1 Tuesday, 9 July 2019 2 (10.12 am) 2 SIR BRIAN LANGSTAFF: Thank you very much. 3 SIR BRIAN LANGSTAFF: I am sorry that we've started late. 3 So back to Mr W, again it's a restriction order 4 4 Technological problems. to preserve anonymity. Now, because it will be very 5 It's perhaps the case that technology is 5 difficult for Mr W to avoid mentioning some names, 6 6 labour-saving. When you try and sort it out, it does family names, in the course of his evidence, there 7 take time. It is actually guite reassuring to know 7 will be no live-streaming. The transcript will be 8 8 that we can manage without it and we're going do that edited to avoid any conflict, any compromising of his 9 9 this morning until ordinary service is restored, and anonymity later, and so you will hear it and hear it 10 here, but the world out there won't for the moment. 10 it won't affect what is happening. 11 The technological problem at the moment is in 11 The order is as follows: the name and address of 12 relation to the provision of document images and 12 witness W2781, that's Mr W to you and me, the name of Ms Richards has agreed to work round that, so that's 13 his wife who died, and the name of any other member of 13 14 what we shall do. 14 the witness's family and any other identifying 15 Before we begin with my making an anonymity 15 information, such as the witness's image or 16 order for Mr W, let we just raise something with you, 16 a description of their appearance, cannot be disclosed Ms Richards, arising out of yesterday's testimony. 17 17 or published in any form unless express permission is Do we have something to report as to a response 18 18 given by me, or by the Secretary to the Inquiry acting 19 19 on my behalf -- the Solicitor to the Inquiry, sorry, to what was being said? 20 MS RICHARDS: Yes, sir, sorry, it was my omission 20 acting on my behalf. 21 yesterday when Mr and Mrs V were giving their evidence 21 Witness W2781 must be referred to only as Mr W. 22 22 I should have mentioned then that Dr Lowe has been The order remains in force for the duration of the 23 asked to respond to the matters raised in their 23 Inquiry and at all times thereafter unless otherwise 24 statements and is proposing to respond and once 24 ordered, and I may vary or revoke the order by making 25 received that response will be published in due 25 a further order during the course of the Inquiry. 2 1 With that introduction, may we have Mr W, 1 A. Yes. 2 2 Q. What was she like as a person? please. 3 MR W, affirmed 3 A. Outgoing, lovely. (Pause) 4 Questioned by MS RICHARDS 4 Beautiful, a very, very nice person. 5 Q. Mr W, you're here to talk about your late wife, 5 Q. She had kidney problems for some years. 6 [redacted]. 6 A. Yes, since she was in her teen years. 7 7 A. Yes. Q. And that gradually got worse and worse? 8 8 Q. And we're going to name [redacted] in the course of 9 9 your evidence because it would not be easy for you to Q. Although she didn't let that stop her from living her 10 give your evidence about her without naming her. So 10 life to the full? 11 those in the room will hear her name, but that name is 11 Oh. no. not at all. no. no. 12 not to be reported or published or disclosed in any 12 But around May of 1984 she started to require regular 13 13 dialysis? respect. A. Yes. 14 And you've shown us two beautiful photographs of 14 15 [redacted], one of you and [redacted] on your wedding 15 Q. And what did that entail? 16 16 day and another of you and [redacted] in 1986 which A. Well, it entailed her having to go down to the 17 the Chair has seen and which I have seen but which. 17 hospital at least three or four times a week and that 18 because of the anonymity order, we won't be showing 18 was a round trip of 120 miles, and then they decided 19 more generally. But thank you for sharing those 19 they were going to put a unit in the back garden and 20 photographs with us. 20 they were just actually in the process of doing that, 21 You met in 1976 and married in 1978. 21 putting a unit in the back garden, and I was getting 22 22 trained up to use the dialysis machine to look after A. Yes. 23 Q. And [redacted] was a civil servant --23 her and, obviously, then a kidney became available. 24 A. Yes, that's right. 24 Q. Because she'd been put on the transplant list? 25 Q. -- at the Department of Health? 25 Straightaway, yeah.

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- 1 Q. And then in September 1984 she received a call about 2 a donor kidney having become available. What can you 3 tell us about that?
- 4 A. We were just at home one day, just sitting and 5 watching the television, the phone rang and I answered 6 it and it was the hospital in Manchester to say --7 they told me straightaway, "Get your wife down 8 straightaway, there's a kidney available but we've got 9 to talk to [redacted] first. Put her on the phone", 10 and she agreed straightaway and that was it, just 11 jumped in the car and drove all the way down to 12 Manchester.
- 13 **Q.** And that -- the kidney was a match for [redacted]?
- 14 A. Yeah.
- 15 Q. As far as you understood?
- 16 A. As far as we understood, yeah.
- 17 Q. And the operation proceeded and was seemingly 18 successful?
- 19 A. Oh yeah, inasmuch as obviously when she came out of 20 the operation, I was told she may be sleeping for 21 a good few hours, so I just went home, came back and 22 when I came back it was an entirely different lady.
- 23 Q. You've said in your statement you saw her the morning 24 after you visited her and she looked absolutely 25 fantastic?

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- 1 actually come with the kidney, and they would treat it 2 as such and, of course, you're just thinking flu-type 3 virus, that's a couple of Anadin and go to bed, you 4 will be okay. You know, you're not thinking anything, 5 because you don't know anything else.
 - Q. But she didn't get better, she --
- 7 A. No.

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- 8 Q. -- was starting to experience lethargy and fatigue, 9 loss of weight, loss of appetite.
- 10 A. Massive loss of weight, yeah, her arms and her legs 11 got very, very thin and she started coming out in 12 spots and the spots turned into blisters. She was 13 just a complete mess, just an entirely different lady 14 whatsoever.
- 15 **Q.** And she started to get repeat infections?
- 16 A. All the time, yeah. It was back and forwards to the 17 hospital all the time. We didn't seem to be away from 18 Manchester at all.
- 19 Q. And then there was an occasion in July of 1986, the 20 end of July, when [redacted]'s brother had taken her 21 into the hospital for an appointment.
- 22 A. Yeah, the reason that happened was because I worked a 23 three-shift seven-day system on -- where I was 24 working, and it happened to be that day. We just 25 thought it was a check-up she was going for.

- A. Brilliant, brilliant.
 - Q. She looked well and you were both so happy?
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- Q. And you thought that she would be able to get on and 4 5 lead a normal life without requiring the regular 6 ongoing dialysis?
- 7 A. Yeah, that's what we were told. She would have to 8 take anti-rejection drugs but obviously we accepted 9 that anyway, and just to get on with life after that. 10 But she was absolutely brilliant. It was a fantastic 11 success. You've already got to thank the Health 12 Service for what they done. It was just brilliant.
- 13 Q. But [redacted]'s health began to decline. What kind 14 of symptoms did she begin to experience?
- 15 A. I keep thinking back how long ago it was since the 16 operation, because she started that -- just weeks come 17 into my mind, four to five weeks she started not 18 feeling well, inasmuch she went to see her own doctor 19 and he said, "I can't do anything. You will have to 20 get in touch with the hospital". We got in touch with 21 the hospital, went down to see them and they said, 22 "We'll have to take her in, it's like she's got 23 pneumonia", plus she just wasn't well at all. 24

When they took her in, one of the doctors just mentioned that they thought that a flu-type virus had

- 1 I couldn't possibly have been there so her brother, he 2 volunteered to take her down. He took her down to the 3 hospital. And when she came back it was about, I'd 4 just actually got into bed in the afternoon and she 5 came upstairs, breaking her heart. 6
 - Q. What did she tell you?
- 7 A. Sorry. (Pause)
 - Q. Take as much time as you need and I can take it from your statement, if that would be easier. (Pause)
- 10 A. Her actual words were "[redacted], you're never going 11 to believe this, but I've got HIV". "HIV?" I was 12 sort of half awake. "HIV, what are you talking about, 13 you've got HIV? Because how is that possible?" 14 Because all we knew about HIV at the end was it a gay 15 plague. That's what we were told. That's what 16 everybody was told.

Of course, when you're not thinking -- "No, no", she says, it's -- "No, it's not -- I've got HIV and we've got to phone Dr Ackrill straightaway and you've got to down there and he's going to explain things further".

Of course, we phone Dr Ackrill and he said, "Could you come down" -- I was actually due back in my work to do another shift, and I phoned my boss and they covered it and said, "Just go, [redacted]".

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We've gone down to the hospital, Dr Ackrill was waiting there and he says, "We've got to take a blood test off you straight away to see if you've got HIV". Of course, you're not thinking, thinking HIV, well I don't care, just find out what's happening, what's going on. He took the blood and I said, "Well, this will take a few days". He went, "No, this will take an hour. We've got everything standing by waiting for you to do an HIV test".

I'm still not taking things in. He came back and said, "You're lucky, you haven't got it", which was a great relief and [redacted] just cried because she thought she'd infected me, because we made love during that period of time, you know, obviously we were a couple, and she was so frightened that she'd passed it on to me and she was so relieved that she hadn't.

- Q. And at this stage you and she still did not know how 18 19 she had become infected with HIV?
- 20 A. No.

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- 21 Q. Can you recall what, if any, advice or information the 22 doctors were able to give you about the condition?
- 23 A. All we were told was -- the first thing we were told 24 was, "For your own good, don't tell anybody. Because 25 of the stigma that's attached to this, we don't want

1 the rest of the family what she had, but we still 2 didn't know how she got it.

- Q. You've said in your statement that you and [redacted] didn't understand what the HIV meant, little was -seemed to be known about it apart from what you'd picked up from gay plague and tombstone adverts on TV and the like.
- A. That wasn't then. The adverts weren't out then, they were just in the throes of coming out.

Every hospital visit, the first thing they always asked was, "Have you told anybody?" And when she did say she'd told her family, I forget this other doctor's name, he just -- he was quite upset about it, because we'd actually spoke to people about it. And then [redacted] started getting angry. That's when she started thinking. And then she said, "How exactly did I get this HIV?"

And she was told then it came -- it actually came from the cadaver, it came from the guy that gave his organs. So that automatically made us think he had HIV, not thinking that he had got it any other way, because we didn't know, and that's all we were told. So even weeks after that we still believed that he was actually the one that gave [redacted] the HIV.

Q. We've got a letter that was written by the Manchester

you going down that road. We don't want you two to be stigmatised with your wife having HIV", and, of course, you taking it in, "Yeah, he's right, we don't want this. Why should we be stigmatised or why should she be stigmatised for having this through no fault of her own?"

And it was a couple of weeks after that, we had to go back to the hospital again, and Dr Ackrill was sitting there, I'm not sure of the other doctor, and he looked more worried about if we'd told anybody. He said, "Have you told anybody?" And she said, "No, we haven't told anybody."

"Don't even tell your family", still not thinking anything of it. It was about six weeks after that, we hadn't told any of the family, but her family started thinking she had cancer and once that word got back to me I said, "This is wrong. We shouldn't have to be going through this. Why should we lie to your family for something that's no fault of your own and they think you've got cancer", which was what her brother was saying, "We think she's got cancer [redacted], what's wrong with her?" I said, "I'll get [redacted] to come round", and the both of us went round to her parents' house and she sat down, and she got her Mum on her own and told her, and then she told

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1 Central Hospitals and Community Care NHS Trust some 2 years later in September 1992. 3

- A. Yeah.
 - Q. I'm going to see if our systems will allow it to be displayed on the screen now, because we've had some problems but if not I'll read it out.
 - A. So, Paul, the number is 2781002.

I will read out -- because this is an important letter, as you know, I will read out the relevant paragraphs in any event:

"[redacted] was admitted under my care as a matter of urgency on 20 September 1984 for a cadaver renal transplant. She had been in chronic renal failure for approximately 13 years."

And then there's some description of the treatment she'd received:

"She received the right kidney from ..."

And there's the name of the donor which obviously we are not going to mention.

A. No.

Q. "... aged 23 years who had died as a result of a road traffic accident and a head injury on 19 September 1984. Prior to the removal of the kidney, the donor was tested for hepatitis, HIV ..."

And then another virus we don't need to concern

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(3) Pages 9 - 12

ourselves with for the purposes of your evidence:
"... and was found to be negative for all three.

The transplant took place on 20 September. The match was almost perfect with only one measured mismatch at A3 on the HLA locus."

Then it says:

"[redacted] was also tested for hepatitis and HIV and was negative."

The letter continues to talk about her progress in terms of the recovery from the transplant and then becoming ill and testing positive for HIV, and then the letter continues as follows:

"Suffice it to say, we then went back to look at the donor to see whether or not that was the source of infection and it transpired that one of the units of blood given to the donor during the course of his resuscitation had subsequently been shown to come from an HIV-positive donor. This was one unit of blood in a transfusion of 15 units of blood, necessitated by his injuries caused in the road traffic accident.

"We then reviewed the other recipients of [the donor]'s organs and found that the recipient of the other kidney, one of our patients, had also converted to HIV-positivity and the recipients of his liver and heart respectively had also converted to positivity.

- A. That's -- well, we discovered it in 1992, about the other recipients, and one particular recipient sticks in mind and that was something [redacted] had found out herself -- I don't know how she found out, she was in hospital in Manchester -- and she phoned me one night and said, "You're not going to believe this, [redacted]", she said, but I've just found out that the guy that was given the donor heart", he was actually told eight months before [redacted] was told about her getting HIV virus. Eight months, before she was told. I don't know who told her but she totally believed the person who told her that.
 - Q. And your statement sets out your understanding, [redacted]'s understanding indeed, that the other recipient of the other kidney had also died from HIV?
- A. Yeah, we actually knew her very, very well. They were very, very close friends because they had the same problems. It was the same hospital, the same ward they were getting treated in, inasmuch as once we found out that [redacted] had HIV, that was the first thing she asked. She asked how was --
 - Q. The other person.
- A. -- and they said, "Oh well, we're not allowed to discuss any other patients". And of course when she got home, she said, "What should we do, [redacted]?"

"In conclusion, there is absolutely no doubt that [redacted]'s HIV infection was transmitted via her kidney transplant from the donor and that the origin of the infection was from a positive blood transfusion given to him in resuscitation."

So you learnt subsequently that the donor himself had not been HIV-positive but he had been given HIV-infected blood during the attempts to resuscitate him following his road traffic accident.

- 10 A. Yes.
- Q. And that the recipients of a number of the organs thatwere donated converted to HIV?
- 13 A. Yes.
- SIR BRIAN LANGSTAFF: It amounts to five people given HIV
 from one blood transfusion, plus the donor.
- 16 MS RICHARDS: Including the donor.
- 17 SIR BRIAN LANGSTAFF: Six.
- 18 A. Six people, yeah.
- MS RICHARDS: Well, I think we have liver and heart, two
 kidneys and then the donor, and one of the kidney
 recipients was [redacted].
- 22 A. Yes.

Q. Do you recall whether you were given that particular
 information during the course of [redacted]'s life or
 was that something you only discovered subsequently?

- And I said, "the best thing to do, if you are going to phone her, don't mention it, just see if she mentions it to you" because it's not something you can go and phone up and just ask directly. And she did phone her and she didn't mention it, so we assumed that she didn't know at that time, and she was probably told obviously after [redacted] was told, but how long after we don't know.
 - Q. The observation you've made in your witness statement is:

"We came in for a life-saving operation and came out with a death sentence"?

A. Definitely, yeah, yeah.

I mean, the comment to -- to go and meet, it was such a match, a great match, we were so happy and it turned out to be a killer disease, we couldn't understand why it happened. And of course you start questioning things then: why wasn't there tests in place? And if there was, why weren't they used? If there wasn't tests in place and you knew what was happening, why didn't you wait until tests were in place? It just wasn't making sense to [redacted] whatsoever.

- Q. [redacted]'s health continued to deteriorate?
- 25 A. Yeah, greatly, yeah.

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- 1 Q. You've said in your statement that she prayed that 2 treatment would be developed to help her but it didn't 3 come in time --
- 4 A. Yeah.

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- 5 Q. -- and she knew she was going to die?
- 6 A. Oh, yeah, she knew. It was constant reminders. If 7 you just refer back to those tombstone adverts, I 8 mean, it was in papers, it was on billboards, 9 television, radios, it was a constant reminder to her, 10 and it ended up she couldn't watch TV. Anything she 11 watched, we had to sort of pre-record on the old tape 12 machine, but she would break her heart every day and
- that's ... I'm so sorry. 14 Q. That's all right. Take as long as you like, please. 15 (Pause)
- 16 A. She just said, "I'm going to die, what can I do?" 17 (Unclear) not just now, because she knew she was. She 18 knew she was.
- 19 Q. And [redacted] died [redacted] 1987. She was just 33 20 years old.
- 21 A. Yeah, yeah.
- 22 Q. And that was less than three years after the 23 transplant?
- 24 A. Yeah, yeah. She did suffer. She really, really 25 suffered that three years. That particular photograph

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- 1 because he liked [redacted] a lot, she was a favourite 2 patient of his and I just got the sense he's not 3 telling us the truth. He's not coming across and he's 4 sorry that he's not able to come across.
 - Q. And you had a conversation after the inquest with Dr Ackrill who is a doctor you are full of praise for in terms of --
- 8 A. Oh yeah, yeah.
- 9 Q. -- his care of [redacted]. He told you about 10 something having happened in France, something --
- 11 A. Well, it was straight after the inquest. We were just 12 coming out of the hall and obviously he had done his 13 thing and he left the hall, and by the time I got out he was standing outside and he was waiting, and I just 14 15 went up to him and shook his hand and I thanked him 16 for looking after [redacted], and he just turned 17 around and he said, his actual words were "[redacted], 18 this happened three years ago, the exact same thing 19 that happened to [redacted] in France, three years 20 ago." He said, "I'm not repeating it", and he walked
- 21 22 Q. Can I ask you about how you coped and managed after 23 [redacted]'s death.
- 24 A. Well, I thought I was coping. I thought I was going 25 to be okay. I was living under false pretences.

that I showed you today, that was the last photograph 2 of us two together and she's so happy in it because 3 I was actually holding her up, because her legs were 4 like that and her arms were like that, and she was so 5 sore with the lumps, blisters, it was bad.

- 6 Q. There was an inquest into [redacted] s death.
- 7 A. Yeah.
- 8 Q. And you've explained in your statement that at the 9 inquest you asked the doctor how long [redacted] might 10 have survived with dialysis if she hadn't had the 11 transplant.
- 12 A. Yeah.
- 13 Q. And the answer was she could have gone on for a few 14
- 15 A. Yes, yes.

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- 16 Q. You've explained to me that you have had a sense that 17 the doctors were not telling you everything at this 18 time.
- 19 A. Yeah, it was like --
- 20 Q. What did you mean by that?
- 21 A. It was like a sixth sense. One particular doctor, 22 whether you name him or not, he was sort of -- he 23 would tell something he was sort of -- as if he was 24 saying to you, "Look, don't believe what I'm saying" 25 or -- and when you sort of asked him something --

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1 I basically just didn't cope at all, I just didn't 2 cope whatsoever. 3

I lost everything, my job, my house. My health deteriorated. I ended up actually with post-traumatic stress disorder with regard to hospitals, which is very, very serious, inasmuch as I can't even go in a hospital. It's been recognised inasmuch as last November I had a massive heart attack, was taken to hospital and it was just into the second day, I got up out of bed and told them, "I'm leaving", because I just couldn't even hold up my head to look. I was getting dizzy.

The consultant came. He'd already read my notes and he understood exactly what was going on. He said, "We're agreeing with you [redacted]. We're going take you in a side room now and we're going to treat you at home". And I got a fantastic care at home, doctors coming up and nurses coming up to my home. I was sorry to be such a burden, but this is what it's left me with, this post-traumatic stress disorder which I couldn't believe that I had.

- 22 Q. In [redacted]'s lifetime, was she or you ever offered 23 any psychological counselling or support?
- 24 A. No, there was only the once and it was a few weeks 25 after she was told. Whether it was psychological help

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(5) Pages 17 - 20

or not I don't know, because we were invited in to -- I think it was Withington, I'm not even sure of the hospital, or it could have been Victoria Hospital, to go down to talk to somebody and when we went down there, I had to take time off work -- like I said, it's a round trip of 120 miles, it's not an easy trip. We got down there.

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This young doctor walked in, we later out found out he was an intern, he was just a young doctor in the third or fourth year and a young nurse. We couldn't find any place to go and have this discussion and we ended up in the stockroom sitting on the floor and all he kept saying is, "We'll have to educate the staff on how to treat HIV patients". And I can see [redacted] and she was starting to get -- she got up and she said, "This is a complete and utter waste of time. You're not helping me whatsoever and I'm not coming back".

He said, "Well, we've got to learn as much as you. That's all. What you know, we know, that's it".

- **Q.** And in the years since [redacted]'s death, have you been offered any support or counselling?
- A. My own doctors, yes, I went to see a couple of psychologists but the treatment they were wanting to give me, I just couldn't handle it at the time.

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was, it just mentioned the fact that there had been an agreement with the Government for HIV people that passed away and the families that there was a compensation order out, and I thought, "Oh, that will give me a chance, if I can get anything, to get back on my feet", because, like I said, I lost absolutely everything.

So what I done, I phoned up the solicitors that I had in Manchester previous and it was a Mr Morton came on the phone and he said straightaway, he said, "I'm glad you've got back in touch [Mr W], I will dig your files out, but I can't see any problems", and I went, "Yeah, okay then". The next thing I got a letter from him saying, "Yes, there is compensation available, but you'll have to sign a waiver to say that you won't bother the National Health people again with regards to your wife's case", and of course I wasn't -- I thought, well, if I can get some money back, you can out it down on maybe a little property and get stuck into that and that will keep us busy and give us a bit of security back. So I did, I signed a waiver and a few weeks later there was a cheque came back through the door, and I don't mind saying what it was for if you need to know.

Q. It's in your statement in any event.

1 I felt like I'm not -- I wasn't quite ready for it,

2 and I just sort of just didn't go back and the doctors

3 understood and said, "That's okay, [redacted], we're

4 patient. We'll start it again when you're ready".

They've been absolutely marvellous because they knew the full history.

- Q. And you remarried. You have had a daughter.
- 8 A. Yes

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- Q. And you say in your statement that they have been thesupport that you needed.
- A. Well, the lady that I married, she was actually worked in the medical profession for a few years.
 When I first met her, she recognised -- I don't know
 what she recognised, but we got married anyway and
 I didn't think that would happen again, I really

didn't. And of course that was the silver lining andthis was the other silver lining.

- Q. You've mentioned in your statement involvement in some
 form of litigation in 1992 and having to sign
 a waiver --
- 21 **A.** Yeah.
- 22 Q. -- in order to receive money?
- A. The way that came about was I was in the car and I was driving through -- the time it was in -- I just
- 25 flicked on Radio 4. I don't know what the programme

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- 1 A. Yeah, yeah.
- Q. Although you've made very clear in your statement how you've rebuilt a life with your wife and your
 daughter, you've said this, that you still have bad dreams and nightmares --
 - A. Yeah.

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- Q. -- regularly, and you'll wake up crying, screaming and sweating.
- 9 A. Oh yeah, that's three or four times a week. Even
 10 today -- last night was not too bad, you just cope
 11 with it, I got up, made myself a cup of tea. And I am
 12 a smoker, I'm a heavy smoker and I shouldn't be,
 13 I know that, but I got up last night at the hotel and
 14 I went outside and had a cigarette and came back in
 15 again, another cup of tea, went to bed and that's sort
- of -- that helped.
 Q. And you've also said in your statement that you promised [redacted] that you would try and find out what happened.
- A. Yeah, and I didn't want that to be just a bare promise. And I did try after it, I did try. There was no Google in them days, there was nothing -- you can just press a button and instantly there. You had to go over libraries, you had to phone, you have to see medical people and they could close ranks on you

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1 and you wouldn't know, you just wouldn't know, so 2 I sort of let it go and I always felt guilty about 3 doing that and when this Inquiry came up -- the 4 previous Inquiry, sorry, the Penrose Inquiry, I just 5 didn't believe in it at all, and I didn't want to get 6 involved. But when this Inquiry came up and I looked 7 into it, and I seen what was involved, I totally 8 believe in it because I think you're totally looking 9 for the truth, and I totally, totally believe in what 10 yous are doing here. That's why I'm here. 11 Q. Thank you. I've got no further questions for you, but 12 is there anything else that you would like to say?

- A. No. I've wrote a little statement of sorts. It's,you might say, a bit hammy.
- 15 Q. If you want to say it, then, absolutely, this is your16 chance to do so.
 - A. Thank you. You'll have to forgive me. Can we just take a minute?
- 19 Q. Of course.

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20 A. It's not a long statement.

I would like to thank the Inquiry for the care and attention that they have shown to myself and my family over the last few months. I cannot believe that I am sitting here giving evidence about events that happened over 30 years ago. Sorry. Believe me,

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out trying to keep us all healthy, regardless of race, creed and colour. They do have safety checks in place with new drugs and treatment before being released to the general public. This has always been the case since the inception of the National Health Service in 1948. I always remember that year because that's the year I was born.

I think that the Ministry of Health during at least the 1980s were very complacent in their attitude in the horrors of HIV and AIDS. They chose not to take any action once news began to leak out regarding tainted blood. If action was taken, it was very kept quiet from the people who were infected by this blood. Perhaps they thought that HIV/AIDS would hopefully go away of its own accord. When it appears that it would not, I think panic set in and we spent millions on so-called tombstone adverts on television, newspapers, cinemas, billboards, et cetera, normally directed at the gay scene, which was of course no help to patients who were already infected. In fact it caused the opposite effect: it just kept reminding them that they had a very short lifespan ahead. This, of course, greatly affected loved ones and carers.

Also, my wife and I totally believed that blood tests were available at the time, but for some reason

if tears were ink, then I could write a book about the wonderful person who was so cruelly taken from me all those years ago.

Please remember, I have no medical training whatsoever. All I do have is some medical knowledge of events of that time. Since then I have often thought why this terrible disease was ever allowed to infect the thousands of innocent people that it did, as well as the many thousands of relatives and carers who were badly affected by these events. I can only comment on personal medical experience that happened to my wife in the mid to late 1980s. My wife always believed that the whole issue of HIV and AIDS via transfusion or transplants, et cetera, could have been avoided if the proper precautions were put in place by the companies who gathered and sold on this blood for massive profit, and blame must go to their customers, one of whom was the British Government who were very lax in not doing checks on the life-giving blood that they were buying from abroad.

In my wife's case, we were told that the one pint of blood that was passed on to her via kidney transplant did originate from America.

We do in this country have a fantastic National Health Service who do brilliant work year in and year

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were never used properly. Why was our Government so slow in doing anything practical regarding the companies supplying this tainted blood? It can only come down to two things: politics and money.

I would and could go on, but we'd just be repeating what has been said over the years. I do have confidence in this Infected Blood Inquiry, and I'm sure that Sir Brian Langstaff and his team will get to the truth very soon. I write this as a layman, just a normal guy who lost a normal girl.

Thank you.

MS RICHARDS: I'm just going to ask Mr Snowden who represents you if there's anything else.

No, nothing further.

Sir Brian?

SIR BRIAN LANGSTAFF: I'm not going to ask any questions, but just pick up on the word that you used in what you were saying at the end, which described what had happened when your wife was cruelly taken. We've heard some very disturbing tales in this Inquiry.

I think few, if any, can be quite as cruel to the sufferer as the story of what happened to your wife, who went in for a life-saving treatment and came out with a death sentence, as you put it.

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A. Yes.

(7) Pages 25 - 28

1 SIR BRIAN LANGSTAFF: It has not been easy for you to tell Q. And we have a detailed witness statement from Bruce 2 us but I think everyone listening will understand how 2 and indeed from you and from each of your children, 3 and I'm not going to ask you to speak to their 3 important it was that you did, so thank you. 4 A. I just thank you for giving me the opportunity to give 4 statements. 5 it and to get it off my chest. 5 A. Right. 6 6 Q. Although there may be a couple of passages from them SIR BRIAN LANGSTAFF: It's important. 7 A. And it should have been told. 7 I refer to in the course of your evidence. 8 8 SIR BRIAN LANGSTAFF: Thank you very much. In terms of background, Bruce has, as his 9 9 A. No. Thank you. statement explains to us, haemophilia B? 10 SIR BRIAN LANGSTAFF: We will take a break until 11.20 am. 10 A. Yes. 11 MS RICHARDS: Thank you, sir. 11 Q. And he has over the course of many years been treated 12 SIR BRIAN LANGSTAFF: 11.20 am. 12 with many Factor IX products? 13 13 (10.51 am) A. 14 (A short break) 14 Q. And I'm going to ask you to start your testimony in 15 1988 when you and Bruce met. 15 (11.25 am) 16 SIR BRIAN LANGSTAFF: Our next witness is Christine, is 16 A. Okay. 17 17 Q. That was in London? 18 MS RICHARDS: It is, sir. 18 A. That was in London. I'd gone down to London to be 19 SIR BRIAN LANGSTAFF: Christine, please. 19 a physiotherapy student and Bruce had moved down from 20 CHRISTINE NORVAL, affirmed 20 Inverness to London to do nursing. Eventually he went 21 Questioned by MS RICHARDS 21 to do nursing when he was down there, and we were 22 22 MS RICHARDS: Christine, you're here to talk about the doing agency nursing to pay the bills and we met, 23 impact on you and your family of your husband Bruce's 23 actually we were put on the same ward on the same day 24 24 infection. and we met through work. 25 Yes, that's correct. 25 Q. And what was your response when Bruce told you he had 29 30 1 haemophilia? 1 Q. You describe in your statement he was experiencing 2 2 A. Well, he was very open. We went for lunch after our nausea, fatigue --3 shift and I burnt a pizza and he told me he was 3 A. Yes, weight loss, yes. 4 4 Q. But doctors were telling him that it was all in the a haemophiliac and I just blurted out, "Oh, have you 5 got AIDS then?" As a 20-year-old, I had, yes, foot in 5 head? 6 mouth disease I would think, yes. 6 A. Yes. 7 7 Q. Now, Bruce didn't know at that time that he had been Q. You said he was told it wasn't AIDS, so there was 8 8 infected with hepatitis C? nothing to worry about. 9 9 A. No. A. Yes. 10 10 Q. But he was aware of being unwell? Q. And you refer to him being described as an AIDS 11 A. Yes. 11 12 Q. What kind of symptoms was he experiencing at that 12 A. 13 13 Q. It was in the course of 1990, when you were pregnant A. Well, shortly after we got together he was struggling 14 with your first child --14 15 to keep up his nursing studies. He was struggling to 15 A. Uh-huh. 16 16 keep up the extra shifts he was doing to pay the Q. -- and you were due to get married --17 bills. I remember one occasion we went to visit 17 A. Yes. 18 a cousin and -- and we slept over at their house, and 18 Q. -- that Bruce was told he had hepatitis C? 19 I remember during the night that the bed was so wet 19 A. Yes. He'd moved centres to, gosh, the name's just 20 that I just thought he had wet the bed. It was so 20 gone out of my head, the one in London. 21 wet, it was so -- I was absolutely just mortified. 21 Q. St Thomas's? 22 22 I realised, you know, later that it wasn't urine but A. St Thomas's, thank you, and they were trialling the 23 23 we had soaked through the sheet or he had soaked new hep C tests, so he took part in the new hep C 24 through the sheet and the mattress and, yes, I was 24 test. 25 embarrassed by that. 25 Q. And I'm just going to read a few lines from Bruce's 31 32 (8) Pages 29 - 32

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statement about how he recalls being told. He said this:

"The doctor actually told me that I have hepatitis C standing in a clinical room doorway. He didn't even come into the room. He was told me he was running late for clinics. I walked into the unit at St Thomas's hospital and said hello to the doctor. I asked if the result had come back. He said it probably had but he was in a rush as he had a clinic to do. I went into the treatment room because at that point they were trying to get on top of my bleeding disorder. I had severe problems with my right leg and had difficulty walking. I was connected up to a needle and the doctor came back into the room but didn't enter the room itself. He just stood in the doorway leaning against the door jamb. I remember it as clear as day. He told me I was positive. He told me it was just a mild infection and not to worry about it. I was actually working in a hepatic unit at the time so I asked what he meant by 'a mild infection' and what the implications were. He said I might get lymphoma, liver cirrhosis or liver cancer but that I probably wouldn't. No information was given to me to help me understand and manage my infection. All I was told was that it might develop into lymphoma,

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- Q. Now, you and Bruce and the baby moved to Lincolnshire
 in late 1991.
- 4 A. Yes.
- Q. And how did Bruce's health develop over the followingyears?
- 7 A. He continued to have the night sweats. He vomited
 8 virtually every day, several times a day. He was
 9 prescribed build-up drinks by the GP. He was very
 10 emotional. He was very angry. He had massive amounts
 11 of fatigue, struggled to hold down a job, and sort of
 12 expressed feelings of feeling useless and being no use
 13 to us.
- Q. And he did attempt various forms of work but he was
 unable because of his health to sustain those
 employments for very long?
- 17 A. Yes.
- 18 Q. You then had to go back to work full-time more quickly19 than you'd planned to.
- A. Yes, I think my daughter was four months old when
 I went back to work full-time.
- Q. And you've recalled in your witness statement one
 occasion on which your daughter called you Maureen,
 which was the childminder's name?
- 25 A. Yes, she was at the childminder all day while I was at

liver cirrhosis or liver cancer but that I probably
 wouldn't."

Now, Bruce came back and told you --

- A. Yes.
- Q. -- that he had been given this diagnosis of hepatitis C. What can you remember about that?
- 7 A. There was a mixture of emotions. Because he had been unwell and there didn't seem to be any reason for it,
 9 actually having a diagnosis almost made -- made it
 10 better because at least it was wasn't all in his head.
 11 At least there was some reason for him being unwell
 12 but he was really, really worried that either he'd
 13 infected me or the baby.
- Q. And you've said in your statement that you weren't
 told or given any information about the risks of
 transmission to the baby?
- 17 A. No.
- 18 Q. And you weren't offered an HCV test?
- 19 A. No.
- Q. And Bruce became very concerned about the risks ofcross-infection following his diagnosis.
- A. Yes, he was doing home treatment and I'd been
 helping -- I'd been putting the IV in for him and he
 stopped me from helping with that yes, and -- yes, he
 was just devastated that he was so worried for me and

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1 work.

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- Q. And that you hadn't been your plan initially?
- A. No, absolutely not. We'd always thought we were going
 to jointly parent the children and I wanted to have
 some time to be a mum and Bruce wanted some time to be
 a dad and this was our idea that we would do that.
 - Q. And during this period when you were living in Lincolnshire, how were things for you financially?
- A. We were in a council house. We'd moved up to
 a council estate, and things were tough. To a pay
 a child minder, Bruce wasn't really earning very much.
 The benefit system was -- seemed to be against us. He
 was having to fight to be able to claim benefits that
 he should have had.

I do remember one day getting an eviction notice through the door from the council because we were late paying our rent that month and it was just one month but to have that letter, it was -- it was just awful.

- 19 Q. Now, Bruce then went on a course of interferon for20 hepatitis C. You think it was I understand a trial.
- A. I believe so. It was from -- the centre had moved to
 the Hallamshire in Sheffield at that time and I do
 remember going to see the doctor prior to him starting
 and the doctor saying, "Your liver enzymes are so bad,
 there's no question that you'll be taken on", and

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(9) Pages 33 - 36

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- 1 I think he must have been quite late getting taken on, 2 because it seemed to be quite rushed that he started 3 the trial.
 - Q. And your statement says that in retrospect you suspect that the dosage he was given may have been too high?
 - A. Again, I -- I'm not sure where I've got that information from, but I'm sure that I've heard that the initial trials, the dose, they were working with the dosages and, subsequently, the doses were reduced.
 - Q. Bruce's description of the side effects of that course of interferon are put in this way:

"Nobody had made me aware about the side effects of treatment. I was told that interferon would give me mild flu symptoms. If what I experienced is a mild flu, I what would like to know what they think is a bad flu is. Mentally and physically I've never recovered from that experience."

18 A. Yes.

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- 19 Q. What you can recall about the symptoms and side 20 effects that Bruce experienced during the interferon 21
- 22 A. I have visions of him with the needle waiting to stick 23 it into his stomach and him in tears, knowing that he 24 had to do it, but knowing that -- how poorly he was 25 going to feel after it. He was trying to continue to

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- 1 hearing their stories, and I think having spoken to 2 each other and working with each other, they suddenly 3 realised, "Hang on, it's not just me. We're all 4 suffering with the same consequences".
- 5 Q. Now, you'd become pregnant with Robbie in 1996, having 6 been told that Bruce had become clear of hepatitis C.
- 7 A. Yes.

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- Q. It was seen I think by both of you, your statement says, as a good moment to have a second child.
- A. Yes, we'd -- there's six years between our children and in that time, before Bruce had had treatment, we had had difficulty coping and we'd been to Relate and counselling and we'd sort of said, that's it, no more children. That's it. It's not fair. But after being told that you're clear of the virus, you will get better, you'll be healthy, I'd always wanted a second child, so this was a definite choice to have a second
- 19 Q. But the symptoms never having gone away, what did it 20 feel like for you and for Bruce having made this 21 decision but nothing had got better?
- 22 A. It -- it was difficult. My pregnancy with my son was 23 very difficult. I had multiple threatened 24 miscarriages, and I do remember thinking maybe it 25 would be better if this child doesn't survive.

work at this time, and again the symptoms just were -he had a brain fog. He really couldn't think clearly. He was angry. He was -- I wouldn't say aggressive, but he was very angry and short tempered I suppose is a better way to say it. Often we felt like we were on eggshells, and there were times when he wouldn't get dressed for days, and then another time I do remember coming back to the house with my daughter having collected her and he'd gone to bed and locked the doors and left the key in and I couldn't wake him up, and we were banging on the door trying to get into the house with Bruce fast asleep upstairs.

And another time he'd put his pan on the stove and fallen asleep and burnt through the pan and caused smoke damage throughout the kitchen.

- 16 Q. So what was the outcome of the treatment itself?
- 17 A. The treatment cleared the virus.
- 18 Q. But Bruce's statement and your statement explains that 19 essentially the symptoms never stopped?
- 20 A. No, no, absolutely not.
- 21 Q. And it was at that point that Bruce started to really 22 involve himself in campaigning.
- 23 A. Yes. It was the start of when the Manor House Group 24 was set up. So he was driving to -- to meetings, 25 a little bit further south, meeting other people and

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- 1 Q. You again had to go back to work earlier than you'd 2 planned.
- 3 A. Yes.
- 4 Q. Because Bruce's health was such that he, despite 5 trying, wasn't able to keep working?
- 6 A. We'd sort of took the decision really that he would be 7 the parent at home and I would work, and we -- we sort 8 of worked that out and just -- that's just how we had 9 to get on with it really.
- 10 Q. But he was still experiencing a lot of the same 11 symptoms --
- 12 A. Yes.
- 13 Q. -- nausea?
- A. Yes, night sweats. We would be up in the night 14 15 changing sheets and, yes, and his weight would drop. 16 My daughter remembers him having to stop the car 17 driving her to nursery school to be sick, and that's 18 one of her first memories is her Dad being that 19 poorly, and him lying on the settee and he wasn't able 20 to cope with looking after our son in the way that he 21 had hoped to. So it necessitated us -- I mean, first, 22 we got help through a charity and gradually he started 23 at a nursery and he started as a day and then two 24 days, and eventually he was full-time at a nursery. 25
 - Q. What was the impact on Bruce of his health conditions,

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his physical health conditions at that time?
A. I think he -- he felt worthless but at the same time he -- he was wanting to -- not campaign but to get to the bottom of this, to find out exactly what had happened and to find the truth out.

So as much as he was poorly, he was unwell, he started devoting more and more and more of his energies into researching what had happened, into campaigning and going on the TV, newspaper articles, this sort of thing to try and highlight the case.

- **Q.** His statement describes depression and a sense of social isolation at this time as well.
- A. Yes. We don't -- we didn't socialise at all. Bruce found it very difficult coping with crowds and also it's that first question when you're introduced to somebody new, it's, "Oh what do you do for a living?" And if you say -- you don't want to tell people the whole story, not that we hid it, I absolutely didn't hide what had happened to us, but it was that difficult question.

People really don't want to know the ins and outs and if he said he was a house husband, which is what he sort of started to say to people, again, a man staying at home and his wife going to work, he felt that that lessened him and took away his -- his

a case of trying to separate myself from the pain and I moved out of the family home into a rental property nearby, and took the children and had to take on huge debt to furnish it and pay the first month's rent and -- and I was still off sick at this time, so I was -- was on sick leave, but it was -- it was just my way of coping.

- Q. In 2004 Bruce received a letter, we've seen a number of such letters, about the potential risk of vCJD.
- 10 A. Yes.

- Q. What can you recall about that?
- A. Well, we have to almost go back a bit from that.

 Bruce and I were watching the vCJD story in the press and we just turned to each other one day and said,

 "These are young people. I wonder how many of these people have given blood?"

So we wrote to, I don't know, we asked our doctors, we asked The Haemophilia Society could this be an issue? And we were told we were scaremongering, we were frightening people and we should shut up.

So when the letter out, it confirmed yet again we that we had been lied to. That we had -- you know, they tried to placate us by saying there's no problem but actually, yeah, you don't -- you stop believing people because time after time after time your

masculinity, I suppose.

- Q. You went through a period in the late 1990s, early 2000s when you were both struggling and your own mental health was suffering.
- A. Yes. I -- Bruce was just so poorly, really, I think -- just so ill all the time and I had two young children. My son didn't sleep so we were all sleep-deprived, and on one occasion a long-time patient that I'd had -- I was a community physio by this time -- had died and I went to her funeral and I remember it was pouring rain and I got in the car and I went to go to my next patient, which just happened to be near a river and I drove the car up to the edge of the river and I sat there thinking, "Do you know, this would end everything, all the pain, if I drove the car into the river".

And at that point, I had two young children and I just think that always brings you back, and I rang Bruce and he just said, "Come home now. Just come home", and I did, I managed to drive our car and go home and just then I saw my GP and got signed off work and started antidepressants and counselling, trying to cope with it.

- 24 Q. You and Bruce did separate for a while.
- 25 A. Just immediately after that, again -- again, it was

1 concerns and theories and thoughts are proved right.

Q. And Bruce says in relation to the fear of vCJD this:

"There's nothing that terrifies me more than CJD.

HIV was a scary disease but the idea of losing yourself, having your personality and everything you are eaten away by death of your brain cells and to end up being completely dependent and unable to even intellectually interact because of CJD terrifies the hell out of me and always has done."

- 10 A. Yes.
- **Q.** "But this is a real risk for people like me. People 12 need to sit up and take notice of that."
- 13 A. Yeah
- Q. Bruce is and has been for a number of years profoundly
 distrustful of the medical profession and medical
 treatments and hasn't wanted to try any further
 treatments.
- A. Yes. When the new treatments started to come out he was asked over and over again, despite the fact that he's PCR negative, that we thought he was, for want of a better word, cured of hep C but they still feel that he should have this treatment, but he sort of said, "Do you know, actually, I've been there at the start before. I've been a guinea pig, for the want of a better phrase, before", and he just didn't trust

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that it was going to be safe, so he's refused to have treatment until now, and it actually speaking to other people who have been through the treatment that's starting to make us think, "Well, maybe it is okay", but it's only -- it's because of speaking to all these people out here, not to doctors, that is sort of reassuring us.

- Q. And yourself as a physiotherapist, working as part of the health service, what's the impact been on you practising your profession of having in the background these questions and concerns and this lack of trust?
- A. I suppose I've been caught in between it, really, because my training and everything I see, I see so much good work, but at the same time I see so much horrendous stories and I've -- when I was working, I used to take on the cases that were long-term, people who had maybe been written off by everybody else, and so I started to understand the needs of long-term conditions and people with long-term problems wasn't necessarily well catered for and so I moved my practice towards that.

But I -- yes, you start to question everything. You start to distrust everything. When you're told something you go away, straightaway, and start to research it because you need to understand it in your

out of hospital wards before. He just -- he's had it -- experiences and if I'm not there, it is often better if I can be there, but he's had experiences where -- yeah, where somebody says the wrong thing and he -- he is just -- he can't control his anxiety levels.

- Q. For many years, as many in this room will know, Bruce has been extensively involved in investigation, research and campaigning and you describe in your statement that that's effectively become his life.
- A. Yes. Yes.
- 12 Q. What has the impact of that been on you?
 - A. He -- I've said this so many times. We -- it's the first thing that he will speak about in the morning and it's the last thing he will speak about before he goes to bed, and within the day, no matter what the conversation is, we don't go half an hour without him discussing it, without somebody phoning up, without him looking on Internet and no matter where we go, what we do, he's constantly speaking to people, looking at things, putting two and two together, and he's done this from his bed a lot of the time.

He's so -- you know, he doesn't have the energy to run around and do -- and literally he -- I would come home from work and I would try to ring him from

own way, rather than just relying on what somebody
 said, because you can't -- you just don't feel like
 you're getting the whole story. They are
 cherry-picking the best bits without giving you the
 background information.

- Q. You describe Bruce at this time being exhausted, unable to do many physical tasks. You used to go hillwalking together and he could no longer do that?
- A. No. We didn't even go on holiday together. I -- when we lived in England, we would come up and visit his family and when we moved to Scotland, we would then go back down, but I would take the children myself because Bruce just couldn't cope with it. And even if we did go away, it would be a weekend in a caravan somewhere, collecting tokens from the newspaper, this sort of thing, because we couldn't afford anything more than that.

But when we're away, he would -- yes, I would take the children for the day and he would sleep.

- Q. And you've said in your statement that you think he has a form of post-traumatic stress disorder because of everything he's experienced?
- **A.** Yeah, I don't know if that's the right term but I know 24 the anxiety levels that he experiences when he has to 25 go into hospital are such that we've actually walked

work sometimes to say, "I'm on my way, do we need
shopping", that sort of thing and every single night
the phone was busy, every night, because -- and I'd
get home and he would still be on the phone speaking
to somebody about one thing or another, either
supporting somebody or getting very angry about
things, yeah, that's what we had to deal with.

- Q. You've described it in your statement in some respects as being toxic and damaging. What do you mean by that?
- A. Yes, I mean we're talking about something that
 happened so many years ago and there have been so many
 opportunities that the state could have taken to
 reduce what -- the harm that this has done.

You can imagine every time he's -- he's gone to talk to so many politicians, been to Parliament, he's had so many TV interviews, phone, and every time you have pieces of evidence that seem to be smoking guns and nobody wants to know. And, you know, when you hear, oh, there's going to be a question asked in Parliament, you think "Maybe this time. Maybe this time they're going to put it right", and every time you get some lame excuse by the government to -- to put you down or to hide it away and you just feel it's -- it's -- you've just been knocked back again

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1 and you can only be knocked down so many times. So, 2 you know, you raise your level up and then you're 3 knocked down, and every single time, and it's just 4 gone on for so long and the evidence is there. 5

- Q. You've explained in your statement that this has given Bruce his purpose.
- A. Yes.

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- Q. But he's also seen so many people die.
- A. Yes, yes. Yes, over the years, you know, I've 10 attended so many events and, you know, there's so many 11 people. I mean, some stick in my mind because I met 12 them as well. I wasn't always there because I was 13 working and then meeting their loved ones after 14 they've died, knowing that they have died in the most 15 horrendous ways, bloated, yellow, attached to machines 16 in intensive care, having amputations. Losing everything, and these people were Bruce's friends and 17 18 he would say to them and they would say to him, "Don't 19 give up the fight. Don't give up the fight. Keep 20 going", and he would say, "I am fighting for you. 21 I am continuing not just for my family, for 22 everybody's family", and it's -- we've often felt

fight, but we understand why that has happened. I don't think you would put up with it if you

within the family that we are second place to that

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- 1 A. Yes.
- 2 Q. And following that you've taken retirement.
- 3 A. Yes.
 - Q. And one of your passions now are ponies and carriage riding, but what's the impact been on you over the decades that we've briefly been talking about, those decades? How has it taken its toll on you?
 - A. I mean, there's -- physically, because Bruce either is -- has been physically unwell to do things and then all his energy that he has had has been in campaigning and I've had to be the breadwinner. I've had to do the house work. I've had to do the gardening, everything, so I've been a sole parent almost. That's how it's felt.

I felt a huge burden to pay the bills to keep working. I would have loved to have worked at a lower level or worked part-time but I didn't have the opportunity to do that, even with my wages coming in money was tight. We were always juggling a credit card or a loan or -- and there never seemed to be any money for what we needed and how can you say save for tomorrow when you don't know if you're going to have a tomorrow?

So I had to -- I was trying to support the children so that -- and we couldn't shield them. My

didn't know the pain and people's stories behind it. I would have walked and left Bruce. I wouldn't have got back together but just simply because it is ten green bottles, you know. It's just less and less all the time to shoulder that burden. Bruce says he stands on the shoulders of dead men.

Well, there's nobody there to support him. He's there doing it with -- he's not on his own by any means, far from it, but there's just this small group of people that are keeping on because of the horrendous stories that we know, the horrendous deaths that we've seen.

Q. Your daughter has described that in his way in her

"People he knew were dying and I recall he had this black address book and when people died he would cross out their names. I remember coming home and there was a hallway connected to an office that he could use. I could hear him crying. I would see the black book open and he had the phone and you knew another person had died."

- 22 A. Yes, yes.
- 23 Q. You had cancer --
- 24 A. Yes.
- 25 Q. -- in 2014.

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daughter was -- has said just last week that she knew when we were trying to hide things and that made her much more upset than ever. And it's also -- Bruce has also been through so much that if you've got a cold or anything, it's nothing, it's really nothing compared to what he's going through, so you would feel I cannot be poorly because I'm nothing like as poorly as he is, and that -- and I went through chemotherapy and radiotherapy and, apart from a few days after each treatment, I would still say I was fitter going through that than Bruce has had for nearly 30 years.

Q. Bruce has recognised in his statement this, he says:

"My infection has an absolutely and completely devastating effect on my family. It has completely changed the way their lives have gone from their earliest point."

Do you agree with that?

- A. Absolutely, yes, yes.
- 19 Q. I will ask just a little about the effect on your 20 children.
- 21 A. Yes.

Q. They've both given statements to the Inquiry. You've described your daughter as a very gentle soul, who holds everything in and she says in her statement she's grown up acutely aware of her Dad being ill and

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that's affected how she deals with people.

A. Yes, and she's never had that security of knowing that her Dad was going to be there the next day or the next day, so living with that insecurity she -- again, it's just recently she admitted to me that she would go to the library after school hoping that I would be in from work before she got in because she was terribly worried that she would find her Dad dead, as a -- and this is as an 11/12-year-old, and she had episodes of school where she ran away one day and we had the police called from school, and she's been to counselling through child services and has continued to have severe mental health issues since then.

She's been hospitalised twice in a psychiatric ward and she spent her 21st birthday on a psychiatric ward. When we went in to see the consultant, obviously she talked about her Dad and I was called in to see the consultant psychiatrist and he turned round and said, "You have to choose between your husband and your daughter. Your husband's campaigning is so awful that if he continues to campaign, your daughter will never be well".

And at the time I was raging about that. I was so angry. How dare he say that? And now my daughter [redacted], and speaking with a different psychiatrist

1 relationship with his father, no.

- Q. And he said in his statement he thought for a long time that his Dad was going to die and that the idea of coming home from school to find his father dead was normal to him.
- A. Yes, it's -- yes. I mean, however rational that is or isn't, that's what's in their mind it is Russian roulette. Somebody said that the other day. There is no rhyme nor reason why, you know, one person has died and another -- and nobody could tell us, so of course when you're in the dark times your brain goes to that dark place.
- Q. And he has said in his statement he would like all the campaigning and infected blood conversations to stop.
- A. Yes. We all would. Let's face it, everybody here would but by God we're not going to let it go until this is sorted out and we -- and in spite of everything, we are standing together because we want to see this done properly. We want to see the people that have contributed to this, for want of a better phrase, being brought to task.
- Q. And you've said this at the conclusion of your statement, Christine:

"I think it's been a compromise between the campaign being toxic and the fact that if Bruce did not take part I reflected on that and thought, "Actually, he was right", but he went about it the wrong way. If he had just said, "Look, this is very damaging, what's happening, and do X, Y and Z", but expecting me to leave my husband, I -- in no uncertain terms it was, "Leave your husband or your daughter won't be well".

No, I went back to my daughter at that point and said, "Please don't think I don't love you enough to put you first, because I will always put you first, but I cannot -- I cannot -- I just don't think it's right. I don't think this is the right way. I don't think this is going to help us", and indeed at that point I think she -- I don't know if that helped her but she did recover for a while. She went back to college. She then went back to university.

In spite of everything, she's got a good degree, and [redacted].

- Q. Your son, you say and he says, struggled with the fact he wasn't able to do with his Dad what other children's fathers did. They couldn't kick a football around in the garden because of Bruce's ill health?
- A. Yes, yes. We didn't go out to theme parks for the day
 or anything like that. He just wasn't fit for that,
 so whenever we did that it was just me or my sister or
 friends or whatever, but he didn't have that

in the campaign, then who would do it? He feels a sense of responsibility."

And you say in your statement that you understand that.

- 5 A. Yes, yes.
 - Q. Then you say this:

"I'd always known that Bruce might die from his infections for the last 20-plus years. He is extremely upset every time someone else dies. Age 54 is the average age that other haemophiliacs who have been infected passed away. I believe this means that Bruce is hyper aware of his own mortality. It feels like we live on a knife edge, forced to live today but planning for a future that he might not have."

- A. Yes. His 54th birthday, again, I know it's an arbitrary date but it was very significant and he was -- his mood was very low around that time, yes.
 - **Q.** Christine, those are the questions I had for you. But is there anything further you would like to say?
 - A. I've just made up a couple of notes. (Pause)

I was asked to come here and speak about the family and tell our story. I've shared secrets with you that I've never -- that I've not told anybody else. I've never told anybody that I almost committed suicide but I don't want anybody to go away thinking,

act that if Bruce did not take part

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"Poor you". We don't want pats on the head. We don't want sympathy. What we want is truth and justice.

I am angry. I might be upset but I am so angry, not just of the infections, but that we have been forced -- that victims who are in the worst situation in their life are forced to keep trying to get this story sorted, that the very people whose lives are blighted, who have very little energy, have to use that bit of energy to fight this, to keep this going, to support everybody else.

I am so angry every time I hear an MP or a minister say, "Oh, we are very sorry". If you're very sorry you do something about it. You make it right, and if one more fatuous overstuffed minister says anything to me, I don't know what I will do. Maybe I will be throwing paint at the Parliament next time. I would love to hope that there would be an end to this. I would like to hope that I can walk into a hospital, because even now my anxiety levels are such that I'm anxious when I go into a hospital and I used to work in one.

How do we rebuild that trust? I dare say there are people here that will never, ever be able to fully trust a doctor again and yet we're reliant on them to keep us healthy, to keep us well.

go half an hour without discussing what -- the latest thing that they'd found, the latest piece of information that they'd uncovered.

In the course of the campaigning work, we have had great kindness shown to us by people in the arts community. We've had plays put on. We've had books written. We've had stories and TV things, and the kindness and the -- I mean, these people are -- just can't believe that we are still in the situation we're in now, but the kindness and the support of these people is in stark contrast to the collective responses of the health service, of state and welfare services, social welfare, who only seem to add to this torment that we're going to through, and I would say the torment of living with the ill health isn't as bad as -- I mean, I've heard stories this week that I've just -- made me cry and I appreciate that everybody's story is individual and some of them it just -- it just breaks your heart and I thought I was hardened to this, but actually the stories I've heard that my teeth hurt I'm so -- and I'm angry, I'm not just upset, I am absolutely angry that this should be allowed to happen.

Q. Thank you. I'm just going to ask Mr O'Neill if there's anything further. Maybe a good starting point would be if they told the story, they came clean and they were absolutely honest, because I don't believe that they've told the story before.

I turned up to the publication of the Penrose Inquiry four days after I'd had chemotherapy, hoping that we would have good news and to stand at the back and -- I'm sorry, Bill -- I was one of the ones shouting at the back of that, to stand at the back and be told we should feel sorry for the medics because they had been affected too, I was the first person to shout "whitewash", and I was so, so angry I had turned up -- and it was only the fact we met up with Shona Robison afterwards at the event arranged by Haemophilia Scotland and she said, "Forget about it. We are going to try in Scotland to put it right", and the Scottish scheme of support has been so much better than what the rest of the UK have offered, not that it's perfect by any means and there's some people who have had nothing from it that should have had some help.

But I mean there was so much hope going into the Penrose Inquiry, that this was an end to it, that we could finally get our lives back, that I would get my husband back, that we could spend time, that we could

Nothing further.

Sir?

SIR BRIAN LANGSTAFF: You've given us a remarkably clear and compelling account, in particular of a driven man.

Don't answer this question unless you feel you can or would want to, but at some stage this Inquiry will have to end, whatever its conclusions may be, what -- have you had any discussion, the two of you, about how life will then be?

A. Well, I mean, everything -- well, I have my ponies.
I've had to wait. I couldn't afford to have them
until I'd got cancer and had got my -- thankfully
I could get insurance, my husband can't get insurance,
but we would just like to live a quiet life. My
husband would like to play music and write and do art,
and if he could he would want to garden and go out for
lunch and sleep at night without worrying about this.

I would -- there was just one thing actually that I forgot. One of the things is the ongoing lack of trust and even now when you go to clinics as a haemophiliac they take syringes and syringes and syringes of blood and you're seen as an awkward bugger if you turn round and say, "What are you taking that for?" And I think it would be a very small thing for it be standard practice that the nurse or the doctor

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1 would say, "Right I'm going to test this. I'm going A. Thank you very much. 2 to be looking at this", and a lot of people, it might 2 SIR BRIAN LANGSTAFF: -- very, very much indeed and in 3 3 not bother them. They might not be worried about it, particular for, as you said, telling us things that 4 but for some of us we do want to know that -- that 4 you've never told anyone before. We've been 5 there's not a vial gone off for some new thing and 5 privileged. Thank you. 6 6 that there's no -- you know, there's nothing new in A. Thank you very much. Thank you, sir. 7 the future. 7 Thank you for having the opportunity. We really 8 8 My daughter is a carrier and after the evidence welcome the opportunity to tell the stories, as much 9 9 we heard last week, we had a tearful session and she as it's hard, it's really important. 10 SIR BRIAN LANGSTAFF: We'll take a break now until 10 said, "Do you know, my genetics mean that this will 11 never go away. The infections -- we might get to the 11 1.30 pm. 12 bottom of the infections but it's what's next". 12 MS RICHARDS: Thank you, sir. 13 SIR BRIAN LANGSTAFF: 1.30 pm. 13 And she -- to the point where she said she won't 14 have children. And if she adopts, although we would 14 (12.15 pm) 15 love the child and she would love the child as much as 15 (The luncheon adjournment) 16 a biological child, they would always be a reminder 16 (1.30 pm) that she has adopted because of what has happened to 17 SIR BRIAN LANGSTAFF: Our next witness wishes to be known 17 18 18 us here. as Graeme, does he? 19 But we would like a quiet life. We would like 19 MS FRASER BUTLIN: That's right. 20 to, yeah, just get on with it and -- because of my 20 SIR BRIAN LANGSTAFF: Graeme, please. 21 cancer diagnosis and because of Bruce's diagnosis, we 21 GRAEME MALLOCH, sworn 22 22 Questioned by MS FRASER BUTLIN don't have that security. So we just -- we just have 23 to live our lives to the best we possibly can, doing 23 Q. Graeme, you have severe haemophilia A. 24 the things we'd like to do. 24 A. That's correct. Q. And when you were young, how often did you need 25 SIR BRIAN LANGSTAFF: Thank you --25 61 62 1 treatment? 1 the walls, and I quite enjoyed going because there was 2 2 A. I think it varied. From speaking to my mother, as a play room and there was a games console and things 3 a sort of young child I was at the hospital maybe as 3 like that. But I remember my Mum sort of sitting in 4 4 a maximum frequency of once a week but it could be the waiting room talking to other parents of children 5 maybe once/twice a month. 5 who had other conditions, not necessarily haemophilia. 6 Q. And what treatment did you receive? 6 Q. And your understanding is that throughout your 7 7 A. Factor VIII. childhood, you only ever received Scottish factor 8 8 Q. Did you ever receive cryoprecipitate? products? 9 9 A. That's correct. A. No. Q. You were treated in Dundee? 10 10 Q. Why is that? 11 A. Yes. 11 A. Well, again I believe largely because Tayside or 12 Q. Was there a Haemophilia Centre there? 12 Dundee was quite disorganised in terms of its 13 A. No, as I understand it, the haemophilia service in 13 haemophilia service, that there was no oversight from Dundee was largely quite disorganised during the 14 a director in terms of procurement, so all supplies by 14 15 1980s. It wasn't until the arrival of Philip Cachia 15 default came from SNBTS lab in Dundee. 16 16 in 1991 that the centre was established. Prior to Q. And that's what you've been told subsequently, that 17 that, I believe then it was a paediatric, I just went 17 that's what was happening. 18 to a general paediatric clinic. 18 A. Yeah, I think we'd established that previously but 19 Q. There was no specialist paediatric haemophilia 19 I've also been told that again recently. 20 clinic --20 Q. In 1985 you now understand you were tested for HIV?

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A. Yeah.

Q. Can we have 2192006, please, Paul.

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A. No, I remember quite clearly going to the paediatric

clinic. It was in a downstairs corridor in Ninewells

and there was sort of cartoon characters and things on

A. No.

Q. -- that you could attend?

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It's a letter from January 1985 which says that

you attended a special clinic for haemophiliacs on

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11 January arranged along with another doctor so that

the problem of AIDS could be explained: "A sample of blood was removed from Graeme for antibodies to the AIDS virus (HTLV-III), and the sample will be sent to Edinburgh along with others obtained at the same time from other haemophiliacs." Then there's some discussion about hepatitis B. As far as you're aware, did your Mum attend such an appointment? A. I obviously don't remember it as I would only have been five years at the time, but I've spoken to my Mum and my Dad about it. They have no recollection at all of this special clinic. They believe if this did happen, it would have been dressed as a standard haemophilia check-up, but they have no recollection of it whatsoever. As a parent myself, I think if I was asked to come in and have my child tested for AIDS I would remember it, and my parents have no recollection of this whatsoever. Q. Do they have any recollection of being told the result of that test?

22 A. No.

Q. In 1992 you changed factor products. What were youtold about that?

A. I don't have a great recollection of it, but

Mum became concerned about the possibility that you might have been infected with a virus through the blood products you'd been receiving. What did she do about that?

A. My Mum had been, I think, getting increasingly suspicious or aware of the sort of rumours circulating about hepatitis C. Up until that point, she hadn't really enquired about it because she actually thought that the SNBTS products were safe.

All the stuff that she had seen in the news or in the literature that came out seemed to be focused on down south, certainly what she saw it was an English problem so she hadn't been concerned up until that point, but I think over the course of 1994 possibly other haemophiliacs in the area had maybe tested positive and Mum attended the local groups, and I think probably she was encouraged to find out if I could have been affected.

So she approached Dr Wilkie who was my paediatric doctor at the time and I think probably asked in quite an offhand kind of way, "There's no chance that Graeme might have been affected by this, is there?" And I think it was probably left at that, and that was just as part of a routine check-up.

Q. Then if we can have 2192008, please, Paul.

essentially I was moving to a new product which was better, I believe it was a higher purity, it would be better for my haemophilia care but nothing else was really told other than, "This is what we're moving to. This will be for your benefit".

Q. Can we have 2192004, please. It's a letter from August 1992 and towards the end of the first paragraph it says:

"I've also spoken to them about the change in the Factor VIII. Scottish Blood Transfusion are going to be changing over to highly purified Factor VIII in September and this will require all the children to be changed over at that time. Because it as yet only has a provisional licence, it will require that those who are being changed over should be monitored carefully and I have explained this to the parents."

Do you know, either from your own knowledge or from talking to your parents, what was meant by "being monitored carefully"?

- A. Well, we understood it to be that they were just going to be checking my inhibitor levels and the effectiveness of the treatment. We didn't expect there to be any sort of virology checks as a result of changing over to the new treatment.
- Q. In late 1994/early 1995, when you were about 15, your

We can see a letter from January 1995 to your Mum and Dad saying:

"I've now gone through and looked at Graeme's results of his viral studies and, in fact, he does have a positive hepatitis C antibody test which means that at some stage he has been exposed to hepatitis C. Obviously, there is a lot of press coverage about this at the moment and we obviously need to talk about this matter when he next comes to the clinic."

Did your Mum go in and talk to Dr Wilkie about this?

- A. I believe she contacted Dr Wilkie the very same day and arranged a meeting.
- Q. And what was she told?
- A. I think she was -- was invited to come in for
 a meeting with my Dad. I don't think I was invited or
 I was excluded in some way, so she did attend
 a meeting, possibly it was about a couple of weeks
 later.
 - Q. We've got a letter from February 1995. It's 2192002. We can see that the purpose of the meeting was to discuss the fact that you were hepatitis C-positive, and the letter says in the second paragraph:

"I think the important thing I have emphasised that most people with hepatitis C positive may have not

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actual activity disease and we have to determine this in Graeme and will organise an ultrasound scan and liver functions tests done on a three-monthly basis to see whether in fact there is evidence of ongoing liver involved. At this stage we will then go on to discuss whether liver biopsy would be an alternative to determine whether he has active liver disease or not."

And if we carry on down the page it says:

"I think the parents were quite relieved in chatting about the situation today but it is still a rare occurrence for people with hepatitis C positivity to go on to end stage liver failure."

Does that accord with what you think your parents were told at that time?

- A. They certainly were not relieved. When I received my notes and saw this letter, I showed it to my parents and I think they -- it's not funny, but they were almost rolling about the floor laughing at the way it was worded. They were not relieved in the slightest. After having had that meeting they were scared for the future and they didn't know really what it meant for me
- 23 Q. What were you told about the hepatitis C?
 - A. From my parents I was told not to worry, that things would get sorted. I think they tried to calm me and

- Q. When you were told about the diagnosis and you were told not to tell anyone what did you understand the diagnosis to mean for you?
 - A. That I was at the beginning of the end of my life. You know, I felt that I had just been given a death sentence and, you know, that I was only 15. I didn't really know what to do with it, if I'm honest. I was very scared, but outwardly I was trying to be brave because I didn't want my parents to see me upset. I wanted them to be -- they had been through the mill enough with my haemophilia. I didn't want them to sort of think that I was scared for my future. I wanted them to see me still as a positive teenager with a bright future, so I bottled it up and I put it away, and tried to carry on regardless.
- Q. And did you talk to your parents much at all about it,or is it something that you --
- A. Very little. I talked to them if they asked meanything, but I didn't go to them about anything.
- Q. And you've said that you had been told not to tell
 anyone about it. What was the impact of that at
 school and with your friends?
- A. Yeah. So nobody during my school days found out. It
 was a closely guarded secret. If you don't mind I'm
 just going to refer to some of my notes, because I'm

reassure me there would be treatments in the pipeline and everything would eventually be okay. I was also told not to tell anyone. Keep it to myself because, obviously, at the time there was lots of stigma attached to it in terms of HIV, AIDS, hepatitis, they were all sort of diseases that were in the press at the time and there was a lot of prejudice.

- 8 Q. Did you have any discussion with the doctors about it?
 - A. I don't recall at that stage, no.
- 10 Q. And how do you feel now about that delay in telling11 you or your Mum?
- 12 A. So that's from the test in 1992 until --
- **Q**. 1995
- A. -- the letter I've received in 1995. I'm very angry about it. You know, if they knew in 1992 why didn't they tell us in 1992? It either means somebody withheld that information from us or somebody wasn't checking my results. Either way, it shouldn't have happened, you know, and if they hadn't checked my results why were testing me in the first place? So it does point to the fact that they probably withheld the information from me.
- Q. And subsequently you've been concerned that if your
 Mum hadn't asked in 1995 when you were told --
- 25 A. When she was eventually told, yeah, yeah, exactly.

1 a clamming up a little bit and I've written everything 2 down that I want to say. (Pause)

Yeah, so I mean I was at school. The actual day that the letter arrived in 1995 I was actually going into school that morning for a prelim exam and I remember going up to school thinking, "What's the point? I don't need to try for exams any more because I'm going to be dead in a few years".

I kept it secret from my friends because I was told to, because my Mum and Dad were worried about people maybe -- they weren't so much worried about my friends but they were worried about other boys and girls that maybe didn't know me very well possibly picking on me and thankfully it never got out, so it never really happened.

- Q. What was the impact on your schooling, on youracademic progression?
 - A. I think I did okay. I got enough -- you know, I was a fairly diligent kid. I did enough to get through all my exams. I got some decent higher results and managed to get to university and I got through university as well, probably didn't do as well as what I should have done either at school or university but that's because I think my mind wasn't really into it as I should have been.

- Q. You said in your statement you developed a carefree
 attitude because you felt that what was the point of
 applying yourself particularly to education when you
 weren't going to be around in a few years.
- A. Absolutely. I was a teenager, I was immature and that
 was the attitude that I adopted. You know, "If I'm
 going to be dead soon then I might as well enjoy
 myself while I can. What's the point of applying
 myself to my studies?"
- 10 Q. In 1999 you became involved in some possible legal
 11 action in relation to the hepatitis C. What were you
 12 told by your solicitors at that early stage to do?
- A. Yeah, they asked us to approach NHS Tayside to find if
 there had been any gap between me testing positive for
 hepatitis C and being informed, and I obviously
 subsequently got the letter through which said I had
 tested positive in 1992.
- Q. We're going to look at that letter in just a moment,
 but do you have any idea of why your solicitors were
 asking you to do that?
- A. I believe it's possibly because they had other clients
 at the time who had also encountered a similar delay.
- Q. Could we have 2192007, please. This is the reply you received in 1999 which says:
 - "Just a note to confirm that you and your parents

- sort of waiting for funding to come through, but
 lalso wonder if it was perhaps to let me get past my
 school days. I don't really know the ins and outs of
 why it was held off until that point but I do remember
 hearing about funding issues.
 - Q. So you had your first round of combination therapy in about 1998/1999.
- 8 A. Yeah.

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- Q. What impact did that have on you?
- A. I remember all the flu-like symptoms. It was pretty
 awful, waking up every day feeling like you had the
 flu and nothing you could do would shake it. I was
 tired and I remember things like headaches quite
 regular as well, but mainly the flu-like symptoms and
 tiredness.
- 16 Q. And at that time you were at university?
- 17 **A.** Yeah.
- 18 Q. What effect did this have on your studies?
- A. It didn't stop me from attending, thankfully, because it was quite important that I got through the course but, again, I don't think I applied myself as well as I could have done if I hadn't been on the treatment.

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- 23 Q. That first round of treatment was unsuccessful.
- 24 A. Correct.
- 25 Q. And then you had a second round in 2001.

were first informed about you being hepatitis C positive in a letter ... on 16 January 1995. The first identification of hepatitis C antibody was in November 1992 as part of a general virological screen when you were changing Factor VIII products."

6 Had you been told or your parents been told in 7 1992 that you were having a general virological 8 screen?

- 9 A. Yes, that was part of changing the product but -- no,
 10 sorry, they weren't told that there was a general
 11 virological screen. They were told that they were
 12 doing routine bloods.
- 13 Q. That was the careful monitoring bit?
- 14 A. Yes.
- 15 Q. But nothing about viruses?
- 16 A. No.
- 17 Q. And so I take it from that you weren't aware that you18 were being tested for hepatitis C in 1992?
- 19 A. Not at all, no.
- Q. Once treatment options were discussed with you afteryour diagnosis, you had to wait for your first round
- 22 of treatment.
- 23 **A.** Yeah.

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- Q. Why was that?
- 25 A. I think there was a mixture of -- I did hear about

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- 1 **A.** Hmm.
 - Q. Why did that come to an end?
- A. It wasn't working, so I was on the treatment for six
 months and I was told, "It's not working. It's very
 unlikely to work at this stage", and given that I was
 suffering from the side effects that it was probably
 best to stop.
- 8 Q. By then you were still at university. You were9 towards the end of your university course?
- 10 A. Yeah.
- 11 **Q.** Again, what was the impact of having the treatment on you?
- A. Similar. I was unwell again. Probably struggled
 a little more the second time round. I lost a lot of
 weight. I remember having to go on nutritional milk
 shakes and things to try and keep my weight up. It
 was pretty tough but, again, I was able to just about
 do enough at university to get through.

It was doubly fortunate that the course I was doing was geography, and it's something that I actually have a background interest in any way, so as much as I wasn't applying myself to the course in the way that I would have liked, I was probably able to infer enough with my own background knowledge just to pad out what I was learning on the course.

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- 1 Q. I think at that point you'd also moved home again to 2 have a bit of extra support during the treatment.
- 3 A. Yeah, I think I'd gone back home to live with my 4 parents, yeah, yeah.
- 5 Q. After university, you were offered a media job.
- 6 A. Hmm.

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- Q. What can you tell us about that?
- A. Yeah, after I graduated I was obviously looking for a career and one of the things that had interested me 10 was this media job. I attended for an interview. The 11 interview went very well, so well in fact that it was 12 more or less concluded that, "We just need to send you 13 for a medical but that's a formality and an offer will 14 come out in the post afterwards".

So I went for the medical, I think it was a couple of days later. I hadn't disclosed my haemophilia or hepatitis at the interview or in my application, but I didn't think it was going to be an issue but I went for the medical and when I was lying on the table the doctor who was doing the medical happened to notice I had three small scars in my stomach area which were from the liver biopsy that I'd had when I was I think 16, possibly, and obviously enquired as to what those scars were, and that's when I disclosed obviously that I'd had hepatitis C as

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and they thought I would be a good fit because they knew me for four years and they knew I had a degree and was looking for a proper career and felt I'd be a good fit for them.

So they made me an offer and that's where I stayed then for I think it was 12 years.

- Q. By -- or not long after that you met your wife and you
- 9 A. We married in 2007 but we met not long after, 2001, 10
- 11 Q. 2007 you got married and your wife was very keen to 12 have children?
- 13 A. Yes.
- Q. As were you? 14
- 15 A. Mmm-hmm.
- 16 Q. But you waited for some time.
- 17 A. Yeah.
- 18 Q. Can you tell us why?
 - A. Ultimately, I was the one who kind of held off more than my wife because of my hepatitis C status. I didn't want to risk the possible transmission of hep C to my wife, but we sort of -- you know, I was absolutely petrified of actually passing it on and that's why we sort of held off and we held off and we

held off, and it was ultimately sort of in 2011/12

a result of my haemophilia.

A week or so passed and the letter never came to offer the job and I eventually got fed up waiting and phoned up and was told that the job had been filled by somebody else.

- Q. How did you feel that point?
- 7 A. Devastated. You know, I was really keen on the job 8 and I'd been more or less told that I had it. I was 9 really looking forward to it, so I think I kind of 10 knew after the medical that there might have been 11 issues but I kind of still hoped that I was going to 12 get it, but it never happened so I was really upset.
 - Q. So what did you do after that, in terms of work?
 - A. Luckily whilst I'd been at university I'd had a summer job working in a shoe warehouse. When I had finished university, they actually gave me a permanent part-time position working in the warehouse and they knew that I was looking for a proper career to fall on from that.

Luckily, I think it wasn't long after the rejection from the media job, they invited me to come through to the office and had a chat with me about possibly moving into a management position. The stock controller of that company was due to retire in a year's time and they needed somebody to replace her,

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1 that we kind of felt we can't really wait any longer.

- Q. You were offered a third round of treatment and you deferred that --
- A. Yes.
- Q. -- in order to start a family?
- A. Yes. It was sort of coincidental that around about the time when my wife and I decided we couldn't wait any longer to start a family that the next sort of round of treatment was made available.

We felt because of the length of time that I would be on the treatment and the time you have to wait afterwards for getting pregnant that it would be best that I deferred the treatment.

At this stage I wasn't unwell from the hepatitis C, not noticeable anyway, so the advice was that there was no rush to get started so that there was time for us to start a family, if that's what we wished to do. So the agreement was we would defer the treatment for a year to allow us to start trying for a family.

It was getting touch and go, so much so that we decided that actually we got involved with freezing my sperm because we were getting worried that we weren't going to fall pregnant before I was due to start the treatment and in case of any complications we wanted

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- 1 to still be able to -- my wife wanted to be able to do 2 the IVF if need be whilst I was on the treatment. 3 Luckily we did fall pregnant just before I was due to 4 start this course of treatment.
- 5 Q. So your wife was pregnant, you started your third 6 round of treatment.
- 7 A. Yeah.
- 8 Q. This time the treatment was successful.
- 9 A. Yes.
- 10 **Q.** But what were the side effects of that third round?
- 11 A. Pretty devastating again. I lost a lot of weight.
- 12 The main two symptoms were the weight loss -- the 13 flu-like symptoms again and I had a quite severe rash
- 14 over lots of my body.
- 15 Q. And what symptoms have you been left with since then?
- 16 A. I think I probably am fatigued some of the time, and 17
 - I think there's peaks and troughs with that. I go
- 18 through weeks where I think I feel quite good and then
- 19 there are a few weeks where I may be below par. I've
- 20 definitely been left with the itchy skin. I just
- 21 can't seem to shake that. Other than that, I don't
- 22 think I've been left with too many symptoms.
- 23 Q. You're also concerned that the interferon treatment 24 has made your ankle arthritis worse?
- 25 A. That's correct, yes.

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- A. No, not that I'm aware. It's been offered but I've declined.
- Q. You've said in your statement you're still very fearful though about your health.
- 5 A. Yeah, I -- the whole hep C thing has given me the 6 sense that I was living with a ticking time bomb. You 7 know, I always wondered when it was that I was going 8 to become unwell. That's stayed with me. I'm still 9 concerned that I had hepatitis C for probably around 10 about 30 years and, you know, I wonder what damage has 11 already been done to me, you know, that possibly the 12 foundation stones have been laid for future ill health 13 and it does make me fearful for the future in that my 14 life may not be as long as what it should have been.
- 15 Q. And what's the effect been on your mental well-being 16 of that?
 - A. Yeah. I think I'm probably not as outgoing a person as I would have been if I hadn't had the diagnosis. I do think I get irritable sometimes. My wife says I'm probably the most laid back person she's ever met but, you know, I know that I get times where I feel very irritable and I kind of go into myself and I just need to take myself into a different room or away from the house or whatever and just have a few -- a bit of

Q. Why is that?

A. That was actually through the Scottish Infected Blood Support Scheme. Some of the information that was -- that I found when I was doing the application suggested that interferon can exacerbate arthritis and that's why I kind of wonder whether that might have been the case with me.

My arthritis in my ankles has primarily been caused by bleeds from my haemophilia, but I don't really remember the arthritis kicking in until sort of the early 2000s, which was not long after the two courses of interferon treatment. It may be coincidental but it may not be.

- 14 Q. For you the timing is pretty close to having started 15 that interferon and the arthritis getting worse?
- 16 A. Correct, yes, yeah.
- 17 Q. What's the situation now with your liver?
- 18 A. I believe I have minimal or no fibrosis based on the 19 last sets of ultrasound scans that I had before the 20 treatment, so I'm hopeful that's still the case.
- 21 Q. Have you had any monitoring since completing the 22 treatment?
- 23 A. I've had liver function tests done for a about a year 24 afterwards, which were all normal.
- 25 Q. Anything since then?

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It's kind of difficult to say, because I don't know what I was like before other than I was a quite an outgoing kid. I feel like I became more reserved after the treatment came and more secretive.

One of the things that kind of sticks out for me is that my haemophilia was actually something I wore very proudly as a child. I was very outgoing and I talked about it all the time. I did demonstrations in a classroom. I did talks in the classroom about it, I even did a treatment demonstration but a couple of kids fainted in the class, so my haemophilia was something I was very proud of, strangely. You know, it was a big part of who I was.

When I got the hepatitis C diagnosis it felt like almost a part of me kind of died because by association the haemophilia became a dirty word and it was something I then had to hide away. Where I had been very open about my haemophilia, it was now something I hid away because I didn't want people to make the connection between haemophilia and hepatitis C. So, yeah, that did affect me quite a lot and it still does. You know, to this day I'm not very open with people about anything, to be honest. I keep a lot to myself.

Q. You describe in your statement being a closed door

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time to myself.

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1 emotionally. I would have been a more affectionate and sort of 2 2 A. Yeah. cuddly kind of Dad if that was the -- if I hadn't had 3 3 Q. And often feeling emotionally detached from reality the hep C. 4 4 Q. And how has it affected your marriage. and kind of flat line. 5 A. Yeah, yeah, I don't get upset the way I should get 5 A. I'm very lucky in a way that Laura has known me since 6 6 upset about things which are distressing or upsetting. 2001 and she was one of the first people I actually 7 I don't get the elation maybe that I should do when 7 probably really confided in about the hep C so she's 8 8 something really good happens. I do feel like I'm always known about it so it's been a part of our 9 9 just kind on a level all the time. relationship all the way through, but I don't think it 10 10 Q. What has been the impact of the infection of your has helped. You know, I've -- as I say, I'm probably 11 family life? 11 not as physically affectionate as what I should be. 12 A. I'm not as affectionate as I should be, I don't think. 12 It is something I have to work as hard at and it's 13 You know, kisses and cuddles with my kids and my wife 13 probably not as natural a physical relationship as it 14 don't come naturally. I really do have to work hard 14 15 15 at it and remind myself that it's okay to do these Q. Throughout this time have you been offered any 16 things, and I think that's partly as well that, you 16 counselling or psychological support? know, for many years I actually felt dirty and 17 17 No, other than attending the usual haemophilia infectious. You know, I didn't want to touch people. 18 clinics, "Are you okay? Is there anything you want to 18 19 I used to think, you know, that my sweat would 19 talk about?" There's not been any sort of specialist 20 be infectious and I would be worried about touching 20 counselling offered. 21 light switches in case somebody came along and touched 21 Q. Do you think if there had been some offered you would 22 22 it after me and got hep C, you know, so it's have taken it up? 23 definitely affected me. 23 **A.** I'm probably a typical guy in that, no, I probably 24 24 wouldn't have. That's not to say that it shouldn't Don't get me wrong, I love my kids dearly and 25 I think they know that as well but, you know, I think 25 have been sort of pushed on me. One of the things 85 86 1 that I've sort of thought about for this is, you know, 1 born on 26 December and I'd actually taken two weeks 2 2 if you're not hungry you're not hungry, but if you off work with the idea that I would have paternity 3 pass a fish and chip shop you'll all of a sudden be 3 leave to follow on after that. So I was off work over 4 4 very hungry. The same with counselling. If it's Christmas and New Year and I think it was on -- my 5 there right in front of you and somebody starts 5 daughter still hadn't been born but it was around 6 a conversation, even if you didn't want that 6 about 5 January I got a phone call from work to say 7 7 conversation, it might happen and it might start the that the business was closing down and you know that 8 8 outpouring of what you need to talk about. obviously they had started the consultation process 9 9 Q. You've reflected in your statement that you think you about redundancy, and then my daughter was born on 10 probably would have benefited from counselling, 10 10 January, five days later. It was very difficult. 11 certainly in the early days --11 I was in a bit of a mess, but I had to put a brave 12 A. Yeah. 12 face on it because my wife had been very unwell during 13 Q. -- even if you hadn't really wanted it? 13 her pregnancy as well, so she needed my support and, A. Correct, yeah, if it had been given to me and almost you know, I wasn't well enough to really give as much 14 14 as I would have liked to have done. 15 made compulsory I think it would have helped. 15 16 16 Q. In terms of your working life, during that third round The redundancy thing, I kind of really just put 17 of treatment your daughter was born and you were made 17 that to the back of my mind because I had bigger 18 redundant. 18 things to deal with. I could worry about work later 19 A. Yeah. 19 but it was still a considerable thing to have to deal 20 Q. And you said the side effects were awful. 20 21 21 Q. When you did come to worry about work, what did you go 22 22 on to do? **Q**. But the impact of that situation with work was also 23 23 very difficult. A. I was fortunate that whilst I'd been working at the 24 A. Yeah, I was -- as you say, I was right in the midst of 24 shoe factory I'd also kind of had some promotions and

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the treatment. I -- my daughter was due to have been

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I'd become the e-commerce manager during that time and

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I'd worked quite closely with another local media company who had developed our website and on hearing about the redundancy, I gave them a phone call just to ask if they had anything that they might be able to offer me and they jumped at the chance. They offered me a job there and then on the phone.

So luckily that situation resolved itself very easily and quite quickly. Yeah.

- Q. And where you're working now, you've said it's been much easier health-wise because it's a family business?
- A. Yeah, I didn't last long in the sort of media world and I'm now in the family business, which is easier because most people there do know my situation. It's a difficult job. It's quite long hours and quite a bit of stress because I'm essentially running the company but, as I say, people do know my circumstances so there's a bit of flexibility for me to come and go.
- 19 Q. In terms of financial effects can you tell us what the20 impact has been financially?
 - A. Yeah, going back again to sort of when I was first told about the hep C, there was that carefree attitude, you're a bit -- I didn't think I was going to be around long, so similar to where I wasn't too worried about my studies I wasn't really worried about

You know, I've taken on a large mortgage for my family. You know, we've got a nice house but ultimately if I do become unwell in years to come, I can't service that mortgage. My wife has moved down to part-time hours to help look after the kids while they're growing up, so if I was to become unwell and unable to work, I would worry about her being able to get back into full-time employment and even with that one income we couldn't support our mortgage and bills.

- 10 Q. And that is your ongoing major worry?
- 11 A. Yeah, it's looking after my family for the future.
- 12 Q. And that something might happen to you --
- 13 A. Yeah.

- 14 Q. -- even though you've cleared the virus --
- 15 A. Yeah.
- 16 Q. -- you continue to be worried about what your health17 will be in the future?
- A. Yes, as I say, I'm worried that the foundation stones for future ill health haven't already been laid. You know, I had hep C for 30 years, so who knows? And I don't think there's anybody who -- nobody can tell you what the future holds for somebody who has had hepatitis C for 30 years because it's not happened yet.
 - Q. Those are the questions I have for you. Is there

money either. I had the sort of feeling I was going to be dead in a few years anyway so I might as well enjoy things while I was around, so I was very carefree with money. I just spent it, spent it it, spent it, spen

- Q. And then subsequently you've had difficulties with life insurance.
- A. I don't have life insurance. I think I tried once andwas rejected, so I've never tried again.
- 12 Q. And you've struggled with travel insurance.
- A. I do get travel insurance but it's much more expensive
 than normal life -- travel insurance.
- Q. You've received a Skipton Fund payment and somepayments from the Scottish scheme.
- 17 A. Yes.
- 18 Q. What are your views of the scheme?
- A. They're helpful but they're a long way short of what
 I think should be available. I've not had any
 difficulties getting those payments. I think my case
 has probably been quite cut and dry but, you know, the
 money has helped but it's a long way short of giving
 sort of financial security should I ever become
 unwell.

- 1 anything else you would like to say?
- 2 A. I've got a short statement which I would like to read.
 - Q. Please do.

A. I would just like start by thanking you for the opportunity to tell my story. It's something I never thought I would do and I've only been inspired to do so by the strong words and commitment to put people like me at the heart of the Inquiry.

I had given a written statement previously to Penrose and prior to that I had looked at private legal action but the outcomes of both of those had ultimately been what seemed like a dead end so I thank you for giving me and all of us a light to walk towards, albeit there is a long tunnel still ahead.

I don't know any of the other haemophiliacs or I'm aware of any friends or relatives who have been affected by this scandal. By not knowing any other haemophiliacs I mean I don't know anybody very well. I'm only acquainted with other members of my local society group. It's therefore been very notable that as part of this process in creating a statement for the Inquiry how closely my narrative seems to follow the experiences of other people like me.

I feel it points to either high-level decision or lack of decision-making, or a total systemic

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failure to prevent or appropriately manage the circumstances that arose in the 1980s and '90s. Either way, innocent lives have been lost. Innocent lives have been ruined and innocent lives have been irrevocably damaged and altered.

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I fear I will forever live with a sense of trauma about what has happened to me and fear and trepidation about what lies ahead. I may have cleared the virus six years ago, but having ultimately lived with hepatitis C for 30 years with slightly elevated liver functions tests, I am not reassured that some damage has not been done. I am also not reassured that three courses of interferon treatment in different guises have not damaged me or added to the burden.

It is my personal feeling that costs must have been put above safe treatment. Damage limitation and a not-my-problem, mentality has been put ahead of patients rights and welfare. Because of this, those of us who still survive will forever bear the burden, as will the loved ones of those who have departed.

Those who are no longer with us have paid the ultimate sacrifice of what has been inflicted to upon us and I conclude by wishing you well in delivering the answers that will lead to justice for all of us

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hepatitis C on me. Of course, that's not the case, but as the person who was actually doing the act of the injection, she does feel, I think, a sense of responsibility which is very unfair on her.

When I was diagnosed with my haemophilia, the -both my parents were actually questioned as to whether they were ill treating me. I had been in and out of hospital with bruising and swollen joints, et cetera, so that's just another thing they've had to deal with over the years and it's -- it's a sort of cumulation of factors it's probably been quite difficult for

- 13 Q. When you were diagnosed you were very concerned about passing on hepatitis C? 14
- 15 A. Yes.
- 16 Q. And washing your hands and being very scrupulous in 17 that regard.
- 18 A. Mmm-hmm.
- 19 Q. You were also worried in case you had passed it on to 20 your Mum.
- 21 A. Yeah.
 - Q. And she was subsequently tested as well and was clear?
- 23 A. Yeah, she was tested because there was a concern that 24 it could have been passed on. My Mum was my 25 treatment-giver up until when I started doing it

and ensuring that nothing like this could ever happen again.

Q. I'm just going to turn and ask Mr Dawson and Mr O'Neill if there's anything they wish me to ask. (Pause)

Just a couple of points they would like me to ask you about.

- 9 Q. When you changed over to the higher purity Factor VIII 10 from -- higher purity Factor VIII from 1992, were your 11 parents told of any risks involved in any of the 12 products, whether that was the higher purity or before 13
 - A. No, they had no awareness at all of any risks.
 - Q. Can you tell us about the emotional impact this has had on your parents.
- 17 A. Yeah. I mean, as I mentioned, I've not really spoken 18 to them over the years about it because I've tried to 19 let them feel that I'm okay.

My parents probably have had a lifetime of stress and worry because of my haemophilia and I think my Mum in particular, who was my main carer and also my treatment-giver as a young child, she feels a sense of responsibility that possibly by treating me with Factor VIII that she was the one who inflicted

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1 myself at about the age of 10 or 11, so she had been 2 at risk of needle stick injuries or handling my blood 3 from cuts and bruises and swellings on. Yeah, I think 4 it would have been awful, if she -- she felt that she 5 had given me hep C and likewise if I had given it back

6 to her it would have been the worst set of 7 circumstances we could have imagined.

8 **Q.** We spoke about your second treatment with interferon 9 and you said you'd ended it because it wasn't working. 10 In your medical records there's a note where it says 11 you came off it because of the side effects.

A. Yes, that's incorrect. That's probably, actually, to be fair, my main complaint of my treatment as an adult. I only found this out when I got the medical records through. I remember I was getting regular check-ups whilst I was on the treatment and I was suffering, but there was nothing that would have stopped me from completing that treatment if I thought there was a chance it was going to work.

I remember coming into hospital for one of the regular reviews and I think it was put to me that, "The treatment is still not working and given the side effects you're suffering, it might be best to stop", so I agreed to it but I never requested to stop.

Q. And a final point just in relation to your medical

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36/11 38/4 39/23 41/14 48/6 52/23 54/3 56/16 56/17 57/7 57/8 57/12 57/13 60/24 62/1 62/2 62/2 62/6 68/12 70/14 71/8 71/18 72/13 76/4 77/11 79/11 83/3 83/22 84/7 84/7 84/12 84/18 84/22 86/5 87/4 87/23 88/10 88/12 89/7 90/3 92/18 92/20 95/4 95/13 95/16 97/10 97/17	41/17 41/21 44/20 44/24 55/18 55/19 55/20 56/25 57/1 57/2 57/2 60/6 60/16 61/4 71/9 71/11 72/2 79/21 84/19 85/18 86/18 87/6 wanted [9] 36/4 36/5 39/16 44/16 71/10 71/13 80/25 81/1 87/13 wanting [2] 21/24 41/3 wants [1] 48/19 ward [4] 15/18 30/23 53/15 53/16	51/6 59/6 59/6 59/7 62/4 68/20 91/2 97/3 97/16 website [1] 89/2 wedding [1] 3/15 week [7] 4/17 24/9 52/1 59/16 61/9 63/4 78/2 weekend [1] 46/14 weeks [11] 6/16 6/17 10/7 10/14 11/23 20/24 23/22 68/18 81/18 81/19 88/1 weight [8] 7/9 7/10 32/3 40/15 76/15 76/16 81/11 81/12	16/23 20/2 21/17 26/5 65/15 65/19 when [70] 1/6 1/21 5/19 5/22 6/24 7/20 8/3 8/17 11/11 11/15 15/24 18/25 21/4 22/4 22/13 25/3 25/6 27/15 28/19 30/15 30/21 30/25 32/13 35/20 36/7 38/6 38/23 41/15 42/3 43/21 44/18 45/15 45/23 46/9 46/11 46/18 46/24 48/19 50/16 51/22 52/2 53/16 55/11 57/20 60/20 62/25	whole [5] 26/13 41/18 46/3 83/5 97/12 whom [1] 26/18 whose [1] 57/7 why [23] 10/4 10/4 10/18 16/17 16/18 16/19 16/21 25/10 26/7 28/1 49/24 55/9 64/10 70/15 70/20 73/19 74/24 75/4 76/2 79/18 79/24 82/1 82/6 wife [22] 2/13 3/5 5/7 10/2 24/3 26/12 26/12 27/24 28/19 28/22 41/24 79/7 79/11 79/20 79/22 80/7 81/1	92/7 wore [1] 84/6 work [33] 1/13 8/24 21/5 26/25 30/24 35/14 35/18 35/21 36/1 38/1 40/1 40/7 41/24 42/21 45/14 47/25 48/1 51/12 53/7 57/21 59/4 76/5 78/13 85/14 86/12 87/22 88/2 88/3 88/6 88/18 88/21 91/7 96/19 worked [6] 7/22 22/12 40/8 51/16 51/17 89/1 working [18] 7/24 33/19 37/8 39/2 40/5
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36/11 38/4 39/23 41/14 48/6 52/23 54/3 56/16 56/17 57/7 57/8 57/12 57/13 60/24 62/1 62/2 62/2 62/6 68/12 70/14 71/8 71/18 72/13 76/4 77/11 79/11 83/3 83/22 84/7 84/7 84/12 84/18 84/22 86/5 87/4 87/23 88/10 88/12 89/7 90/3 92/18 92/20 95/4 95/13 95/16 97/10 97/17 via [3] 14/2 26/13 26/22	41/17 41/21 44/20 44/24 55/18 55/19 55/20 56/25 57/1 57/2 57/2 60/6 60/16 61/4 71/9 71/11 72/2 79/21 84/19 85/18 86/18 87/6 wanted [9] 36/4 36/5 39/16 44/16 71/10 71/13 80/25 81/1 87/13 wanting [2] 21/24 41/3 wants [1] 48/19 ward [4] 15/18 30/23 53/15 53/16 wards [1] 47/1 warehouse [2] 78/15	51/6 59/6 59/6 59/7 62/4 68/20 91/2 97/3 97/16 website [1] 89/2 wedding [1] 3/15 week [7] 4/17 24/9 52/1 59/16 61/9 63/4 78/2 weekend [1] 46/14 weeks [11] 6/16 6/17 10/7 10/14 11/23 20/24 23/22 68/18 81/18 81/19 88/1 weight [8] 7/9 7/10 32/3 40/15 76/15 76/16 81/11 81/12 welcome [1] 62/8 welfare [3] 59/12	16/23 20/2 21/17 26/5 65/15 65/19 when [70] 1/6 1/21 5/19 5/22 6/24 7/20 8/3 8/17 11/11 11/15 15/24 18/25 21/4 22/4 22/13 25/3 25/6 27/15 28/19 30/15 30/21 30/25 32/13 35/20 36/7 38/6 38/23 41/15 42/3 43/21 44/18 45/15 45/23 46/9 46/11 46/18 46/24 48/19 50/16 51/22 52/2 53/16 55/11 57/20 60/20 62/25 66/25 68/9 69/15 70/24 70/25 71/1 73/3	whole [5] 26/13 41/18 46/3 83/5 97/12 whom [1] 26/18 whose [1] 57/7 why [23] 10/4 10/4 10/18 16/17 16/18 16/19 16/21 25/10 26/7 28/1 49/24 55/9 64/10 70/15 70/20 73/19 74/24 75/4 76/2 79/18 79/24 82/1 82/6 wife [22] 2/13 3/5 5/7 10/2 24/3 26/12 26/12 27/24 28/19 28/22 41/24 79/7 79/11 79/20 79/22 80/7 81/1 81/5 83/19 85/13 88/12 91/4	92/7 wore [1] 84/6 work [33] 1/13 8/24 21/5 26/25 30/24 35/14 35/18 35/21 36/1 38/1 40/1 40/7 41/24 42/21 45/14 47/25 48/1 51/12 53/7 57/21 59/4 76/5 78/13 85/14 86/12 87/22 88/2 88/3 88/6 88/18 88/21 91/7 96/19 worked [6] 7/22 22/12 40/8 51/16 51/17 89/1 working [18] 7/24 33/19 37/8 39/2 40/5 45/8 45/15 49/13 51/16 76/3 76/4 78/15
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