

Thursday, 6 June 2019

(10.34 am)

SIR BRIAN LANGSTAFF: Good morning.

Our first two witnesses this morning together are both members of the same family and wish to be known as Pe and Bronny.

MS FRASER BUTLIN: That's correct, sir.

SIR BRIAN LANGSTAFF: So Pe and Bronny.

PENELOPE RAE AND BRONWYN RAE-LE BOURN, affirmed

SIR BRIAN LANGSTAFF: Pe, you are probably going to have to come a little bit closer to the microphone. I am not quite sure what has happened with the sound this morning because I think I sound very loud and you don't and it's more important people should hear from you than me.

Questioned by MS FRASER BUTLIN

MS FRASER BUTLIN: Pe and Bronny, you are here to tell us about Paul, your husband Pe, and your Dad, Bronny.

Pe can you start by telling us how Paul came to be infected with hepatitis C.

PE: Paul was infected after a motorbike accident. He had some treatment back in the 1980s and had a blood transfusion.

MS FRASER BUTLIN: He had a motorcycle accident on 31 August 1981 and it was really very serious.

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Paul was like.

PE: Well, that just picture sort of sums him up as he was then. He was chirpy, happy, fit, amusing. He'd left school early and then gone back and did a load of education became a social worker and he was just game for anything back then, yes, yes.

MS FRASER BUTLIN: Despite the amputation you described he did lots of swimming --

PE: Yeah, it was pretty annoying!

MS FRASER BUTLIN: -- walking, camping.

PE: Yes, did the whole shebang and I was a very fit swimmer and he could beat me, which I thought was a little frustrating because he only had one leg. He was very game for anything. So the prosthesis didn't really, I mean apart from when it, you know, was bleeding or whatever but, you know, most of the time he was absolutely game for anything, tootled round France camping, you know, everything. He was a happy sort of chap.

MS FRASER BUTLIN: Bronny, you were 6 when your Dad was diagnosed with hepatitis C, but what are your memories of your Dad before that?

BRONNY: Little bit sketchy. I remember him being a very strong, tall, funny, caring, loving man.

MS FRASER BUTLIN: You have described a trip to Legoland

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PE: It was.

MS FRASER BUTLIN: Can you tell us more about what happened.

PE: I wasn't there.

MS FRASER BUTLIN: What you understood had happened.

PE: He had a motorbike crash, had a head injury and a leg injury and the leg was completely mashed. They tried to save it. He had some treatments had external fixations for a while and then it had to be amputated.

MS FRASER BUTLIN: And from the records you have established that Paul received a transfusion of six units of blood on 22 January 1982.

PE: Yes.

MS FRASER BUTLIN: You met Paul in 1985.

PE: I did.

MS FRASER BUTLIN: We have a photo that you would like to be shown during your evidence.

PE: Just so that he's not just a number.

MS FRASER BUTLIN: Absolutely. Here it is. Roughly when was that photograph taken?

PE: 1980 --

BRONNY: No.

PE: No, 1990. How old is Bronny? She was born in 1992 so '94, maybe.

MS FRASER BUTLIN: Can you tell us a little bit of what

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in your statement.

BRONNY: Yes, I think that's probably one of my earlier memories of him taking me to Legoland. At that point he was able to walk round with me for most of the way, which obviously changed.

MS FRASER BUTLIN: Paul had smoked for a number of years and developed some lung problems.

PE: Emphysema.

MS FRASER BUTLIN: Can you tell us what they were.

PE: He had emphysema. As soon as he was diagnosed he gave up smoking but it progressed and hence the referral to -- because he was really young, to Papworth for potential lung transplant.

MS FRASER BUTLIN: That happened in October 1997 and he attended an initial assessment.

PE: Yes.

MS FRASER BUTLIN: Can you tell us a little bit of what happened down at Papworth.

PE: Strange, isn't it. You go down for, I can't remember how long, two or three days, they go through various tests to see (1) whether he needed the lung transplant, whether it was advanced enough, and (2) whether he was healthy enough in other ways to take it. A weird few days.

MS FRASER BUTLIN: You then understood that there would be

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1 a follow-up assessment --
 2 **PE:** Absolutely.
 3 **MS FRASER BUTLIN:** -- that would be scheduled.
 4 **PE:** Yes.
 5 **MS FRASER BUTLIN:** You chased in early 1999 to see what
 6 had happened.
 7 **PE:** Yes.
 8 **MS FRASER BUTLIN:** What were you told on the phone?
 9 **PE:** I can't remember the whole conversation obviously,
 10 but we were asked if he had had the treatment.
 11 I didn't know what on earth they were talking about,
 12 to be quite honest. Anyway, it turns out that they
 13 meant the treatment for his -- to clear the HCV
 14 because he had to clear that before getting the lung
 15 transplant but we didn't know anything about it.
 16 **MS FRASER BUTLIN:** Papworth said, "Well, we sent a letter
 17 to the GP".
 18 **PE:** Yes.
 19 **MS FRASER BUTLIN:** Could we have document 1962005, please.
 20 This is the letter from Papworth to Paul and if we go
 21 down to the body of the letter and we can see:
 22 "As per our telephone conversation, I enclose
 23 a copy of the correspondence dated 4 November 1997
 24 sent to your GP following your assessment ..."
 25 If we go to the next page, here is the letter

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1 what the current wisdom is in counselling patients
 2 with hepatitis C. Can I therefore pass the buck?
 3 Paul is due to see you in early January."
 4 That would be January 1999?
 5 **PE:** Yes.
 6 **MS FRASER BUTLIN:** "We clearly have to inform him of this
 7 finding and I will tackle it next time if you feel
 8 unable to raise the matter in January. I am sorry to
 9 pass this on. I normally see him several times year
 10 in which circumstances it would have been easier to
 11 raise."
 12 **PE:** What a load of rubbish.
 13 **MS FRASER BUTLIN:** If we then look at 1962008, which is
 14 the reply from the Royal Hospital to the GP:
 15 "I didn't know we had to counsel people with
 16 hepatitis C and I'm going to try find out about this
 17 from the microbiologists. I shall try to have some
 18 definite information about it by the time I see Paul
 19 in January."
 20 Then 1962007, November 1998, from the Royal to
 21 the Southampton General Hospital to the virology
 22 department:
 23 "I wonder if you can advise me about counselling
 24 and hepatitis C. This patient has very severe
 25 emphysema and may be going for lung transplantation in

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1 from Papworth to the GP indicating:
 2 "His virology screen has now revealed that he's
 3 positive for hepatitis C antibody. I'd be grateful if
 4 you could bring this positive result to Paul's
 5 attention along with the necessary counselling."
 6 **PE:** Yes.
 7 **MS FRASER BUTLIN:** Can we then have document 1962006.
 8 **PE:** Oh gosh, that's tiny.
 9 **MS FRASER BUTLIN:** It will come up. Don't worry. This is
 10 a letter from the GP to the Royal South Hampshire
 11 Hospital.
 12 If we just go up slightly, Paul, so we can see
 13 the date of it, 2 November 1998, and we can see there
 14 that the GP is asking the Royal South Hampshire
 15 Hospital:
 16 "A year ago I had a letter from Papworth that
 17 was copied to you saying Paul's virology screen had
 18 been positive for hepatitis C antibody. They asked
 19 that I bring this to Paul's attention along with the
 20 necessary counselling. The reality has been that Paul
 21 has not returned to my surgery until now. He had
 22 a good deal to tell me and I was pleased to find him
 23 in a fairly positive frame of mind. I, therefore, did
 24 not have the heart to add to his worries when I had
 25 not seen him for so long. I am also uncertain as to

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1 the foreseeable future. We have been asked to counsel
 2 him about hepatitis C, but he is an extremely anxious
 3 man and I do not want to raise yet more fears in his
 4 mind. I'd be grateful for your comments ..."
 5 Throughout this correspondence you and Paul were
 6 completely unaware that he had hepatitis C?
 7 **PE:** Yes.
 8 **MS FRASER BUTLIN:** As you said, in early 1999 you chased
 9 the result of the lung assessment and at that point
 10 you were told about the hepatitis C.
 11 **PE:** Yes.
 12 **MS FRASER BUTLIN:** You then phoned the GP straight away.
 13 **PE:** I'm afraid so, yes.
 14 **MS FRASER BUTLIN:** What did you say? What did they say?
 15 **PE:** To be quite honest, again, I can't remember exactly.
 16 We were both really shocked and extremely -- well, at
 17 that point probably not extremely angry because we
 18 didn't know all the connotations of what hep C
 19 involved really. We knew a little bit but not enough
 20 and they organised for Paul and I to go down and talk
 21 to the GP and the GP practice manager or, I don't
 22 know, somebody like that.
 23 I think it was done in such a way that it seemed
 24 very -- it seemed official and they tried to defend
 25 the fact that they hadn't told him, basically, which

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1 I think is quite incredible. He was the family GP.
 2 It wasn't that he was just -- I don't mean just Paul's
 3 but, you know, he was the family GP and he was putting
 4 Paul at risk, yes, absolutely. He was supposed to be
 5 looking after Bronny and I as well; so basically he
 6 didn't look after any of us, you know.

7 **MS FRASER BUTLIN:** You have said in your statement that
 8 the GP said he received the letter but hadn't told
 9 Paul about his diagnosis because he didn't think Paul
 10 was emotionally ready to hear about it.

11 **PE:** Yes. I mean, yes, Paul by that point had become more
 12 anxious and more -- he was a very feisty chap, in
 13 a good way, but the feistiness then became a little
 14 bit more feisty-feisty and of course he was anxious,
 15 and at that point he was extremely anxious because,
 16 "What the heck, hey, I've got hep C and what's going
 17 to happen", and this could put a stop to the lung
 18 transplant which would, you know, help his quality of
 19 life.

20 Yes, it was just frustrating and difficult and
 21 whatever his anxiety, surely knowing what's happening
 22 and to medically support him in that and stop putting
 23 other people at risk, because he was the sort of chap,
 24 he had one leg, often when you put a new leg on, it
 25 bleeds, it's this and that, you have to do all of

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1 respond to the documents and to your statements and
 2 his response will be published when it becomes
 3 available.

4 **SIR BRIAN LANGSTAFF:** May I just ask something? You were
 5 asked about whether he was emotionally ready to hear
 6 the information. Your response was I think telling us
 7 what he was like after he had had the information. If
 8 you had been in the shoes of the GP --

9 **PE:** Yes.

10 **SIR BRIAN LANGSTAFF:** -- not knowing or, sorry, knowing
 11 that he had hepatitis C but looking at a man who was
 12 facing the particular challenges of this lung
 13 condition as he was, would you have thought he was
 14 extremely anxious?

15 **PE:** No. I mean he was feisty. I am not saying that he
 16 was --

17 **SIR BRIAN LANGSTAFF:** Well, feisty is not necessarily
 18 anxious.

19 **PE:** No, he wasn't anxious or -- no, not at all.

20 **MS FRASER BUTLIN:** Paul was then referred to the
 21 hepatologist. Can we have document 19620010, please.
 22 It's the second page and it's the last couple of
 23 paragraphs.

24 We can see in the -- sorry my fault, Paul, the
 25 paragraph above that:

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1 that, so we were doing all of that naturally and he
 2 was doing all of that, and people fitting his leg were
 3 doing all of that, and we did it at home regularly.
 4 He did woodwork. He was bashing himself all the
 5 time, you know, woodwork for fun, and we were all put
 6 at risk and Paul -- I mean, in a way we're, you know,
 7 we didn't contract anything and that's incredible.
 8 But if we had, imagine what Paul would have felt. It
 9 just seems really, really unethical and unfair and --
 10 not dangerous, that's the wrong word but, yeah,
 11 difficult. I'm amazed that they thought that he
 12 couldn't have coped. He's a feisty man, you know, it
 13 wasn't that that ... you know.

14 I think it was an excuse not to talk to him, you
 15 know. He was an intelligent man. There's nothing
 16 that he couldn't have -- it would have been better for
 17 him to have known from then rather than to find out
 18 like we did and then have all of the stuff that
 19 happened.

20 **BRONNY:** I'm not really sure how you can prejudge who will
 21 or won't react badly to being told that they have
 22 a lifelong illness.

23 **PE:** Yes.

24 **BRONNY:** So ...

25 **MS FRASER BUTLIN:** I should say the GP has been invited to

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1 "During routine testing for possible lung
 2 transplantation it was discovered he is hepatitis C
 3 positive."

4 Then if we go to the next paragraph:

5 "I've not told Mr Le Bourn that his tests have
 6 also shown evidence of previous hepatitis B. I did
 7 not want to question him closely on his sexual and
 8 possible IV drug habits, although I think you may have
 9 to do this. As far as I know, he's never had a blood
 10 transfusion but, again, I haven't asked directly."

11 **PE:** Or checked in the records. It's quite --

12 **BRONNY:** He also has one leg, so like it had to have gone
 13 somehow, like ...

14 **PE:** Exactly.

15 **MS FRASER BUTLIN:** In fact, it was later established that
 16 Paul had not had hepatitis B and this was entirely
 17 incorrect about the hepatitis B.

18 **PE:** Yes, it was.

19 **MS FRASER BUTLIN:** If we go to the last paragraph:

20 "I would be most grateful if you would see him.
 21 He is a rather introverted, anxious and questioning
 22 man who will require quite a bit of your time. I'm
 23 sure you will be able to put his mind at rest on the
 24 hepatitis question much better than me and you may
 25 feel he deserves treatment at this stage."

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1 PE: (1) -- sorry, you didn't ask me.
 2 MS FRASER BUTLIN: I was about to say what's your
 3 response.
 4 PE: Sorry. I don't see how he can be seen one minute as
 5 anxious and out there and the next one as introverted.
 6 He certainly was questioning. He would question
 7 everything, you know, everything in life, and that was
 8 the way he was. It's not something that -- it seems
 9 that -- the insinuation seems to be quite patronising
 10 like that and the way it says "whether you feel he
 11 deserves treatment". That's the wrong wording.
 12 You know whether he can have treatment, whether
 13 he is medically whatever -- but not "deserves it", bit
 14 of a -- Yes, I wouldn't say introverted either,
 15 certainly not. Who was that from, sorry?
 16 MS FRASER BUTLIN: This was from the consultant physician
 17 across to the --
 18 PE: Consultant physician at ...?
 19 MS FRASER BUTLIN: It was the -- I think it was the Royal
 20 Hospital, consultant at the Royal, who then referred
 21 him across to the hepatologist.
 22 PE: Yes.
 23 MS FRASER BUTLIN: So this was the referral that got him
 24 to see the hepatologist and when you saw them what did
 25 he tell you?

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1 I can't -- a really nice family and he saw them
 2 reasonably regularly but they were very shocked and
 3 I think scared and their initial response was, "Oh my
 4 God, you're going to get AIDS, get out", sort of
 5 thing, so it wasn't very nice.
 6 MS FRASER BUTLIN: Would you prefer me to read what you
 7 said in your statement?
 8 A. Probably best.
 9 MS FRASER BUTLIN: "Trying to explain it to his family was
 10 really hard to him due to the stigma around HCV. Paul
 11 was different to the rest of the family. They were
 12 less educated and informed about life in general."
 13 PE: I don't mean that rudely. It's just -- yes, sorry,
 14 shut up, Pe.
 15 MS FRASER BUTLIN: No, no. His Mum, you've said in the
 16 statement, reacted very badly and he was very shocked
 17 and scared by her reaction.
 18 PE: Yes.
 19 MS FRASER BUTLIN: The big fear, I'm slightly
 20 paraphrasing, but the big fear from his family was
 21 this was somehow connected to AIDS.
 22 A. Yes.
 23 MS FRASER BUTLIN: And that they would contract it.
 24 PE: Yes, and I think the only information that they
 25 seemed to go back to were those funny -- well, not

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1 PE: If I remember rightly, that was a chappy called
 2 [redacted], I can't remember. I'm not allowed to say
 3 his names, whoops, sorry. He was super, straight down
 4 to earth, it was the first time we spoke to anybody
 5 who just sat down and spoke to you as if you were
 6 human beings, you know.
 7 So he said, basically, "This is what you have
 8 got. These are the treatments available. We need to
 9 see if Paul can take the treatment, but you need to
 10 get rid of it in order to have your lung transplant",
 11 so he was just totally practical and sensible, super.
 12 MS FRASER BUTLIN: What advice did you receive from the
 13 doctors about the risks of Paul infecting you and
 14 infecting Bronny?
 15 A. Nothing really. I asked because I was a little uneasy
 16 that maybe we had contracted it somehow and -- this is
 17 going to sound really embarrassing now because he only
 18 said one thing and it's really embarrassing to say it
 19 out loud, "the only way you'll ever get it is if you
 20 are intimate during your period", and that's what
 21 I was told, and that was the end of the counselling.
 22 MS FRASER BUTLIN: When Paul told his immediate family
 23 about his infection, what was their reaction?
 24 PE: I think they were scared, actually. I think the
 25 only -- it's difficult because they're a really --

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1 funny, those horrendous advertisements on the TV in
 2 the '80s; so they just thought having Paul in the
 3 house was just going to kill them all off, so it was
 4 out.
 5 MS FRASER BUTLIN: How much contact did you have with
 6 them?
 7 PE: For a while not really. I think Paul was really
 8 upset, obviously. You know, it turned, it turned
 9 around but it was a while.
 10 MS FRASER BUTLIN: There was an early discussion about
 11 whether Paul should have treatment for the
 12 hepatitis C.
 13 PE: Yes.
 14 MS FRASER BUTLIN: If we look at 19620012, and the last
 15 paragraph of that letter, it's a letter to the GP
 16 setting out some of the things that had been
 17 discussed. It's right, isn't it, that you were told
 18 the optimal treatment was alpha interferon --
 19 PE: And ribavirin.
 20 MS FRASER BUTLIN: -- and ribavirin, but the difficulty
 21 with that, we can see that at the bottom of the
 22 letter:
 23 "... other complications of treatment were
 24 discussed. It's my understanding Mr Le Bourn has
 25 severe emphysema and he's unlikely to tolerate

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1 a significant deterioration in his chest disease. The
 2 symptomatic breathlessness and the pulmonary
 3 infiltrates associated with interferon are both
 4 reversible on cessation of the treatment. Thus if his
 5 chest doctor considers it to be safe Mr Le Bourn we
 6 could attempt a trial of interferon and monitor his
 7 symptoms.

8 **PE:** Yes, but without it he couldn't get the -- well, it
 9 didn't work anyway but, you know, at that point it was
 10 frustrating because without it he couldn't go forward
 11 and, have the transplant.

12 **MS FRASER BUTLIN:** At that stage it was decided he
 13 shouldn't have the hepatitis C treatment.

14 **PE:** Yes.

15 **MS FRASER BUTLIN:** You said you feel Paul wasn't given
 16 enough information to make a proper decision.

17 **PE:** No.

18 **MS FRASER BUTLIN:** Can you tell us about that.

19 **PE:** We weren't given any, so I think that probably sums
 20 it up. No, that's not quite true. We were told that
 21 it was interferon and ribavirin and either he would be
 22 eligible for it medically or he wouldn't be and that
 23 was the information we were given, so I don't think
 24 that's very much information.

25 **MS FRASER BUTLIN:** He had treatment in 2006 which we will

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1 **MS FRASER BUTLIN:** And it became a big deal each time.

2 **PE:** In and out of that bloody hospital. So one little
 3 chest infection -- with emphysema you are going to get
 4 little chest infections and things and that's just
 5 quite common but for him it would become a big deal,
 6 or if he caught a tummy bug, anything, it would mean
 7 ending up in hospital and you couldn't work out why,
 8 but everything, everything was a bit of a pain really.
 9 And his memory didn't seem quite as right as it should
 10 be but, yes, so that was about it really.

11 **MS FRASER BUTLIN:** You said his personality also changed.

12 **A.** It changed over the years and I can't put a thingy
 13 on -- he just seemed kind of fuzzy and became more --
 14 so the parts of him and I don't know looking back --
 15 I know it was a lot more after or during and after the
 16 treatment but up until that point there were things
 17 beginning to be noticeable, like his memory loss, like
 18 not quite being able to work things through in the
 19 same intelligent normal way that he did, you know.

20 **MS FRASER BUTLIN:** How did that impact you and your
 21 marriage?

22 **A.** It was poo. Yeah, you become a carer, don't you,
 23 rather than a wife and, you know, his -- yeah, well,
 24 that's ... it changes it, doesn't it? It just does.
 25 It made it difficult and it must have been far more

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1 come to but until 2006 can you tell us a little bit
 2 about what Paul's physical condition was like?

3 **A.** Lung-wise he -- it wasn't until 2001 that he had
 4 a secondary respiratory failure so up until that
 5 point, yes, he was breathless but it wasn't anything
 6 really drastic. He wasn't on continuous oxygen or
 7 anything like that. But what did seem to happen was
 8 that his ability to -- he got more and more I can only
 9 describe it as fuzzy headed and that was before the
 10 treatment.

11 He lost his job, he was low, he was depressed,
 12 every little medical thing became -- it's as if he
 13 couldn't fight anything off. At the time, we didn't
 14 realise that that was potentially something that with
 15 hepatitis things were that more difficult, you know,
 16 but we had not really got an idea of that.

17 He was going downhill. I mean, I don't know how
 18 else to say it really, mentally and physically, but it
 19 didn't seem to be related -- I mean, his lungs were
 20 one thing and you could see that deteriorate, not
 21 dramatically but it did, but the rest of him, it just
 22 wasn't right, you know. He struggled.

23 **MS FRASER BUTLIN:** You have said he caught every bug
 24 going.

25 **PE:** Everything.

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1 difficult for Bron because I couldn't explain,
 2 especially when we get to the treatment bit, you know,
 3 you just have to say he's ill and its not an easy
 4 thing when he's being difficult.

5 **MS FRASER BUTLIN:** Bronny, you were six when your Dad was
 6 diagnosed and 13 when he started the treatment in 2006
 7 but in that in between stage how did your Dad's
 8 illness affect you?

9 **BRONNY:** My recollection of exactly what happened in which
 10 year is not very clear. I think I've done a fairly
 11 good job of blocking it out. It was incredibly
 12 difficult. His reasoning completely went out the
 13 window. He had moments where his memory would go and
 14 I would return home from school and he would have no
 15 idea who I was, and he could become very violent and
 16 aggressive through no fault of his own but I didn't
 17 understand why he was doing those things. It was
 18 really hard.

19 **MS FRASER BUTLIN:** You have described that over time that
 20 feistiness became aggression and volatility.

21 **PE:** Yeah, yeah, that was post treatment really, or during
 22 treatment and post treatment.

23 **MS FRASER BUTLIN:** Paul had to retire from work in 2003 in
 24 his early 50s. What brought that about?

25 **PE:** I think it was the early parts of his not being able

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1 to organise himself in the same way of his logical
 2 thinking and his memory and all of that sort of thing.
 3 It just -- he wasn't able to -- he was a social work
 4 care manager and he just couldn't do it. But he'd
 5 fought so hard to get that job and to educate himself
 6 to get it. It was hard for him.

7 **MS FRASER BUTLIN:** He was actually quite senior in the
 8 Social Services structure, conducting assessments of
 9 patients eligible for disability benefits.

10 **PE:** Yes, and children and families, you know, they kind
 11 of swap around, don't they. But, yes, that was a bit
 12 ironic but, you know, hey.

13 **MS FRASER BUTLIN:** His confusion was getting worse and his
 14 short-term memory was getting worse.

15 **PE:** Yes, not most -- but it was, yeah, enough to find it
 16 very difficult to hold a job like that, yeah.

17 **MS FRASER BUTLIN:** What was Paul's reaction to him losing
 18 that job?

19 **PE:** He got very low, really, I suppose, angry with the
 20 situation and thinking, "Well, if I have my lung
 21 transplant that will make all the difference, if I can
 22 get treated for the hep C that will make on the
 23 difference and I can go back and", you know. So he
 24 was cross but understood, so he got very low, yes.

25 **MS FRASER BUTLIN:** You and he understood why he couldn't

21

1 important evidence. Your concern is that if he had to
 2 have it in 2006 to have the transplant --

3 **PE:** Yes, he needed it whenever it was, '90-whatever it
 4 was, to have the transplant.

5 **MS FRASER BUTLIN:** Paul ultimately had two courses of
 6 treatment.

7 **PE:** Yes, that was stinky.

8 **MS FRASER BUTLIN:** Neither of which was successful.

9 **PE:** No.

10 **MS FRASER BUTLIN:** Can you tell us something of the side
 11 effects and the impact on him.

12 **PE:** We were told, to be fair, that it might make -- the
 13 treatment might give slight mood swings, might make
 14 you feel a bit low, might make you -- you know, that
 15 was sort of it might affect your mood a bit is what we
 16 were told. So you think that's okay.

17 He'd go through the treatment, he was put on
 18 antidepressants after a while, I can't remember
 19 exactly when. It was foul and how they can give you
 20 that treatment without telling you and telling the
 21 people who are looking after you what it entails.
 22 It's hard.

23 He became -- sorry, sweets -- he became very
 24 depressed, very angry, very illogical and, yes, you
 25 never knew what you were going to walk into basically

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1 carry on working.

2 **PE:** Yes.

3 **MS FRASER BUTLIN:** But emotionally it was a huge --

4 **PE:** It was a big deal, yes.

5 **MS FRASER BUTLIN:** By 2006 his emphysema had advanced
 6 considerably.

7 **PE:** Yes.

8 **MS FRASER BUTLIN:** And he needed to have a lung
 9 transplant.

10 **PE:** He did.

11 **MS FRASER BUTLIN:** What was he told then about the
 12 hepatitis C?

13 **PE:** Again, that it would have to be treated in order to
 14 have it otherwise he would have to go on a ventilator,
 15 blah, blah, blah. So we were told that, yes, he
 16 needed treatment and the chap who was dealing with the
 17 possibility of treatment said that they would start
 18 the interferon and ribavirin but, again, I don't
 19 understand how they could start it then and I know now
 20 it doesn't make any difference because it didn't work
 21 anyway but you don't know that at the time. So if
 22 they could start it in 2006 why couldn't they have
 23 started it earlier when his lung condition wasn't
 24 nearly as bad? But anyway, sorry, they, yes ...

25 **MS FRASER BUTLIN:** Please stop apologising. It's

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1 and he shut himself in the kitchen and became this
 2 person who watched food programmes, which is just
 3 really bizarre for him, and got fixated on these
 4 things and then if he came in he would just, yeah, he
 5 became very difficult and he didn't -- he didn't
 6 know -- you know, you know it's the treatment in the
 7 end but you think all of this can't be. They just
 8 said you would feel a bit low and this whole thing
 9 explodes in your face really.

10 But you know he's got to go through it, got to
 11 finish the treatment because otherwise he can't have
 12 the transplant but, yes, it was pretty stinky.

13 **MS FRASER BUTLIN:** Bronny, during this time you were
 14 bullied at school. What was going on?

15 **BRONNY:** I don't know. You'll have to ask them. It was
 16 really not particularly fun. Other people knew that
 17 my Dad was sick. They'd seen him in his mobility
 18 scooter and with his oxygen cylinders and I think my
 19 personality started to change but they definitely
 20 clung on to the fact that he was ill and I was
 21 different and that was a reason to bully me for that.

22 Yeah, if you wouldn't mind reading.

23 **MS FRASER BUTLIN:** "The children at school knew I was
 24 different and I was having problems at home and
 25 targeted me because of this. They bullied me

24

1 physically as well as emotionally. Once at the
2 playground at school some girls came and throw stones
3 at me and tore my dress off. As a result of this
4 bullying, I often tried to hurt myself so I could go
5 to the infirmary and be taken home from school.
6 I used to repeatedly hit my wrist on the bannisters at
7 school to try to fracture my bones so I could leave.
8 I spent a lot of time in my room at home."
9 You then started to have panic attacks at school
10 and started to take paracetamol obsessively.
11 **BRONNY:** Yes, unfortunately, I did, yes.
12 **MS FRASER BUTLIN:** Would you like me to just read some of
13 your statement.
14 **BRONNY:** If you wouldn't mind.
15 **MS FRASER BUTLIN:** "I ended up overdosing on it.
16 I believe I did this as a call for help, to have some
17 control over part of my life when most of it seemed to
18 be completely out of my control. I was taken to
19 hospital and stayed there for around a week.
20 I remember that the mental health services came to
21 visit me in hospital and they told my mother I was
22 completely fine. At this point I was on the cusp of
23 needing a liver transplant and they discussed
24 transferring me to Great Ormond Street Hospital.
25 I can't imagine what this would have done to my

25

1 I could look after Paul by going down there talk to
2 him a zillion times day, but going down there and
3 looking after him there.
4 Then when Bronny was at boarding school then he
5 would come back for weekends and we'd do the
6 visitation, and we did it like that, just so there was
7 some -- trying to get some stability, which was really
8 difficult for Bron and it was really difficult for
9 Paul but he did, sort of, after the initial going
10 through it, he did sort of -- he did come to terms
11 with the fact that that had to be the way it was for
12 a period of time until we were assuming or I was
13 assuming that his calmness and everything else would
14 at some point come back and he would be able to be him
15 again, you know, mentally, and so that was the logic,
16 so just while he was doing this I thought it was
17 safest to do that, and so I looked after him and
18 Bronny saw him down there rather than him being in the
19 house.
20 **MS FRASER BUTLIN:** You described that he rang you every
21 day, up to five times a day, wanting to be in touch.
22 **BRONNY:** Yes, I have -- the thing is that makes it so
23 difficult is that he didn't understand --
24 **PE:** No.
25 **BRONNY:** -- why any of this was happening and I wanted to

27

1 mother. My mother had to give up work to look after
2 me. When I was round 15 I ran away from home and
3 after this my mother told my father he had to move and
4 live in sheltered accommodation."

5 Pe, can you tell us a little bit about that time
6 in relation to, particularly, the sheltered
7 accommodation.

8 **PE:** Yes, I didn't say he had to go to sheltered
9 accommodation. I did say, no, he'd -- you know, we
10 had Social Services and the whole bloody lot going.

11 **BRONNY:** Which is where he ended up.

12 **PE:** It is where he went. So he was trying to move in
13 with his family, so his mother was still alive and he
14 had six other brothers and sisters, so it was to move
15 in with his sister or his mummy. One of the sisters
16 he was really close to. The mother refused to have
17 him in the house and his sister, one of his sisters,
18 did have him for a couple of weeks until he could find
19 something, but it was two weeks.

20 Luckily there was a place in Lymington which is
21 about 20 minutes away from us, which was some
22 sheltered accommodation that he got. So I helped him
23 move in there and that way my logic was that it
24 probably wasn't right, I've no idea at that point, my
25 logic was then Bronny could be safe at home and

26

1 add that the reason that I was having those problems
2 is because of the difficulties we were having at home.
3 It wasn't just a random thing that I decided to do.
4 It was -- I didn't really decide to do it but I think
5 mental health is something that people don't talk
6 about and it needs to be spoken about more and that,
7 you know, actually things that happen in your life can
8 affect you in a number of different ways.

9 But, yeah, he was not very well and mentally he
10 was not very well and he had tried overdosing on his
11 antidepressants and he had become quite violent at
12 home and --

13 **PE:** And with the paramedics.

14 **BRONNY:** -- he would assault medical physicians that would
15 try and come and help him and every day was really
16 hard, and I can't verbalise actually what that was
17 like but, yeah, unfortunately he didn't really
18 understand. But he wrote me lots of letters
19 apologising but saying I just don't -- "please tell me
20 what I've done wrong, I don't understand".

21 But actually that did work eventually and my
22 relationship with him grew and it was really
23 beautiful, and then he went.

24 **MS FRASER BUTLIN:** After your overdose you had problems
25 with your school, Bronny.

28

1 **BRONNY:** Yes.
 2 **MS FRASER BUTLIN:** Can you tell us what happened.
 3 **BRONNY:** Yes. So I was just about to sit my GCSEs and my
 4 school decided that I wasn't allowed back to finish
 5 anything and they said that I was too much of an
 6 insurance risk on the school grounds.
 7 I was a very driven person and academics to me
 8 meant a lot, and I had been predicted very good grades
 9 and to have got that far and then just being told,
 10 "No, you are not allowed to come back. That's it.
 11 You've blown it", was really hard because I didn't
 12 feel like I had done anything wrong and I posed no
 13 risk to anyone else.
 14 We asked if they would let me in with mummy to
 15 come and, like, supervise I suppose, particularly for
 16 sort of like science practicals, stuff like that, and
 17 they were really not happy about it. We had to attend
 18 a number of meetings there. Eventually, they let me
 19 go and sit my exams but I wasn't allowed to complete
 20 the actual taught lessons.
 21 **MS FRASER BUTLIN:** After your GCSEs what did you do in
 22 terms of education?
 23 **BRONNY:** So I went to a school near Bath, it was
 24 a boarding school, and absolutely loved it there. It
 25 was amazing and --

29

1 absolutely infuriated.
 2 **MS FRASER BUTLIN:** You later found out about Harvoni. Was
 3 Paul ever offered it?
 4 **PE:** No.
 5 **MS FRASER BUTLIN:** How do you feel about that?
 6 **PE:** Well I don't know whether it would have helped or not
 7 helped but from what I've read it can also be really
 8 helpful for people in last stage liver disease from
 9 hep C and he was never offered it, he was never told
 10 about it.
 11 The poor chap, that time he was in hospital
 12 from May until he died, well, went to Oakhaven and
 13 then died but in those few weeks I was there for every
 14 dotting ward round. I didn't leave because they
 15 weren't very good at looking after him and I know he
 16 was difficult, I'm not pretending he wasn't, but -- he
 17 was -- but he also had false teeth because had to have
 18 his teeth out because the potential transplant, they
 19 couldn't put him under for getting the teeth out
 20 because of the emphysema so he had to have them out
 21 individually awake and it was absolute torture for
 22 him. But they didn't take the false teeth, out they
 23 didn't take the false leg off --
 24 **BRONNY:** They didn't turn his oxygen on.
 25 **PE:** They didn't turn his oxygen on. So they would give

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1 **PE:** It really helped.
 2 **BRONNY:** -- I'm grateful. But I did my A levels and that
 3 was all good and then I went to Exeter University.
 4 **MS FRASER BUTLIN:** Which we will come to in a minute.
 5 Pe, the treatment that Paul had was
 6 unsuccessful.
 7 **PE:** Yes.
 8 **MS FRASER BUTLIN:** How did Paul react when he was told
 9 that?
 10 **PE:** I don't think you want a blow by blow account but
 11 pretty much that really. He was -- yeah, I mean, you
 12 go through all of that and mentally he hadn't come out
 13 the other side because there was six months' wait to
 14 check if the virus had gone.
 15 So he was still having the effects of the
 16 treatment, he was cross and angry and determined that
 17 he would get the transplant and anyway, so he had
 18 another load of treatment basically. It wasn't a good
 19 reaction. It was very depressing and difficult.
 20 **MS FRASER BUTLIN:** But the second round of treatment also
 21 failed.
 22 **PE:** It did.
 23 **MS FRASER BUTLIN:** You described that he was infuriated
 24 about it.
 25 **PE:** Yes, putting it very politely, yes, he was,

30

1 him a ventilator every night and then forget to turn
 2 the oxygen on at the wall. So I was there from
 3 breakfast until he went to sleep in the evening so
 4 that those things could be done. So I didn't miss
 5 anything. I'm sure it peeved them horrendously but
 6 what else can you do, yes. Sorry, I can't remember
 7 the original question now.
 8 **MS FRASER BUTLIN:** Let us track back slightly.
 9 January 2010 he had a liver biopsy and was diagnosed
 10 with grade 1 fibrosis.
 11 **PE:** Yes.
 12 **MS FRASER BUTLIN:** January 2013 he was diagnosed with
 13 cirrhosis.
 14 **PE:** Cirrhosis, yes, and I thought -- well, I don't know
 15 because I'm not a liver person or medic of any sort
 16 but he and I were just, in a way when -- we thought
 17 that he would have probably got as far as cirrhosis
 18 earlier than he did but it was never classified as
 19 cirrhosis or never was, I don't know, but when it was
 20 classified as cirrhosis, and I'm sorry because it's
 21 a financial thing, they said, right, then you're able
 22 to get the next thing on the Skipton doodah or
 23 whatever it is, our next payment, and then you will
 24 also have some way of living.
 25 They give you an amount per month, so we thought

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at least for the next few years then he will have, you know, something to live on each month and it will just make life a little bit easier for him, and he was arranging to -- we all went on -- he wanted a cruise which I wasn't keen on -- all went on holiday with his monthly income.

But anyway he got classified with cirrhosis in -- diagnosed in January. By April, he had ascites and so he had that drained and we were told then that that would be happening probably a couple of times a year from now on because that's just the way it is.

MS FRASER BUTLIN: From your perspective, in the April he was relatively stable.

PE: We thought so. We weren't told otherwise. But we were told that ascites would happen and once he had it we were told it would just carry on happening now and again and he would probably have to have the draining on a reasonably regular basis.

MS FRASER BUTLIN: But on 12 May 2013 he went back to hospital because he was vomiting blood.

PE: Yes.

MS FRASER BUTLIN: At that point you were told things were not good at all.

PE: I wasn't told it wasn't good at all. I was told this is another part of it. If I had any idea at that

33

PE: Something was very wrong.

MS FRASER BUTLIN: Can you tell us about it.

PE: Yes. He -- the day before he'd been normal Paul, normal Paul at that point, so they were still doing physio, they had the dietitian down checking what he could eat and all the rest of it so that he could go for this -- I thought -- so he could keep going with this rehab situation, but I went in that morning about half 7 as usual and he wasn't sure who I was and then this doctor, not the normal ward round doctor not his consultant or anything, this doctor who I'd never seen before came and said something's wrong and I know that right at last stage that this can happen, but I was thinking, you know, that can't be it because we're off out, we've got rehab in a minute, and he just said, "That's it, he's -- nothing we can do. We'll put him on pathway", and I just stood there.

I hadn't a clue what they were talking about and then he walked off, and that's how I was told he was dying, just -- that was it. So I'm just standing there at the end of a bloody bed in a ward with a doctor saying, "It's all right. We'll put him on pathway", and this chap walked away.

MS FRASER BUTLIN: You didn't even understand what the pathway was at that stage.

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point that that was the end, I don't know. Anyway, you can't look back, can you, on it and think if only, but at that point thought, right, this shouldn't have happened but it is part of the same thing, this bleeding, he will need a stent. I thought, okay, fine, he'll need a stent, not that's okay but it's not life-threatening in any way, nobody said it was life-threatening. I knew it wasn't good and until they got that stent in there was that kind of wobble few days and got poor Bronny up from her exams and then we just thought that was tickety-boo and we were trying to arrange -- he wanted to go the Oakhaven, which is the hospice he did voluntary work in, because they did a two-week rehab when people come out of hospital before they go home. So we were arranging that, thinking that was what was happening, and it was just a hiccup, you know, along the way. So how foolish was I?

MS FRASER BUTLIN: The plan was to go to the hospice just for two weeks. It wasn't permanent stay. It was a two-week rehabilitation programme.

PE: No, no, it was a two-week rehab. Yes, yes, two-week rehab, spoke to them and everything.

MS FRASER BUTLIN: Then one day you went into the hospital to see him and knew something was wrong.

34

PE: No, I didn't. It's pathetic, isn't it, but no, I'm naive.

MS FRASER BUTLIN: Your understanding now is that that was an end of life pathway.

PE: Yeah, I know, totally, but how do you know that when somebody just walks up and just says that and walks away? No talking to me, no nothing. Just quite amazing. Sorry.

MS FRASER BUTLIN: You phoned Bronny.

PE: I did.

MS FRASER BUTLIN: Bronny, you came home from university straight away. You stayed with him all night and you made sure there was sufficient pain relief.

PE: Well, there was to start with, yes.

BRONNY: The last word he said was, "It hurts, help me". That was the last sentence he said ever, so that was awful --

PE: Yes.

BRONNY: -- actually.

PE: There wasn't a doctor on the ward to sign off some more morphine. So to go from he's coming out to he's dying and there's no meds is a bit of a leap.

So to go charging round the hospital to try to find a bloody doctor because there wasn't enough staffed and nobody could get hold of anybody to get

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1 some more morphine, it was a bit of a ludicrous night
 2 really.
 3 **MS FRASER BUTLIN:** Paul survived the night.
 4 **PE:** He survived the night, much to everybody's surprise,
 5 so I thought the only thing he ever wanted was -- he
 6 worked at Oakhaven Hospice doing an education
 7 programme for schools for three or four years and
 8 I knew that's always where he -- you know, we thought,
 9 right, we'll get him to Oakhaven and the palliative
 10 care team at Southampton General were super. They
 11 were so lovely. One really organised lovely lady, the
 12 rest of the staff on that ward ... horrendous, didn't
 13 give a toss, but this lady was brilliant. Said, "Yes,
 14 we'll get him to Oakhaven. We'll organise an
 15 ambulance".
 16 Then his consultant, whose name has gone out of
 17 my head but I realise now I'm not allowed to say it
 18 anyway, came and said, "No, don't take him to
 19 Oakhaven. He'll be dead in half-an-hour".
 20 Luckily, my sister and her husband were there
 21 too who helped me say, "Sod you, we're going to try".
 22 The ward was a difficult ward. It had two people who
 23 had, through no fault of their own again, quite
 24 emotionally aggressive dementia; so they were coming
 25 round and pulling things and hitting him and it was

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1 We became really good friends and I loved spending
 2 time with him."
 3 **BRONNY:** Yes, I did.
 4 **MS FRASER BUTLIN:** After his death, you had some further
 5 mental health difficulties. Do you want to tell us or
 6 would you rather I read your statement?
 7 **A.** No, if you wouldn't mind.
 8 **MS FRASER BUTLIN:** Of course.
 9 "Around six months after my father died,
 10 I started to become severe anxious and experienced
 11 very extreme moments of what's probably best described
 12 as existential crisis. My mind would think of what
 13 death was and how someone could become nothingness and
 14 then I'd just get this overwhelming feeling of
 15 blackness and it would make me very scared. I'd also
 16 see bits of flesh falling off my hands when I looked
 17 at them. I was completely unable to go about my
 18 normal daily life. I've since managed to bring that
 19 under control, but I still really struggle with the
 20 feeling of darkness and nothingness and the idea of
 21 death is extremely difficult. I now recognise these
 22 as potential symptoms of post traumatic stress
 23 disorder."
 24 You feel it has also had a significant impact on
 25 your education and your career.

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1 just the most ridiculous situation.
 2 Anyway, so we got the ambulance. Bronny and
 3 I went in the ambulance. It had a flat tyre, which
 4 was just par for the course on that day. And anyway
 5 we persuaded them, they still us and he lasted another
 6 few days -- a very strong old ox was Paul -- lasted
 7 another few days at Oakhaven but at least he was there
 8 and out of that ward and that situation and we could
 9 be there and -- so we stayed with him. And the poor
 10 chap didn't get a break from us at all in those few
 11 days, did he? We just stayed with him the whole time.
 12 **MS FRASER BUTLIN:** And Paul died on 5 June 2013.
 13 **PE:** Yes, exactly. Anniversary yesterday. Great timing.
 14 **MS FRASER BUTLIN:** Bronny, in the last few years of your
 15 Dad's life, you said your relationship with him
 16 improved. Do you want to tell us about that?
 17 **BRONNY:** Yes, it was brilliant. I finally felt like I was
 18 understanding who he was as a man and our friendship
 19 grew and it was really lovely. It was like putting
 20 a plaster on all of the things that had come before to
 21 try and help you forget. I only got two or three
 22 years with him like that. Sorry.
 23 **MS FRASER BUTLIN:** You said:
 24 "My relationship with my father certainly
 25 improved over the last few years and it was wonderful.

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1 **BRONNY:** Yes.
 2 **MS FRASER BUTLIN:** Can you tell us a little bit about
 3 what's happened.
 4 **BRONNY:** I studied law at university and took a module in
 5 medical law. I became very, very interested in it and
 6 did my dissertation on the global organ deficit,
 7 particularly because of everything when he was looking
 8 at having a lung transplant. I then took a master's
 9 in medical law and medical ethics and I've now decided
 10 to pursue a career in law as a medical negligence
 11 solicitor.
 12 **MS FRASER BUTLIN:** But you have had some difficulties
 13 because of your exam results in Exeter. Because you
 14 went to be with your Dad as he was dying, your second
 15 year results weren't as good they might have been.
 16 **BRONNY:** No.
 17 **MS FRASER BUTLIN:** And, unfortunately, that has had an
 18 ongoing impact in terms of your solicitor training and
 19 obtaining the training contract to become a solicitor.
 20 **BRONNY:** Yes. So my uncle was waiting for me at the back
 21 of my second year law exam to go take me to my Dad,
 22 unbeknown to me. I did continue up to my --
 23 I finished my degree but I didn't do as well as I was
 24 meant to have done and my mitigating circumstances
 25 weren't taken into account by Exeter. They said,

40

1 "Well, you're meant to tell us within five days of the
2 event happening" and I said, "Well, I was at his
3 funeral, it wasn't my first priority".

4 And it meant that I had to show -- when I went
5 to do my master's, I had to show -- I had to have
6 a letter from Exeter to confirm that they didn't take
7 it into account. I had to have extra letters from my
8 supervising lecturers saying that I was capable of
9 doing it and that event happened and I had to provide
10 his death certificate. But it also meant that when
11 I've been applying for training contracts with law
12 firms, they claim that even if you didn't get a 2:1
13 and you have mitigating circumstances that they take
14 that into account, but I don't believe that's
15 necessarily true, and I had to fight really hard to
16 get one and it made it really difficult.

17 **MS FRASER BUTLIN:** Pe, in terms of the effect on your
18 financial situation, in 2003 you were advised that
19 Paul wouldn't be eligible for any financial assistance
20 because the transfusion was in 1983 but Paul was
21 advised to talk to the Citizens' Advice Bureau.

22 **PE:** Mm-hm.

23 **MS FRASER BUTLIN:** But you didn't really manage to find
24 out about The Skipton Fund until about 2004.

25 **PE:** We didn't know. That probably sounds really silly as

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1 when he came home and say, "Well, I don't know what
2 they said and I didn't understand". So you make the
3 effort to try and go to everything. So that obviously
4 affected my work and when he had stays in hospital
5 I would do that. When Bronny had her hiccup, then
6 I did that.

7 So, yes, my career was put on hold, I suppose,
8 and now I'm pretty antique, it's a bit hard cheddar,
9 but it had also meant I couldn't be on contract
10 because I needed so much time to do the stuff to
11 support things. So I now have -- not no pension,
12 I think it's 5,200 (so not amazing when you've worked
13 all your life apart from these bits) because
14 I couldn't have the contract. And also I know this
15 is -- I don't even know I'm allowed to say it here
16 really -- but that EIB whatever.

17 **MS FRASER BUTLIN:** EIBSS.

18 **PE:** Thank you, that thing says that when your income gets
19 so when I do have to retire, which is in a nanosecond,
20 that they will do bereavement payments if your income
21 is below, whatever, 10,000 or something, which mine
22 will be, but then it says "household" income, not "my"
23 income. So if I'm living with somebody else, why
24 would EIB hoodlepith not -- why would the Government
25 then stop paying the bereavement payments if that's

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1 well but we just didn't know. We weren't given any --
2 we didn't even know about the Hep C Trust. We didn't
3 know that these things, that Skipton and the other
4 one --

5 **MS FRASER BUTLIN:** Caxton.

6 **PE:** -- Caxton existed. So, you know, it's just hard and
7 maybe that's -- you know, it's fine for me to go off
8 and do my research on the illness and this, that and
9 the other but ... I don't know.

10 Anyway, sorry, we didn't know particularly but
11 we did in the end and he got the, you know, initial
12 payment and they gave a little help towards what they
13 thought would be Paul's contribution to Bronny's rent
14 for one year down at uni and then when he got
15 diagnosed with cirrhosis, he got the second payment,
16 but unfortunately he only got one month or two months
17 of the actual normal ongoing payments because he died.
18 So I don't know if most people who have hep C die
19 within a nanosecond of being diagnosed with cirrhosis.
20 That just seemed a little bit unfair to him.

21 For me, it's obviously affected -- not obviously
22 necessarily, sorry -- but it has affected my work. In
23 a way, that was my choice because I wanted to support
24 Paul at every appointment and everything, but partly
25 because he would get confused and then he would angry

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1 due because of what happened with Paul, that they then
2 think some other chap can take it on who's nothing to
3 do with anything? Do you know what I mean? It just
4 doesn't seem if it's an individual payment or
5 a household payment and I know it has to be done on
6 income but that's me and mine. Why should I then have
7 to rely on anybody else? Anyway, sorry, just a rant.

8 **MS FRASER BUTLIN:** It was very relevant. You also in your
9 statement wanted to raise something else about the
10 process of receiving financial assistance.

11 **PE:** Yes. Well, I didn't -- because -- I sound as though
12 I'm a really bossy cow, and maybe I am, but it was
13 hard for Paul to go through all that process and do
14 all the paperwork and do everything that goes with it,
15 so then you're trying to do it. And it felt for him,
16 he would sit there and just say, "It feels like we're
17 begging and having to prove things and it just felt
18 really wrong". If it's diagnosed and it is and they
19 know why, then it should just happen, you know. You
20 shouldn't be there having to prove and beg and he felt
21 much that he was asking for things and having to prove
22 things rather than this has happened, therefore this
23 happens, you know.

24 **MS FRASER BUTLIN:** You put it rather more forcefully in
25 your witness statement.

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1 **PE:** Yes, I probably did.
 2 **MS FRASER BUTLIN:** "In my mind they screwed his life
 3 up ..."
 4 **A.** Yes. Well, I think they did really.
 5 **MS FRASER BUTLIN:** "... and compensation for this should
 6 be provided automatically."
 7 **PE:** Yes, I think that's pretty Pe language, yes. Well,
 8 they did. They screwed him up but they weren't
 9 forthcoming in sorting -- not that they can sort it
 10 out because he's not here but you know what I mean.
 11 There's just other things you shouldn't have to be
 12 begging for. You know, it should just happen.
 13 **MS FRASER BUTLIN:** Those are the questions I have for you
 14 both. Is there anything else you would like to say?
 15 **BRONNY:** You forgot the piece of paper.
 16 **PE:** I'll get the piece of paper. We wrote it down.
 17 **BRONNY:** If you wouldn't mind.
 18 We are, of course, extremely honoured to be
 19 representing Paul here today. However, he should of
 20 course be here to represent himself. It is impossible
 21 for us to vocalise the suffering he has experienced
 22 and we know he would have had a lot to say. His
 23 absence represents the importance of this Inquiry and
 24 we can't help thinking about those who may have no-one
 25 to represent them.

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1 **MS FRASER BUTLIN:** -- but from your father's clinicians
 2 was there any offer of support to you?
 3 **BRONNY:** No, and the only reason I got some help is
 4 because school said, "If you don't, we won't take you
 5 back" but they didn't take me back anyway, so ...
 6 **MS FRASER BUTLIN:** Just two points in relation to the
 7 treatment that Paul received, were you ever told about
 8 the criteria set by the NHS in the 1990s for Paul
 9 receiving or securing access to the interferon and the
 10 ribavirin treatment?
 11 **PE:** Criteria for them? No, no. It was just whether he
 12 was medically capable of taking it.
 13 **MS FRASER BUTLIN:** Do you know why Harvoni was never
 14 offered to Paul?
 15 **PE:** No.
 16 **MS FRASER BUTLIN:** If you had known about Harvoni, what
 17 would you have done?
 18 **A.** I would have gone and bloody got it, yes, to see if it
 19 would work. Anything was worth a try.
 20 **SIR BRIAN LANGSTAFF:** Thank you both very much for coming
 21 and telling us about Paul and your life with him.
 22 Thank you.
 23 **PE:** Thanks.
 24 **SIR BRIAN LANGSTAFF:** We will take a break until 12.20,
 25 and then who do we hear from?

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1 We also ask the Inquiry not to overlook the
 2 severity of the effects on those left behind alongside
 3 those living with their own experiences and the people
 4 continue together support them. Sometimes the damage
 5 isn't always something you can see.
 6 **MS FRASER BUTLIN:** I am just going to turn to Mr Lock
 7 (who, as you know, represents you) if there are any
 8 points he would like me to raise.
 9 (Pause)
 10 There are just a couple of points he asks me to
 11 raise with you. We've obviously heard the impact on
 12 both of your mental health and the impact on you. Pe,
 13 were you ever offered any counselling or psychological
 14 support?
 15 **PE:** No, not once. And actually considering I went down
 16 to about 7 stone and being this big is pretty skinny.
 17 But, no, I wasn't offered anything.
 18 Actually, after the initial, you know, the first
 19 two days back at Church House, we went to that and
 20 I did actually ring them and say, "Actually, hey" but
 21 I never heard anything back. So that was odd. But
 22 generally I haven't been offered anything.
 23 **MS FRASER BUTLIN:** Bronny, you obviously had some mental
 24 health input --
 25 **PE:** Not much.

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1 **MS FRASER BUTLIN:** We will be hearing from Michelle Baker.
 2 **SIR BRIAN LANGSTAFF:** Thank you. 12.20.
 3 (11.41 pm)
 4 (A short break)
 5 (12.22 pm)
 6 **SIR BRIAN LANGSTAFF:** Our next witness is Michelle, is it?
 7 **MS FRASER BUTLIN:** That's correct, sir.
 8 **SIR BRIAN LANGSTAFF:** Michelle.
 9 **MICHELLE BAKER, affirmed**
 10 **Questioned by MS FRASER BUTLIN**
 11 **Q.** Michelle, you met your late husband Vincent in 1999?
 12 **A.** Yes.
 13 **Q.** You have got a photo of him you'd like to have on
 14 screen while you're giving your evidence. Just to
 15 explain, we've just received the photograph and we've
 16 redacted the faces of your daughters because we don't
 17 have explicit consent from them to show their faces
 18 for today because we've just got it, okay?
 19 **A.** Yes.
 20 **Q.** We can see Vincent there in the photo.
 21 Before you met, Vincent was involved in
 22 a motorbike accident?
 23 **SIR BRIAN LANGSTAFF:** Is there any way that we can portray
 24 the picture without the big blank white bit in the
 25 middle?

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1 **MS FRASER BUTLIN:** Sir, this is the first time I've seen
 2 it redacted and it's not ideal --
 3 **SIR BRIAN LANGSTAFF:** Thank you.
 4 **MS FRASER BUTLIN:** Thank you, Paul. Before you met
 5 Vincent was involved in a motorbike accident. What do
 6 you know about that?
 7 **A.** Not a lot, really. I just know he was in hospital for
 8 about six months. He fractured -- well, broke his leg
 9 and he got given four units of blood.
 10 **Q.** That accident was on 11 March 1983?
 11 **A.** Yes.
 12 **Q.** He was put in traction, as you say. He was in
 13 hospital for about four or six months before returning
 14 home.
 15 **A.** Yes.
 16 **Q.** It was during that stay that he was infected with
 17 hepatitis C from a blood transfusion?
 18 **A.** Yes.
 19 **Q.** Can you tell us what Vincent was like.
 20 **A.** Happy-go-lucky, adored his children, loved his car
 21 boot sales, a very family-orientated man, loved his
 22 Mum and Dad to death, hard working.
 23 **Q.** You had three children together?
 24 **A.** Yes, three children.
 25 **Q.** Until 2008 Vincent was well.

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1 **A.** Infections, yes.
 2 **Q.** So he would go on to some antibiotics.
 3 **A.** Antibiotics, yes, backwards and forwards from the
 4 hospital, having endoscopies to see what was going on
 5 inside. His stomach kept bloating out. I can't
 6 remember what they call it now. He had to have that
 7 drained. Must have had that drained about four times,
 8 I think.
 9 **Q.** In 2009 Vincent was diagnosed with cirrhosis of the
 10 liver and was told it was probably caused by alcohol?
 11 **A.** Yes.
 12 **Q.** In your statement, you disputed that Vincent was
 13 a heavy drinker and Dr Li has responded to your
 14 statement and highlighted a number of medical records
 15 from different doctors saying that Vincent was
 16 drinking heavily.
 17 **A.** Yes.
 18 **Q.** You have reflected and you accept that Vincent was
 19 drinking heavily and, as you said, was an alcoholic
 20 but only from about 2006 and he'd stop drinking by
 21 Christmas 2008?
 22 **A.** Yes.
 23 **Q.** Is that right?
 24 **A.** Yes, that's correct.
 25 **Q.** So although he had been drinking it had only been for

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1 **A.** Yes.
 2 **Q.** As far as you were concerned, it was a normal family
 3 life together?
 4 **A.** Yes. Yes, we had our family holidays camping down in
 5 Cornwall, yes, weekend family things.
 6 **Q.** Just ordinary day-to-day life together.
 7 **A.** Yes.
 8 **Q.** What changed in 2008?
 9 **A.** He just started getting quite ill. His skin started
 10 getting quite thin. The slightest knock he used to
 11 start bleeding. He did start drinking. Then admitted
 12 he was an alcoholic and went to the doctor's to get
 13 help from that, from which he did give up drinking, he
 14 gave up smoking when he realised that he had problems
 15 with his liver but at that point we didn't realise it
 16 was HCV.
 17 He got, yeah, they all presumed it was just the
 18 alcohol from the liver, cirrhosis of the liver.
 19 **Q.** Let's take the in stages. 2008 to 2009 Vincent just
 20 wasn't well?
 21 **A.** No.
 22 **Q.** You have said his skin kept bleeding with the
 23 slightest knock.
 24 **A.** Yes.
 25 **Q.** He kept getting infections.

50

1 a couple of years, it hadn't been for the decades that
 2 the doctors seemed to be suggesting.
 3 **A.** No. I mean, obviously prior weekend drinking, sort of
 4 thing, as any young person does but not to the extent
 5 that he did build up to.
 6 **Q.** Then Christmas 2008 you're clear that he stopped
 7 drinking.
 8 **A.** Yes.
 9 **Q.** Vincent worked as a long distance lorry driver --
 10 **A.** Yes.
 11 **Q.** -- during this time and he was involved in an accident
 12 in August 2009. Can you tell us what happened.
 13 **A.** Well, he used to deliver operating tables, actually,
 14 to hospitals. He lost consciousness at the wheel and
 15 ended up going into the back of another car, got taken
 16 into the hospital. I had a phone call saying that he
 17 had been involved in an RTA and it was really, really
 18 serious. So I phoned his Dad and his Dad and myself
 19 drove up there to Sandwell Hospital.
 20 I can just remember walking in there and he was
 21 in his bed and the priest was standing over him
 22 because they didn't think he was going to survive it,
 23 and it was at that point that the doctor there
 24 confirmed that he was hepatitis C positive and I just
 25 remember the shock because we didn't realise that

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1 before.

2 Q. When he was in hospital in Manchester, at that point

3 in time you were told that he had hepatitis C and that

4 it was likely the cause of the cirrhosis of the liver.

5 A. Yes.

6 Q. That was the first time you were aware that Vincent

7 had hepatitis C?

8 A. Yes.

9 Q. In your statement you've said that you were upset that

10 Dr Li hadn't told Vincent he had hepatitis C.

11 A. Yes.

12 Q. Dr Li has responded to your witness statement and said

13 there was an error in the hospital systems, so he

14 never knew about the result of the hepatitis C test

15 that he'd ordered.

16 A. No, according to his statement, because at the time

17 I didn't know that but I couldn't understand how come

18 Sandwell Hospital picked up on it and Worthing

19 Hospital didn't, even though Vincent had been to the

20 hospital numerous times prior to that.

21 Q. If we can have document 3175015, please, it's a letter

22 from Dr Li saying:

23 "Please could you let me know if Mr Baker is

24 hepatitis C positive. I've heard from two separate

25 sources, i.e. his GP and a hospital in Birmingham

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1 A. That is a good possibility. It's just what if. We'll

2 never know.

3 Q. Dr Li has responded and said that Vincent was too

4 unwell to receive the antiviral drugs, even when he

5 was seen in February 2009 because he needed treatment

6 of the ascites and the variceal haemorrhage at that

7 point. Again, what is your response to that?

8 A. But what if? You just don't know. Like that three

9 months, all right it's only three months, but that

10 three months could have saved his life or he could

11 have had the treatment or had his liver transplant

12 earlier but it's just the not knowing.

13 Q. After Vincent had received treatment for the varices

14 and the ascites, Vincent was referred to King's

15 College London for assessment for a transplant.

16 A. Yes.

17 Q. Could we have document 3175011, please. It's the

18 second and third paragraphs of the letter. Thank you.

19 He doesn't have any major contraindications for

20 consideration of transplantation at that stage in

21 August 2009, but if we look at paragraph 3 there were

22 some concerns about his heart condition and whether he

23 would be suitable or not.

24 Do you remember that discussion?

25 A. I can remember going up to King's College and --

55

1 called Sandwell Hospital, that he's positive. I have

2 yet to receive a report of this and I can't find any

3 record of the result being filed in the notes.

4 I would be very grateful if you could look into this

5 for me ..."

6 Have you ever seen this document before?

7 A. No.

8 Q. Despite asking for Vincent's medical records, until

9 Dr Li provided this letter you weren't aware that this

10 is what had happened?

11 A. No, no.

12 Q. Dr Li, we know from the documents he has provided to

13 us, then escalated the issue and raised an incident

14 report about it with the hospital but you remain

15 concerned that the hospital had failed to pass on the

16 result to Dr Li.

17 A. Yes, if they knew in February, we didn't find out

18 until April after the RTA accident, where was that

19 piece of paper? Surely they should have informed

20 Dr Li about it straight away as soon as they had the

21 results.

22 Q. Your concern is that if Vincent had been told that he

23 had hepatitis C in February 2009 when the test result

24 came back, you are concerned that he could have had

25 treatment and wouldn't have died.

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1 because he reached the top of the list and thinking he

2 was going to go ahead with the liver transplant but,

3 unfortunately, because of his heart failure it was

4 just too risky for them to operate, so he got sent

5 back to Worthing Hospital.

6 Q. We can see at the end of that letter that there was

7 a discussion about whether he would have the PEGylated

8 interferon as well but it was subject to, again,

9 further investigation of his heart condition.

10 If we can then go to 1825002, please, and the

11 fourth page which should be a letter dated

12 22 February 2010. I think it's the next page, Paul.

13 It's a letter from King's Hospital to the GP and

14 if we go down towards the end there's a useful summary

15 of his medical history noting that he had been seen at

16 King's College Hospital in 2009 where he was

17 considered for transplantation work up. That was in

18 August 2009 and at that time the only issues

19 prohibiting him from listing was of ST depression

20 identified on a CPEX testing. That's his heart

21 condition. He had then undergone an angiogram in

22 October 2009 which delineated no significant coronary

23 artery disease.

24 So in October 2009, as you say, he had gone on

25 to the liver transplant list and it looked very much

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1 like he was going to have a transplant?

2 A. Yes.

3 Q. Unfortunately, Vincent became very unwell shortly

4 afterwards. Do you remember what happened?

5 A. What, from King's College?

6 Q. Yes, from October 2009. He had a heart condition.

7 A. Yes, I just know he got sent back to Worthing. He was

8 constantly at Worthing Hospital. He kept getting

9 infections, getting confused, tried to escape from the

10 hospital once and the police had to bring him back.

11 He just sort of went downhill.

12 Q. He had two episodes of a very serious heart valve

13 infection called infective endocarditis, didn't he?

14 He had a really nasty infections.

15 A. Yes.

16 Q. We can see if we go back to the letter we were just

17 looking at, when he was seen at King's, here at the

18 last paragraph of the letter, he's now a Child's B/C

19 cirrhotic and the fact he has had an intra-cerebral

20 bleed in the last 24 hours an aortic valve replacement

21 was felt to be a too high risk because of the liver

22 and also then secondly and currently liver

23 transplantation in the setting of acute active

24 infection and a recent intra-cerebral haemorrhage

25 would be totally contraindicated.

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1 the next day he decided that he wanted to go up to

2 Crawley to go and pick it up. I told him that he

3 wasn't in no fit state to drive the car but I couldn't

4 argue with him, sort of thing. He got in the car. He

5 was meant to go from Brighton to Crawley. He ended up

6 down in Hastings in a ditch in a tree and he phoned me

7 up and he says, "I don't know what I'm doing. I can't

8 move the car", but because he was on the stump of

9 a tree and then the police come and found him.

10 Q. That was one of the few times he was home in that

11 period?

12 A. Yes.

13 Q. Then in the later stages of his illness he realised

14 nothing could be done for him and he phoned you quite

15 regularly.

16 A. Yes.

17 Q. What did he tell you?

18 A. Can you read that.

19 Q. Of course.

20 "He sometimes expressed the fact that there was

21 nothing that could be done in strange ways such as

22 phoning me and telling me he was having affairs in an

23 effort to make me angry at him so I'd be less

24 distressed when he passed away."

25 Vincent died on 20 March 2010. Can you tell us

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1 So by the time he was seen here in King's there

2 were just too many things going on for Vincent,

3 weren't there, for him to be either have a heart

4 operation or to have his liver transplant.

5 A. Yes.

6 Q. So as you say he was transferred back to Worthing for

7 palliative care.

8 A. Yes.

9 Q. That was your understanding at the time?

10 A. Yes.

11 Q. From August 2009 Vincent was mostly in hospital

12 because you weren't able to manage him at home.

13 Can you tell us a little bit of how Vincent was

14 physically and mentally in those last few months.

15 A. Physically there was nothing of him. He'd just lost

16 so much weight. He was all skin and bone. Mentally,

17 he was confused. He turned nasty towards the family.

18 He stopped having treatment because he knew that he

19 wasn't going to last much longer. It wasn't him, no.

20 Q. You have given some examples in your statement, one of

21 them was when he'd ordered something from the internet

22 and missed the parcel delivery. Can you tell us about

23 that.

24 A. Yes, he ordered something. Yes, he was asleep when

25 the delivery come, so he decided rather than wait for

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1 a little bit about the impact and the effect of his

2 death on you.

3 A. It was very hard. Hard on the kids. Obviously, they

4 didn't have their Dad no more.

5 Q. They were just 9, 7 and 5 --

6 A. 5, yes.

7 Q. -- when he died.

8 A. Yes, my older two not too bad, my younger one it's

9 affected her quite a bit. She was Daddy's girl, sort

10 of thing. Yeah, no, it's been a struggle with the

11 girls.

12 Q. For you you've had to become a single Mum with your

13 girls?

14 A. Yes, my three girls.

15 Q. And you have other caring responsibilities you are

16 shouldering on your own.

17 A. Yes, at that point I took on my two brothers that were

18 21 years younger than me, they're twins. One of

19 them's [redacted] so I'm his carer. Yeah, I was just

20 looking after all five of them and trying to work and

21 keep the house going.

22 Q. You have said to me that the girls now are still in

23 education. They're only in their teenage years.

24 A. Yes.

25 Q. Two of them have been okay but the little one has had

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1 quite considerable mental health difficulties.
 2 **A.** Yes, yeah.
 3 **Q.** Financially -- sorry, before we go there, while
 4 Vincent was ill, how much did your daughters know
 5 about it?
 6 **A.** At first I think they just grew into it was an
 7 everyday thing but the more he deteriorated I didn't
 8 want the girls seeing their Dad this way and losing
 9 his way and not being him, as I said because of his
 10 confused state from the infections and I took them to
 11 see him but not as much. Over time, it just got less
 12 sort of thing because I didn't feel it was the right
 13 place to take three girls in hospital.
 14 **Q.** What do they remember of their Dad?
 15 **A.** Well, they got their photographs. They just remember
 16 Chessington, Pontlands Park, not quite so much
 17 Cornwall, not my younger one, but no, they just
 18 remember playing with him in the garden.
 19 **Q.** But once he was ill you have said in your statement
 20 that they don't really remember him, apart from the
 21 fact that he was in and out of hospital.
 22 **A.** Yeah, they don't -- no, they can't recall how serious
 23 he was sort of thing. I didn't feel it was the right
 24 place to keep taking the girls, even though, yeah, it
 25 was their Dad but the way he was, no.

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1 I managed to find a part-time job at the school
 2 running the kitchens and thought it was a bit of an
 3 income, the girls were at the school as well, so it
 4 just worked.
 5 **Q.** You have received some payments through The Skipton
 6 Fund?
 7 **A.** Yes.
 8 **Q.** What are your views of the financial assistance that
 9 you've been provided?
 10 **A.** It sounds a lot but it's not a lot, no, not when the
 11 girls were so young. I mean, he was on a very good
 12 salary, sort of thing, my youngest was five at the
 13 time, sort of thing, so she's 15 now. Yes, it's been
 14 hard but I've managed.
 15 **Q.** But financially it's been a struggle as the girls have
 16 grown up?
 17 **A.** Yes. Three girls, want, want, want.
 18 **Q.** You feel that the financial assistance simply hasn't
 19 been anywhere near enough.
 20 **A.** No.
 21 **Q.** Compared to what Vincent would have earned if he --
 22 **A.** Would have earned, he was on between £35,000 and
 23 £45,000 a year sort of thing and so what they paid out
 24 was a year and a half's salary, so ... we could have
 25 had a house by now, bought a house. I'm still in my

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1 **Q.** You have said that when the family knew about your
 2 husband having hepatitis C they Googled it and what
 3 did they say to you?
 4 **A.** Well, his uncle, he turned round and said to me,
 5 "Don't use his toothbrush because you will get it",
 6 sort of thing. Yes, of course, touching the blood
 7 I used to touch his wounds all the time, clean him up,
 8 put his dressings on sort of thing and like I didn't
 9 think nothing. I was just doing the wifely thing,
 10 looking after him.
 11 **Q.** Your feeling about the family was they were trying to
 12 helpful but actually for you it was just too hard?
 13 **A.** No, it was the opposite. That's the worst thing you
 14 can actually do is Google. I've learnt that.
 15 **Q.** Financially things have been difficult for you as
 16 well. You stopped a part-time job in November 2009
 17 when Vincent also stopped work?
 18 **A.** That's when I started.
 19 **Q.** Sorry, apologies, that's when you started. Can you
 20 tell us about that?
 21 **A.** Yes, because after Vincent's accident, he realised
 22 that he couldn't actually go back to work because of
 23 everything that was going on; so he actually resigned
 24 from his job because he thought it was unfair on them.
 25 So of course we went on benefits then, but then

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1 council house, no disrespect to that. I love my house
 2 sort of thing but things could have been different.
 3 **Q.** Those are the questions I have for you. Is there
 4 anything else you would like to say?
 5 **A.** No.
 6 **MS FRASER BUTLIN:** Just stay there a moment I want to ask
 7 Ms Gibbs whether there's any points she wants to
 8 raise.
 9 There's nothing Ms Gibbs wants me to raise.
 10 Sir, is there anything?
 11 **SIR BRIAN LANGSTAFF:** Yes, there is, when you first heard
 12 that Vincent had hepatitis C, were you told anything
 13 about it?
 14 **A.** To be honest, I can't honestly remember because it was
 15 just such a shock hearing that he had that. I mean,
 16 Dr Li, bless him, he does us good because he managed
 17 to find out where he contracted it from. He went back
 18 through the records sort of thing but, no, I can't
 19 recall being told anything.
 20 **SIR BRIAN LANGSTAFF:** Before your uncle Googled, did
 21 anyone tell you what to do to keep yourselves safe
 22 from a chance of cross-infection?
 23 **A.** I can't honestly remember because so much was just
 24 going on. I probably got given a leaflet or something
 25 I just ...

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1 **SIR BRIAN LANGSTAFF:** So somebody might have said
 2 something but you can't remember?
 3 **A.** Yes.
 4 **SIR BRIAN LANGSTAFF:** And you can't remember because of
 5 all the stress of everything that was happening?
 6 **A.** Yes. Sorry.
 7 **SIR BRIAN LANGSTAFF:** Thank you very much. Did anyone
 8 offer you any counselling at all or Vincent any
 9 counselling, perhaps, about it?
 10 **A.** I think someone mentioned something but because I've
 11 had my three young girls I just focused -- they kept
 12 me strong. I had to stay strong for them.
 13 **SIR BRIAN LANGSTAFF:** Do you remember who said something?
 14 **A.** I can't honestly remember, as I say, because it was
 15 just so long ago and that sort of nine-month period
 16 was such a blur in and out of hospitals every day and
 17 like.
 18 **SIR BRIAN LANGSTAFF:** That's all that I have to ask.
 19 Thank you very much indeed, Michelle, for coming
 20 to give us your evidence.
 21 **A.** Thank you.
 22 **SIR BRIAN LANGSTAFF:** We will take a break now, shall we,
 23 until 2 o'clock.
 24 **MS FRASER BUTLIN:** Thank you.
 25 **SIR BRIAN LANGSTAFF:** At 2 o'clock we have Peter Buckland,

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1 **A.** He was a great kid. I mean, all sons and daughters
 2 are lovely, aren't they, but he was indeed someone
 3 special. Why? He had such nice nature, calm, always
 4 time for you and a great kid, very happy with him.
 5 **Q.** Now, Mark did well at school and went to Manchester
 6 university.
 7 **A.** Yes, he did.
 8 **Q.** He was studying a computer science degree but in the
 9 second year his condition worsened.
 10 **A.** Yes.
 11 **Q.** He went to Hope Hospital Salford and underwent surgery
 12 which left him with a stoma.
 13 **A.** Yes, it did. That's exactly what happened, yes.
 14 **Q.** Although he went back to university to complete his
 15 degree, understandably as a young man he wasn't
 16 particularly happy with having the stoma?
 17 **A.** No, very unhappy, had a girlfriend.
 18 **Q.** Yes. He took the decision to have the surgery
 19 reversed?
 20 **A.** Yes, he did.
 21 **Q.** That reversal of surgery took place at the same
 22 hospital in Salford in September 1997.
 23 **A.** Correct.
 24 **Q.** But there were a number of complications and he
 25 received a blood transfusion.

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1 do we?
 2 **MS FRASER BUTLIN:** That's correct, sir, yes.
 3 **SIR BRIAN LANGSTAFF:** And tell us about vCJD?
 4 **MS FRASER BUTLIN:** That's right.
 5 **SIR BRIAN LANGSTAFF:** 2.00.
 6 (12.48 pm)
 7 (Luncheon Adjournment)
 8 (2.04 pm)
 9 **SIR BRIAN LANGSTAFF:** Our next witness wishes I think to
 10 be known as Peter, does he?
 11 **MS RICHARDS:** Yes, sir.
 12 **SIR BRIAN LANGSTAFF:** Peter.
 13 **PETER BUCKLAND, sworn**
 14 **Questioned by MS RICHARDS**
 15 **Q.** Peter, you're here with the support of your wife, Eve.
 16 **A.** Yes.
 17 **Q.** To talk about your late son, Mark Adam Buckland.
 18 **A.** Indeed.
 19 **Q.** Mark was born in 1974.
 20 **A.** Yes.
 21 **Q.** And from a relatively young age he suffered from an
 22 inflammatory condition called ulcerative colitis.
 23 **A.** That is true, yes.
 24 **Q.** What can you tell us about Mark growing up, what was
 25 he like?

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1 **A.** Yes as a result of the surgery he had, he had
 2 complications and he had to have a transfusion of
 3 blood as a result.
 4 **Q.** I'm just going to ask for a document to be put up on
 5 screen, Peter, and it will come up in front of you.
 6 Paul it's 694010, please. If we just look about
 7 halfway down the page where it begins, "It appears
 8 that Mark received ...", if you can just highlight
 9 that, please, Paul and the following paragraphs.
 10 We can see here the blood components that Mark
 11 received in September 1997 during that in-patient
 12 admission. 22 units of red cells, 15 units of fresh
 13 frozen plasma, two or three doses of platelets.
 14 Then we can see if we look at the last sentence
 15 of the next paragraph it said that this makes the
 16 total number of donors whose blood was transfused into
 17 Mark in some form or another as over 40.
 18 **A.** Yes.
 19 **Q.** That can come down, thanks, Paul.
 20 You have explained in your statement it took
 21 Mark a while to recover from his surgery about he did
 22 as far as you and he were aware?
 23 **A.** Mmm.
 24 **Q.** Mark then secured a place to do a master's degree in
 25 artificial intelligence?

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1 A. Yes, in 2000 he went to Sussex University to gain
2 a degree there, which he did ultimately. In the
3 meantime, he was toing and froing sometimes in
4 holidays to BT for work and they were looking to him
5 eventually if he got a good degree to work for them.
6 Q. You have explained he did do well in that degree and
7 they effectively came knocking at his door asking him
8 to come and work for them.
9 A. Yes, they wanted him to work, so that's exactly what
10 happened. He ended up working at Martlesham Heath,
11 the research department.
12 Q. So he moved to Ipswich for that job?
13 A. Yes.
14 Q. But you noticed as a family, he'd noticed over the
15 course of the period to the completion of the degree
16 he'd been becoming very tired?
17 A. Very slightly tired, yes. More than usual because
18 during his first degree at UMIST there wasn't that big
19 problem. He had the one problem with the eventual
20 ileostomy but generally he was getting more tired now.
21 Q. But you all put it down to the fact that he was
22 working hard.
23 A. Yes.
24 Q. He was rapidly promoted whilst he was working at BT?
25 A. Very quickly promoted to senior research engineer

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1 he was before, bubbly and full of life, and he used to
2 cycle around the Pennines a lot, for instance, he'd
3 become quite lethargic and she was unsure like him
4 exactly what it was.
5 She thought it may be CFS and agreed with him
6 but he wasn't getting anywhere with the CFS studies or
7 research and he didn't know, of course, what was wrong
8 with him.
9 Q. Now, in early January 2004 Mark received a letter from
10 the Health Protection Agency?
11 A. Yes.
12 Q. We don't have a copy of the letter but we've got
13 a summary and a quote from it in a document that was
14 produced by the Coroner who subsequently held an
15 inquest into Mark's death.
16 Could we have on screen, please, Paul, 694008.
17 In fact, the second page was the right page, please,
18 Paul.
19 If we just look at the first paragraph the last
20 six lines of the first paragraph it says:
21 "Mark Buckland was not informed that he may have
22 received blood that carried the risk of infection
23 until he received a letter dated 31 December 2003 from
24 the Health Protection Agency in early January 2004.
25 The letter includes the following paragraph as part of

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1 within two years.
2 Q. But by 2003 Mark had begun to feel that there was
3 something seriously wrong. He was feeling very tired
4 all the time.
5 A. Yes, he thought he'd had something else. He wasn't
6 sure what it was, he didn't know what it was, but he
7 was getting tired and he was trying to research
8 himself online what it might be.
9 Q. He was finding it harder than normal to concentrate?
10 A. Yes. He was finding it a bit of a strain, yes.
11 Q. At some point it was suggested to him by the doctors
12 he'd gone to see that he might have ME or chronic
13 fatigue syndrome.
14 A. Yes, CFS was a thing they thought he might have at
15 this stage because, yes.
16 Q. Then there came a time as well, you say in your
17 statement, following a visit Mark made to his sister's
18 that his sister reported a concern about some kind of
19 change in his personality. He was much more quiet and
20 withdrawn than normal.
21 A. Yes, she noticed it. Because he was working and
22 studying -- well, living in Ipswich now we didn't see
23 so much of him obviously, or his sister. So when his
24 sister eventually saw him, he went down to see her in
25 [redacted], she noticed this big transience from what

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1 a national programme of blood recipient screening:
2 "You have been identified as having received
3 a significant volume of blood transfusions that may
4 carry a theoretical risk of infection."
5 The risk of infection that was being spoken of
6 in that letter was the possible risk of infection with
7 vCJD.
8 A. This is correct.
9 Q. That was January 2004, but your understanding from
10 everything you learnt subsequently and indeed the
11 inquest into Mark's death is that the Blood Service
12 and/or Department of Health had been informed in
13 August 2000 -- so over three and a half years
14 before -- that a blood donor who had subsequently
15 developed vCJD had died.
16 A. Yes.
17 Q. We can see that if we have the same document back up,
18 please, Paul, first paragraph again, and this is still
19 taken from the Coroner's summing-up at the inquest,
20 third line down:
21 "I am told that the Blood Service was informed
22 on 18 August 2000 that the blood donor who had
23 subsequently developed vCJD had died. That person had
24 died in April 2000."
25 What's your understanding, Peter, of the

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1 reasons, if any, why Mark wasn't told until the
2 beginning of 2004 that he was at risk of vCJD from the
3 transfusions he'd received in 1997?
4 **A.** Good question. I asked that question subsequently to
5 the Health Protection Authority and the answer I got
6 was, "We were worried about Mark and the fact that if
7 he knew he may die he may commit suicide". So I said,
8 "Is that the reason?" And they said, "Yes, that is
9 the reason we didn't tell him. We thought he may --
10 we formed a risk assessment committee", and I learnt
11 this in the House on Commons when I went up there on
12 a meeting with them. To be fair they said, "and we
13 subsequently looked what Mark might think and might
14 not think and he might commit suicide. We were
15 concerned with this so we decided not to say anything
16 until January 2004".
17 So for four years he was living in -- well, none
18 of us knew, and he thought he had CFS and and was sat
19 here looking at that for four years and really looking
20 at it online and going to places to get well and all
21 the rest of it and, of course, it was vCJD.
22 **Q.** You've said in your statement why you think that that
23 withholding of that information from Mark was wrong.
24 You've said they didn't consider that had he been told
25 he could have lived his short life to the full.

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1 Mark's inquest, that that particular drug has been
2 given to other sufferers with vCJD?
3 **A.** Yes.
4 **Q.** One of whom at least lived for a number of years
5 before eventually dying.
6 **A.** Yes. There was a poor boy in Ireland that eventually
7 died of vCJD but he remained alive for a number of
8 years on this particular drug pentosan polysulphate.
9 All right, so he wouldn't have lasted forever but at
10 least he would have lasted longer than he did off it.
11 **Q.** In relation to my next question, Peter, I am going to
12 ask you not to mention any names.
13 **A.** Yes, I won't mention any names.
14 **Q.** Because there are risks in relation to third party
15 confidential information of others.
16 **A.** Okay, fine.
17 **Q.** You have said in your statement that it's your
18 understanding that the donor of the blood that was
19 infected with vCJD and in respect of which Mark was
20 transfused, was themselves the recipient of
21 a transfusion and you've been informed that that
22 person was not a person who consumed meat but was
23 vegetarian or vegan.
24 **A.** Yes, my understanding of the matter, and it's been
25 investigated, and there are no names no pack drill,

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1 **A.** Well, there were two things, basically. He could
2 have -- certainly he would have, you know, he was
3 a free thinking guy, very intelligent, he would have
4 thought to himself, "Okay, if this is the case and
5 I don't know, but if this is the case I'll make sure
6 I live a full life", I would have told him to do that,
7 instruct him, I'm sure he'd have thought the same. At
8 least he would have known the truth.
9 So he'd got four years to live and he didn't
10 know. I did mention this at the time but whether or
11 not this would have worked but there was a drug on the
12 market.
13 You see, if you've got vCJD, it's not long you
14 can hang about with it. If you get transfused with
15 vCJD you can't last very long unless you wash the
16 whole lot out very, very quickly. But you can take
17 a drug called pentosan polysulphate which is an
18 extract of beech wood, but it has to be taken
19 intravenously via a shunt. There wasn't enough time
20 to do that because he wasn't aware of it.
21 Had we been aware of this in 2000 there was
22 a chance before it crossed the blood brain barrier
23 that it might be -- it might work for him.
24 **Q.** You're aware, I think you have mentioned it in some of
25 the material that you put before the Coroner into

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1 that he was not a meat eater, that he was vegetarian,
2 so the fact that he ate meat was not true.
3 I learnt that conclusively but previously,
4 I think eight years previously to this occurring, to
5 his death, he had a very bad car accident and had
6 a large transfusion of blood. I'm just thinking it
7 might have come that way.
8 **Q.** Again, without mentioning any names but so there's no
9 mystery about it, you were informed of this through
10 the work of an investigative journalist, and you have
11 given the relevant names to the Inquiry.
12 **A.** Yes, I have.
13 **Q.** It's right I should also say that we do have
14 a statement from Dr Hewitt, who was a clinical lead
15 with the National Blood Transfusion Service in England
16 and I should point out she says that they are not
17 aware that this is the case.
18 **A.** Yes, they weren't aware because this investigative
19 journalist was not known to her.
20 **Q.** Now, Mark having received that letter in January 2004,
21 it seems again from the material that we have from the
22 inquest that in January 2004 Mark was seen by
23 a neurologist, Dr Wroe.
24 **A.** Yes.
25 **Q.** There was a discussion with Mark about the

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1 implications of the risks of vCJD but nonetheless the
 2 view seemed to be still at that stage that Mark's
 3 symptoms maybe attributable to chronic fatigue
 4 syndrome rather than the development of vCJD?
 5 A. Yes. One of the problems with Mark's prognosis and
 6 the way he was dealt with by the clinical lead, which
 7 was Dr Wroe at the time, W-R-O-E, in Ipswich was (a)
 8 he wasn't with Mark for long enough because he --
 9 although he said to Mark, "You've disappeared off my
 10 radar screen", in fact it was Dr Wroe who moved off of
 11 Mark's radar screen by leaving the Ipswich
 12 neurological hospital and joining Professor Collinge
 13 in the Prion Clinic in Queen Square, so he eventually
 14 left Mark, abandoned him, gone, and left him to his
 15 GP, no neurologist present.
 16 So Mark had no neurologist at that time when
 17 Dr Wroe left and joined the prion clinic in Queen
 18 Square because Mark didn't know he was vCJD.
 19 Q. Again, I am going to ask to have up on screen the
 20 Coroner's summing-up, 694008, and if we can go back to
 21 the bottom of page 2, please, Paul, let's just pick it
 22 up in the middle of page 2, the paragraph above.
 23 So we see the Coroner there recording that he
 24 had been told during the source of the inquest that
 25 the delay between 2000 and 2003 resulted from a

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1 I think there's a word missing there] that the
 2 predominantly cognitive rather than psychiatric
 3 symptoms and some recent improvement with no other
 4 signs would not be typical of a spongiform
 5 encephalopathy. Subsequent investigations, including
 6 an EEG and MRI scan were reported as normal. Dr Wroe
 7 had contacted the National CJD Surveillance Team in
 8 Edinburgh and was advised no further action should be
 9 taken."
 10 Then we can see from January 2004 Mr Buckland
 11 was treated for chronic fatigue syndrome. At that
 12 stage the risk was notified to Mark but it was still
 13 assumed or determined that he was suffering from
 14 chronic fatigue syndrome, rather than vCJD.
 15 A. Despite the symptoms, yes.
 16 Q. Now, Mark's symptoms continued. He was having to try
 17 to work from home.
 18 A. Mmm.
 19 Q. Then by the autumn of the following year, so
 20 October 2005, Mark was beginning to experience or to
 21 report severe leg pain, difficulty sleeping.
 22 A. Yes.
 23 Q. And he was referred back to the National Prion Clinic
 24 or referred to the National Prion Clinic, in fact, in
 25 London and seen by Dr Wroe who, as you have explained,

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1 decision reading and advice given by the CJD Incidence
 2 Panel and that possibly affected individuals shouldn't
 3 be informed.
 4 Then if we pick up the next paragraph, please,
 5 the Coroner had evidence from Dr Wroe, didn't he, at
 6 Mark's request?
 7 A. Hmm.
 8 Q. So this is really taken from the evidence of Dr Wroe:
 9 "Mr Buckland [that's your son, Mark] was invited
 10 to meet Dr Steven Wroe at his local hospital at
 11 Ipswich on 1 January 2004 and did so. Prior to this,
 12 Mr Buckland had been seen in the gastroenterology
 13 department at Ipswich Hospital in November 2003. He
 14 was then complaining of poor concentration, lethargy
 15 and headaches following suspected flu in May 2003. In
 16 fact, Mr Buckland was off work from May 2003. When
 17 Mr Buckland met Dr Wroe on 5 January 2004 he told him
 18 that he had been well until May 2003 when he had the
 19 flu-like illness with sore throat and fogging in the
 20 head. Although these symptoms resolved over two to
 21 three weeks, he then had difficulty concentrating with
 22 excessive fatigue on exertion. At that time,
 23 January 2004, Dr Wroe discussed with Mr Buckland the
 24 implications of the risks of vCJD after transfusion
 25 [if we can have the next page] but advised [and then

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1 had transferred from Suffolk to the National Prion
 2 Clinic, on 5 December 2005.
 3 Again, we see from the inquest summing-up -- and
 4 I don't need this back of screen, Paul -- that Mark
 5 was now describing that he was experiencing "searing
 6 pain that subsumes me".
 7 A. Yes, indeed.
 8 Q. At that point it was concluded that he indeed probably
 9 or almost certainly had vCJD?
 10 A. *(The witness nodded)*
 11 Q. You and Eve knew that Mark was unwell and you went up
 12 to Ipswich one weekend to see him and you were shocked
 13 by how he was. What can you tell us about that?
 14 A. Yes, I visited Mark it was January 2006, I think,
 15 early January 2006, and I was shocked at his
 16 appearance because I had not seen him for a little
 17 while and I knew he wasn't very well, but when
 18 I actually managed to ring him from outside the house,
 19 he lived in an old disused rectory, it was a lovely
 20 place right in the middle of the country, and I drove
 21 up and I rang the bell, tapped the door, and I think
 22 he had left it unlocked and I actually saw him from
 23 the bottom of the stairs. He was living in a flat.
 24 He had something called the vCJD stare. In
 25 other words his pupils had become dilated and he was

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1 looking like that, really strange, and I knew there
 2 was something immediately wrong and he had completely
 3 altered. He was slow. Before he was fast. He was a
 4 very bright intelligent boy. He was a computer whizz
 5 kid, to be honest, with you, very clever, very quick.
 6 But he had a job to type now. Before, he was
 7 you know all day long, but he was like one finger and,
 8 "Hello, Dad", and walking around hanging on to things.
 9 Immediately you could see there was something
 10 profoundly wrong. So, yes, that was the start of me
 11 seeing Mark for the first time in 2005 -- sorry, '6.
 12 Q. 2006. Now, you brought Mark home to [redacted].
 13 A. It was the same month, yes.
 14 Q. You were visited on 19 January 2006 by Dr Wroe, the
 15 neurologist.
 16 A. Yes.
 17 Q. To explain to you and to Eve in Mark's presence that
 18 Mark had vCJD?
 19 A. Yes, indeed.
 20 Q. That was the first you knew, is that right, or had you
 21 been told beforehand?
 22 A. Yes, he -- I think Wroe came down to state that this
 23 is a fact now, that they knew this for a fact that he
 24 was CJD and he'd only got a short time to live.
 25 Q. You described that meeting and you wrote a book,

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1 small mews house in [redacted] and we'd got two small
 2 bedrooms. So we got those two small bedrooms knocked
 3 into one and made for Mark, because he had to have
 4 a fairly large bedroom, and we moved down to the
 5 garage and converted the garage to a bedroom. We also
 6 converted the bathroom into a wet room so he could be
 7 showered in there. What else was it? Oh, he had
 8 a stairlift, a Stannah stairlift. That was all done
 9 very quickly by the vCJD -- I can't remember her name
 10 now.
 11 Q. It was a lady called Margaret who you said was --
 12 A. Margaret Leitch was the prime mover there. She was
 13 from Scotland and she supported us monetarily-wise in
 14 getting these things installed while he was still
 15 alive. Bearing in mind that we knew he'd only got
 16 a few months to live.
 17 Q. Mark received assistance from nurses coming in as time
 18 went on.
 19 A. Absolutely, yes. The vCJD Foundation, via Margaret
 20 Leitch mainly, was such a boost and an asset to us.
 21 We couldn't have survived without them because every
 22 week was like a year, you know. It went by so fast,
 23 and we knew Mark wouldn't last much more than May or
 24 June.
 25 Q. Mark came under the care of Professor Collinge at the

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1 Peter, the Witches within Westminster, and you
 2 described that meeting in very vivid terms. You
 3 clearly had a strong memory of it. You said this:
 4 "A quietly spoken middle-aged neurologist was
 5 wearing a very distinctive red and white spotted bow
 6 tie and had seated himself opposite Mark, Eve his
 7 mother, and myself in our small muse lounge. Mark sat
 8 silent and listened. The mantelpiece clock I remember
 9 thinking had stopped as if it too were focussed on
 10 that moment. We were then told the results of Mark's
 11 latest brain scan and that it had conclusively proved
 12 that Mark was a victim of variant CJD."
 13 Then you describe a single tear running Mark's
 14 cheek and the only words Mark speaking, "That sounds
 15 like a death sentence to me."
 16 A. Exactly. He was normally a very calm boy. He would
 17 never get flustered at anything, but he realised it
 18 was the end coming and what could he do, you know.
 19 Q. You and Eve, along with Mark's large collection of
 20 friends, spent the next few months looking after Mark
 21 in your house?
 22 A. Yes.
 23 Q. You had to have substantial adaptations made to the
 24 house, I think?
 25 A. Yes, we did, yes. We lived in a very, well, fairly

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1 Prion Unit at Queen Square in London.
 2 A. Yes, he did.
 3 Q. Over the following weeks and months he had a number of
 4 appointments there?
 5 A. Yes.
 6 Q. He participating in the clinical trial of a drug?
 7 A. Yes, he did.
 8 Q. Quinacrine?
 9 A. Quinacrine is a derivative of quinine and its served
 10 a purpose, although it was never going to save him.
 11 It was the only thing the Government could say that
 12 they would administer to him. They wouldn't use other
 13 drugs. They were too powerful or were frowned upon,
 14 but quinacrine was a drug they had used before. I
 15 think what it does, it lifts a person but it doesn't
 16 do much for their liver, but it helps them momentarily
 17 so are a few weeks he was slightly better so we got
 18 Collinge to thank that for.
 19 Q. Over the months between January when he came back to
 20 live with you and May 2006, how did his condition
 21 deteriorate?
 22 A. Very rapidly, almost daily. First of all, you know,
 23 when he first came to the house in January he could
 24 walk up and down the stairs, great. Within two or
 25 three weeks he was sliding down on his bum. He

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1 couldn't walk down the stairs or up the stairs, so he
 2 had the Stannah lift fitted. That was an amazing
 3 thing, so he could go up and down easily.
 4 The garage was converted, as I just mentioned.
 5 The bathroom and the bedroom. Everything was sorted
 6 out for him because to maximise his lifespan
 7 comfortably at [redacted] where we were.
 8 **Q.** His vision started suffering?
 9 **A.** Yes. Everything about -- he was in this searing pain.
 10 If you saw him go to bed every night he would
 11 constantly move, moving about all the time, he was
 12 asleep but he was moving and so we had to have night
 13 carers come in and I installed a TV with a camera so
 14 if there was no night carer there I could see him
 15 downstairs in the garage all the time and usually I
 16 didn't go to sleep or go to bed so I stayed down in
 17 the -- we were on three floors. The top floor had the
 18 bedrooms, then it was the next floor was the lounge
 19 and kitchen and the bottom level was a garage. So
 20 I was mainly on the middle, if there was no carer,
 21 night carer, but we got more and more night carers as
 22 time went on.
 23 **Q.** Mark's memory started to suffer as well?
 24 **A.** Yes. I mean, it's ridiculous. If you knew what he
 25 was like, he was such a bright -- everything he'd done

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1 **Q.** -- the last?
 2 **A.** Yes.
 3 **Q.** Mark had a great many friends and a very supportive
 4 girlfriend who continued to spend a lot of time with
 5 him over this period?
 6 **A.** Amazing amount of time, yes.
 7 **Q.** Then you arranged a particular trip to the Savoy in
 8 London.
 9 Can you tell us about that.
 10 **A.** Yes. We went up I think it was March, wasn't it.
 11 **EVE:** Mark's birthday.
 12 **A.** Yes, Mark's birthday, which was the 28th, we arranged
 13 we hoped a memorable trip for him. We knew his days
 14 were numbered, so I think we had three days at the
 15 Savoy and some friends and relations up there, and
 16 family, and money no object because he was dying, you
 17 know. So we spent the time up there and also at the
 18 same time arranged a photo exhibition for him very
 19 near the Savoy Hotel so it wasn't a long way to walk,
 20 the Proud Galleries in London. So he had a couple of
 21 days up there, one open for the public and one not.
 22 **Q.** That was an exhibition of Mark's photos --
 23 **A.** Yes.
 24 **Q.** -- that he had taken.
 25 **EVE:** He was in a wheelchair.

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1 was bang on, you know. He was a great guitarist, he
 2 was a great photographer, a great cyclist. He done
 3 everything to the maximum. A good mathematician,
 4 brilliant on computers, good at Dungeons and whatever
 5 it was.
 6 **Q.** Dragons.
 7 **A.** He was a whizz kid. To see him come from that and he
 8 him falling over with the brain problem he had. When
 9 the prions started to misform it rapidly happened, he
 10 went downhill quickly.
 11 **Q.** He was started going on respite visits to Martlets
 12 Hospice?
 13 **A.** Yes, he did.
 14 **Q.** You have put it this way in your witness statement,
 15 Peter, I am just going to read a passage from it:
 16 "He would wave to us from the van where he was
 17 going to and from Martlets Hospice like a little boy
 18 going to school. He had bed sores towards the end and
 19 he was like a little boy and an old man all at the
 20 same time."
 21 **A.** Yes, he was.
 22 **Q.** You celebrated Mark's birthday in March 2006.
 23 **A.** Correct.
 24 **Q.** You knew it was likely to be --
 25 **A.** The last.

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1 **A.** Yes. He was in a wheelchair. He was quite happy
 2 pushing himself around the exhibition, talking to his
 3 friends. Everyone was there. It was all organised by
 4 his girlfriend and us and he had a wonderful weekend
 5 in London at his own photo exhibition, and then took
 6 in the big wheel afterwards.
 7 **MS RICHARDS:** You went on the London Eye?
 8 **A.** Yes, the London Eye. We recorded that. We've got
 9 a video. It was wonderful to see but it was tragic at
 10 the same time.
 11 **Q.** He went to Hamleys toy shop and you were buying
 12 presents --
 13 **A.** Oh, we went to Hamleys.
 14 **Q.** -- for your grandchildren.
 15 **A.** For the, grandchildren --
 16 **Q.** But you bought something for Mark as well.
 17 **A.** -- and for Mark, yes. Because he was into robotics
 18 and studying that at BT, artificial intelligence, he
 19 got a brilliant degree in that. He loved robotics so
 20 I bought this massive great robot for him and he
 21 played with that in the Savoy. But, you know, he was
 22 limited to now just sitting down mostly and -- but
 23 still managing conversation when he was fresh, you
 24 know, just about making it. He even had a good
 25 conversation with Professor Collinge at the Prion

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1 clinic and he was quite impressed with it.
 2 **Q.** I am going to actually put something up which is
 3 a letter from Professor Collinge.
 4 It is 694011, please, Paul. It was a letter to
 5 Mark's sister from Professor Collinge and it's just
 6 the second paragraph please, Paul, I don't need the
 7 rest.
 8 "I understand that Mark's illness and diagnosis
 9 must be extremely distressing to you. Although I have
 10 only met Mark on a few relatively brief occasions in
 11 our clinic and ward, what you say about his remarkable
 12 character shines through very clearly, despite his
 13 illness. It is very moving and inspiring talking to
 14 him and I know this view is shared by all of my staff
 15 who have had the privilege to meet him and to be
 16 involved in his care."
 17 In May 2006 you and Eve went on a holiday for
 18 respite. You were talked into it I think by friends
 19 and family.
 20 **A.** Yes, we were, yes. They said we were getting too into
 21 it all so, yes, we managed to get away.
 22 **Q.** But you received a telephone call pretty quick into
 23 your holiday?
 24 **A.** I can't remember where we went.
 25 **EVE:** It doesn't matter.

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1 and said goodnight to him but I felt like that was the
 2 end, you know, that was the last night, and I was
 3 right.
 4 So, yeah, he went.
 5 **Q.** You have written about that also in your book, Peter,
 6 and I'm just going to read, if I may, what you have
 7 said there --
 8 **A.** Yes, sure.
 9 **Q.** -- because it's your words and it's very powerful:
 10 "Our precious son had left us at 7.10 that
 11 Tuesday morning. He'd gone where there was no
 12 suffering, no longer in a space restricted by a
 13 brain-wasting disease that slowly stripped the very
 14 essence of who Mark was and spat it out. My son, God
 15 rest his soul, couldn't go on any longer. He finally
 16 gave up his fight to an incurable disease that was a
 17 direct result of a tainted blood transfusion within
 18 the NHS."
 19 You very kindly shared some photos of Mark with
 20 us that we're going to show.
 21 **A.** Sure.
 22 **Q.** Can we do them in this order please, Paul. Put up,
 23 please, 694017.
 24 Mark as a teenager with his camera.
 25 **A.** Yes.

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1 **A.** A long way away, to Italy, and we had a phone call
 2 halfway through the holiday from Martlets -- no, it
 3 wasn't from -- oh, from Luke, sorry, from Mark's
 4 friend, he was at Martlets Hospice, while we were on
 5 holiday, saying he was very ill and come quick. So we
 6 jumped on a plane come straight home.
 7 **Q.** Mark was very unwell. He deteriorated very rapidly
 8 indeed.
 9 **A.** Very, yes.
 10 **Q.** And he was in the hospice.
 11 **A.** Yes.
 12 **Q.** He died there on 23 May 2006?
 13 **A.** Yes, I shall never forget that day. Yes, we had
 14 a phone call again when we were at home then and they
 15 said, "Come quickly he's going". That was 7 o'clock
 16 in the morning and by the time we got there he'd gone.
 17 He was still warm but, you know -- and we knew that
 18 was it.
 19 **Q.** You had seen him the night before and given him --
 20 **A.** Yes, luckily I was the last one -- well, it was
 21 luckily for me, I was the last one to see him for five
 22 minutes just to talk to him, but by that time he found
 23 it hard to swallow so, you know, you've got a lot of
 24 muscles in here you swallow water with, so he had to
 25 have thickeners and I fed him some thickening fluid

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1 **Q.** Then 694016, please.
 2 Mark as a young adult.
 3 Then 694014.
 4 This is when Mark had become unwell.
 5 **A.** That was the last picture I ever took of him, yes.
 6 That was at home.
 7 **EVE:** Thumbs up, he felt all right.
 8 **A.** Although wasn't well.
 9 **MS RICHARDS:** You have also provided a picture of Mark's
 10 headstone, 694015.
 11 **A.** Yes, indeed.
 12 "You are our star. We love you."
 13 **Q.** There was an inquest into Mark's death and if we just,
 14 really as a matter of record, have up the inquisition
 15 from the inquest, which is 694009, please, Paul.
 16 We see there the verdict.
 17 Just further down, please, Paul:
 18 "Mark Adam Buckland died as a result of
 19 infection with variant CJD from prion agent
 20 transmitted to him by transfusion of variant CJD
 21 infected blood in surgery in September 1997."
 22 **A.** Yes.
 23 **Q.** Following the inquest, the Coroner wrote to the
 24 Secretary of State for Health and I'm going to ask for
 25 that letter to be displayed at 694002. If we just,

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1 please, have the bottom half of the page. Thank you.

2 So we see there a narrative first being set out
3 about the Blood Service being informed in August 2000
4 that the blood donor had developed vCJD, he/she having
5 died in April 2000, and Mr Buckland not having been
6 informed until early January 2004, then a description
7 of the meeting with Dr Wroe.

8 If we could go on to the third page, please, of
9 that letter, Paul, second half of the page, if we
10 could have that enlarged. Thank you.

11 So we can see here that this is the Coroner's
12 summary of what Dr Wroe said to him during the
13 inquest:

14 "Dr Wroe believed that had Mr Buckland been in
15 regular contact with the National Prion Clinic for
16 review and follow-up the diagnosis would have been
17 established at six months or possibly 18 months
18 earlier. Although that would not have allowed him
19 a cure, it would have enabled earlier entry on to the
20 experimental trial of quinacrine that in his case was
21 not commenced until January 2006 and, further, it
22 would have allowed him and his family and friends to
23 come to terms with what had happened to him rather
24 than struggle with the diagnosis of chronic fatigue
25 syndrome. Dr Wroe contended that as soon as the

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1 the past will now be reviewed and that other persons
2 who may be at risk will be fully informed as soon as
3 there is knowledge that risk has arisen with advice to
4 both him or her and their GP of the appropriate steps
5 to take including I would suggest reference to the
6 National Prion Clinic for assessment."

7 So that's the letter the Coroner wrote to the
8 Secretary of State.

9 Then we have the response of the Minister at
10 694004. These are all documents you, Peter, have
11 kindly shared with the Inquiry. We will just look at
12 the main paragraph, please, there, the bottom half of
13 the page:

14 "The Department of Health took the decision not
15 to inform potentially exposed transfusion recipients
16 about the possible risk of exposure to the agent of
17 vCJD in 1998, following advice from experts in ethics.
18 The level of risk of transmission through blood
19 transfusion was uncertain and the Department
20 commissioned Det Norske Veritas to undertake a risk
21 assessment to evaluate the overall risk to patient
22 groups which was published in 1999, revised in 2003.
23 The decision was particularly difficult as certain
24 experts thought transmission via blood was unlikely,
25 no test or treatment was available and the incubation

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1 National Blood Service and the Department of Health
2 became aware in 2000 that Mr Buckland had received
3 blood from a donor who developed vCJD, the National
4 Prion Clinic should have been informed and asked to
5 contact Mr Buckland and his GP directly with a view to
6 offering expert assessment and advice on management
7 options. That is a view with which I [that's the
8 Coroner] found myself in agreement. In my judgment,
9 patients should have the opportunity of receiving
10 appropriate assessments advice and treatment if they
11 wish and be enabled to deal with the possible future,
12 doing what they may wish to do and helping their
13 families come to terms with the future as well.
14 A cure may at some stage become possible and it's only
15 right that potential victims of the disease should
16 know at the earliest possible stage so that
17 appropriate treatment can be offered."

18 Then if we go over the page please, Paul, and if
19 we have the second paragraph:

20 "At the hearing I indicated that I would write
21 to your department [that's the Department of Health]
22 expressing my concern that Mr Buckland had not been
23 told of the risks that he faced at the earliest
24 possible stage. That is the purpose of this letter.
25 I trust that the procedures that have been adopted in

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1 period was unknown but could be decades long. To
2 date, there is still no test or treatment and the
3 incubation period is still unknown. In addition, the
4 early symptoms of disease are the same as for many
5 common and treatable illnesses, thus telling people of
6 a potential exposure may result in a lifelong worry
7 that every minor depression or episode of clumsiness
8 is the first sign of impending vCJD. As a result,
9 telling healthy transfusion recipients that they may
10 have been exposed to vCJD agent as a result of their
11 treatment could also undoubtedly do harm."

12 Just pausing there, Peter, that was the
13 explanation that was provided by the Minister in
14 response to the Coroner's letter. Is that an
15 explanation you accept or agree with?

16 A. I don't accept it. I was told the same thing.

17 I mean, I rang the HPA up and they said virtually the
18 same, but they knew about bloods. They'd known about
19 deaths of vCJD through bloods as early as the 1990s.
20 I mean, the Australians had proved it. Lots of other
21 people had proved it. BSE was proved by it, by all
22 5 million cattle being wiped out, because they are
23 born to cows calves die, it's through the blood. So
24 everyone knew that blood was a carrier and a way of
25 carrying forward.

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1 I didn't accept their excuse.

2 **Q.** It remains your view, recorded in your witness
3 statement, that Mark should have been told earlier.

4 **A.** Yes, for whatever reason. Simply, if they couldn't
5 have saved him, that's fine, but he would have had
6 another few years living a full life. If I was told,
7 for instance, that I might die, there's a possibility
8 that I might die within a few years, I'd have the time
9 of my life. I'd do all those things on my bucket
10 list. He unfortunately didn't and couldn't and
11 because he was becoming more ill and more ill by the
12 day but he had a chance a few years to get sorted out.
13 I think seriously it's wrong because he's dead now and
14 he can't do anything.

15 **Q.** For the sake of completeness, we will go over the page
16 where the letter explains, and it is the first three
17 paragraphs, please, Paul. I won't read all of it:
18 "The situation is now different. The results of
19 experiments in animals have indicated that
20 transmission by transfusion can occur. Furthermore,
21 there's been a general shift in attitudes towards
22 patients' rights to information. In the summer of the
23 2000 the Department of Health established the CJD
24 Incidence Panel."

25 Then it goes on to set out their consideration

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1 receiving a transfusion from donors who subsequently
2 developed vCJD. The risk to the remaining recipients
3 of such transfusions is probably high and these
4 patients should be offered specialist follow-up and
5 investigation."

6 Then if we just turn, please, on to the next
7 page we see under the heading "results" in the bottom
8 right-hand column, the reference to a 35-year old male
9 patient. That's Mark. There's a fairly detailed
10 account there and over the page of Mark's
11 deterioration over the period that we've just been
12 discussing and his ultimate death.

13 **A.** Yes.

14 **Q.** That can come down, thank you.

15 **A.** Thank you.

16 **Q.** Mark, as you have already mentioned, received
17 financial assistance from a vCJD fund located the
18 Scotland.

19 **A.** Yes.

20 **Q.** As well as the adaptations that were put in place, as
21 I understand it from your witness statement very
22 quickly, that financial assistance enabled Mark to be
23 taken to and from hospital in London, it enabled Mark
24 to have a holiday?

25 **A.** Yes, it did.

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1 of a consultation, consideration in the next paragraph
2 by the four chief medical officers for the England and
3 the devolved administrations. Then it says this:
4 "While the necessary support mechanisms were
5 being put in place, the first case of vCJD
6 transmission via blood transfusion was confirmed in
7 December 2003. The department acted as quickly as
8 possible to ensure that all similar recipients were
9 contacted and given the information and support
10 needed. In future all such patients will be contacted
11 as soon as they have been traced."

12 **A.** Yes.

13 **Q.** You have also drawn the Inquiry's attention to an
14 article in the Lancet or a study in the Lancet that
15 was published in 2006. I will just briefly put that
16 up on screen. It's 694007, please, Paul.

17 We can see it was authored by, amongst others,
18 Dr Wroe and Professor Collinge. Then if we just look
19 halfway down the page at interpretation:
20 "This case of transfusion-associated vCJD" --

21 **A.** This was Mark.

22 **Q.** That's Mark:
23 "... identified ante mortem [before his death]
24 is the third instance from a group of 23 known
25 recipients who survived at least five years after

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1 **Q.** And, indeed, it paid for the headstone that we've
2 seen?

3 **A.** Yes.

4 **Q.** Whatever else has happened, you are grateful for and
5 praise the assistance you received from the nurse
6 based there, Margaret Leitch, who helped you and Mark
7 access this assistance?

8 **A.** Absolutely.

9 **Q.** Can I just ask a little about the impact of the events
10 that you've been describing on you and on Eve. Your
11 wife gave up work to help look after Mark?

12 **A.** Yes.

13 **Q.** You were working at the time in a school?

14 **A.** Yes, I was a caretaker.

15 **Q.** And you had to retire early because you couldn't face
16 being --

17 **A.** I couldn't carry on longer. Yes, I broke down
18 virtually. I retired at 62. Eve had to retire. We
19 were both affected.

20 **EVE:** Because of the boys, they reminded you of Mark.
21 That's why you couldn't --

22 **A.** Yes, because it had all been transformed, you know, we
23 were constantly reminded of what happened.

24 **EVE:** The boys at the school.

25 **MS RICHARDS:** You were seeing healthy children and young

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1 adults?
 2 A. I was working with healthy children five days a week
 3 and, great, you know, when you're okay but when you
 4 have just experienced a six-month death of your own
 5 son in your own house, it's not funny, so --
 6 five-month death. So, yeah, I couldn't do anything.
 7 All I done was got on my bike and cycled over the
 8 Downs.
 9 Q. You're very candid in your witness statement that you
 10 began to drink?
 11 A. Yes, I did. I wrote my book on red wine and I became
 12 an alcoholic.
 13 Q. That had an impact, obviously, on your relationship
 14 with Eve?
 15 A. Yes. It ruined a lot of things.
 16 Q. It had an impact on your relationship with your other
 17 children?
 18 A. Yes, big time.
 19 Q. You developed --
 20 A. My children don't speak to me now.
 21 Q. You developed type 2 diabetes?
 22 A. Yes, I did.
 23 Q. You no longer drink?
 24 A. No, I gave it up. Remarkable, wasn't it?
 25 Q. You have tried to make new friends and new lives for

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1 cycling and raising awareness took its toll on your
 2 heart and you had to have surgery?
 3 A. I had to have major heart surgery this year. It
 4 wasn't too good. And I'm okay. I've got a new valve
 5 now and a new bypass. I'm up for another 20 years at
 6 least.
 7 Q. You have said in your statement that your wife Eve,
 8 she had to internalise her own grief and anger, she
 9 had to deal with you during the period that you've
 10 talked about, and you said:
 11 "She had to live with me and found it very
 12 difficult to control me."
 13 A. I don't know how she did it, to be honest, with you
 14 because she never complains. It's me. I've got to
 15 take, you know, drink and she never has; so she's
 16 marvellous.
 17 Q. Then you've said this and I'm just going to read what
 18 you've said about Eve, if that's okay, in your
 19 statement:
 20 "My wife was very angry. She's told me at the
 21 time it felt as though nothing could put it right.
 22 She couldn't travel on buses and trains because she
 23 was scared of sitting next to a young man and being
 24 reminded too much of Mark. She couldn't go down the
 25 biscuit aisles in supermarkets because chocolate

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1 yourselves?
 2 A. Yes.
 3 Q. You've said, amongst other things, people who had
 4 known you and known Mark didn't know what to say to
 5 you anymore?
 6 A. No, it's embarrassing. I used to go round when Mark
 7 died or was dying, go around [redacted], which is
 8 a big park near where we lived in [redacted], and talk
 9 to old ladies and old men, and just talk to anyone, to
 10 someone. And, yes, I sort of lost it for quite a long
 11 while.
 12 Q. You then became something of a cycling fanatic and
 13 trying to raise awareness about these issues.
 14 A. Yes, I decided to become a cycling fanatic and
 15 I decided to, with a friend, ride John o' Groats to
 16 Land's End to raise awareness of bloods that go wrong
 17 and I done that in 2007. And then I went on a trip to
 18 Paris to London.
 19 EVE: By bike.
 20 A. By bike again, yes. And even went one day down to my
 21 daughter, who lives in Exeter, to Exeter in one day.
 22 I thought it was quite good. I thought that was quite
 23 good, actually. I left at 7 in the morning, got there
 24 at 7 at night. It was 200 miles. Maniac but ...
 25 MS RICHARDS: But that's taken its toll, all that furious

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1 biscuits had been Mark's favourite and she was
 2 reminded too much of him.
 3 "There was one occasion she was in a chemist and
 4 she saw a sign that said 'donate blood and save
 5 a life'. She got hold of the sign and threw it across
 6 the shop because it made her so angry.
 7 "Now she's just sad about what happened to Mark.
 8 He was the most lovable and caring son. We have
 9 photos and all the good memories but it will never be
 10 the same life for my wife or myself."
 11 A. No. All that's gone.
 12 Q. You've seen, I know, a statement from Dr Patricia
 13 Hewitt which details her recollection of a discussion
 14 you had with her, different from your recollection.
 15 A. Yes.
 16 Q. I'm not proposing to ask you anything about that,
 17 Peter, unless there's anything you particularly want
 18 to say about it?
 19 A. Not really, no. I mean, she has a view. She was
 20 probably just trying to do her job but, you know, my
 21 anger is not against her, it's just about I can't
 22 understand politics. It's the politics bit of all of
 23 it and the risk assessments that were wrong, both in
 24 haemophilia and vCJD. Risk assessments must be taken
 25 more seriously and that's what they're on about here.

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1 Q. Peter, that completes the questions I had to ask you
2 but is there anything else you would like to say?
3 A. Yes, it's just a brief thing. I'm good at writing but
4 I'm not good at standing up and reading.
5 This from my wife Eve. Just to say Peter and
6 I want to thank you all about your concern in bringing
7 this Inquiry together and all these families must be
8 very upset and thank you for hearing us. And the best
9 thing I would like to say is that we both know that
10 our Mark would be proud of us for whatever we are
11 doing, knowing it won't bring him back, but telling
12 the world that it can't happen again hopefully.
13 Q. Thank you, Peter, and for telling us all about Mark.
14 A. Thank you.
15 MS RICHARDS: Sir, do you have any questions?
16 SIR BRIAN LANGSTAFF: No, I don't. You thanked us for
17 hearing you. It is us who should be thanking you for
18 answering the call to come and give evidence.
19 A. Pleasure.
20 SIR BRIAN LANGSTAFF: Thank you, Eve, for supporting as
21 you have.
22 A. That's okay. You're very welcome. Thank you and good
23 luck to everybody.
24 SIR BRIAN LANGSTAFF: We'll take a break there until
25 tomorrow 10.30 tomorrow.

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1 MS RICHARDS: Yes, sir.
2 SIR BRIAN LANGSTAFF: Can you tell us what we have in
3 store tomorrow.
4 MS RICHARDS: We have an anonymous witness and then we
5 have Maria Fletcher and Graham Manning.
6 SIR BRIAN LANGSTAFF: So the anonymous witness is Ms or
7 Mr L.
8 MS RICHARDS: Mr L.
9 SIR BRIAN LANGSTAFF: Tomorrow then at 10.30.
10 (2.59 pm)
11 (Adjourned until 10.30 am the following day)
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I N D E X

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