, but that's where I sent out for you. I heard 5 what Eddie has echoed in his is: cancer and I nearly fell off the chair". 6 6 "We are now left in limbo waiting to hear about 7 MS RICHARDS: What you've said in your statement is there 7 Eddie and worrying whether he awaits the same fate as 8 8 was going to be a further scan. Eddie was told he was Shea." 9 TINA: 9 going to be scanned in May, which would be this month. Yes. Well, I think Eddie is in no doubt that he -- I mean, you know, he feels that he is -- this is TINA: Yes, which was really -- well, I actually was 10 10 a wee bit cross with Dr McDougall, I'll be honest with 11 11 something that's very much in front of him, hopefully 12 you, because he said he would send Eddie for a scan in 12 years down the line, but it definitely needs six months. I mean, we were very aware by -- I mean, 13 13 monitored. 14 my understanding is what Simon said yesterday, how he 14 MS RICHARDS: I have no further questions for you, but do you have anything that any of you would like to add? 15 is treated. Now it is still a very difficult 15 16 condition to monitor and look after, as we heard from 16 JOHN: No. 17 My head has gone blank. Simon, but Simon's scans every six months to me seems 17 TINA: like a normal way to deal with this, maybe even three PATRICIA: No. 18 18 19 monthly scans, because I know some people in England 19 JOHN: No. 20 would at certain stages get three monthly scans. So 20 TINA: If I could just say this is a platform -- and 21 whenever he said he would give Eddie a scan, you know, 21 thank you so much for bringing it here -- this is 22 in six months' time "... and we'll do it at 22 a platform that really should go on being maybe used 23 Altnagelvin for his convenience". I says, "That's not 23 in a very positive way. I know there has been talk 24 necessary", you know, because Eddie enjoyed -- he 24 about maybe myself and others criticising doctors. 25 enjoyed the day out and we would have made a day of 25 I am not saying that any of those doctors are 161 162

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incompetent, because I believe they are very excellent doctors. I just feel that maybe they are not using their excellence in a way that is positive certainly for our family and our experience, and I would please urge them that if there is anybody out there that they believe could be of any risk at all, please bring them in, scan them, blood test them, anything that has to be done, because this was a frightful experience.

Actually I did speak to you about what has gone on with myself recently, which has left me a bit

MS RICHARDS: You have your own investigations. You have 12 13 family members who have ongoing treatment requirements. 14

TINA: 15 Yes

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MS RICHARDS: You are left, you were explaining and you 16 17 say it in your statement, with a mistrust of the 18 medical profession?

TINA: Total mistrust. After Seamus died I felt -- I am not normally a stressful person. In fact, everybody would say I would be a bit hyper, but after Seamus died I took very severe chronic fatigue, just exhaustion, and I couldn't explain it. I had other

symptoms. I went to the GP, which is not something I have to go too often. As it panned out, I was sent

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1 to ENT for investigations, thinking that I had vertigo, which was horrendous, throwing up. It was 2 3 just a horrendous experience. Because of that I ended 4 up in the ENT clinic.

The doctor there what I didn't realise was very concerned that the symptoms I was showing was a brain tumour. He had red flagged me to an MRI scan. Now hence the difficulty of getting Eddie from 2017 to getting the scan pretty much a year later. The fear that went through my body that the scan was going to be guick, and it was guick. It was about three days later. Thankfully it is not a brain tumour, but unfortunately the symptoms also are very in line with hepatitis C, and the only way that I could have contracted hepatitis C -- because I am not a sex worker; I have never had Factor VIII blood; I have been married for 25 years; I have never taken drugs -so the only way I could have contracted, if it is, and I am going now next week for more investigations, and I have sent off a secret test, which is shocking that I even have to do this, but this is the only way I can feel confident that maybe I am getting a proper result is I had to send for a kit online. I will go through the GP as well, but I have had to send a kit offline on an alias and anonymous address just in the

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1	hope that if it is, that it is identified.	1	Lowry, Mark Donnelly and Caroline Carberry.
2	I have, as I've spoke to you, dealt with my	2	SIR BRIAN LANGSTAFF: And we start at 10.30?
3	brother, which I would do a thousand times over, but	3	MS RICHARDS: I'm not sure, sir. 10.00.
4	not only did they not warn Seamus of symptoms and	4	SIR BRIAN LANGSTAFF: We start at 10.00. 10 o'clock then
5	things to look out for. Even when Seamus took cancer,	5	tomorrow.
6	they didn't say to the family members "Be careful".	6	MS RICHARDS: We've been told it is 10.30.
7	Like I am mopping up bodily fluids and I don't know	7	SIR BRIAN LANGSTAFF: Let us say 10.30, if that is what
8	what I have touched. I don't know how I should have	8	has been published.
9	been protecting myself. I didn't wear gloves. I had	9	(Adjourned until 10.30 am the following day)
10	Dettol and I had wipes. So that's where it's left me.	10	
11	So I don't I have maybe bordering on a paranoia.	11	
12	I have no trust left and I would love that restored.	12	
13	MS RICHARDS: I am just going to ask Mr Snowden, who, as	13	
14	you know, represents you and the family, if there is	14	
15	anything further. There isn't.	15	
16	TINA: Thank you very much.	16	
17	SIR BRIAN LANGSTAFF: Can I thank each of you, Tina, John	17	
18	and Patricia, for telling us about your brothers and	18	
19	your cousin.	19	
20	TINA: Thank you.	20	
21	SIR BRIAN LANGSTAFF: Thank you very much.	21	
22	PATRICIA: Thank you so much.	22	
23	SIR BRIAN LANGSTAFF: Well, that's where we finish today	23	
24	I think. Tomorrow, Ms Richards?	24	
25	MS RICHARDS: Tomorrow we have three witnesses: Sharon	25	
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