

1 Wednesday, 28 September 2022

2 (10.00 am)

3 **SIR BRIAN LANGSTAFF:** Can I thank you, each of you and all

4 of you, for coming to give us your evidence. Now,

5 although we have five of you, I know that the person

6 sitting nearest to me is Patricia, is it?

7 **MS PATRICIA WARD:** Yes.

8 **SIR BRIAN LANGSTAFF:** She is there to support yourself,

9 Linda. You wish to be known as Linda?

10 **MS LINDA KITSON:** Yes, please.

11 **SIR BRIAN LANGSTAFF:** Then we have someone who will be known

12 as Tony, although I think when you hear him swear the

13 oath you may hear a different set of given names. And

14 you are supporting Dot, is it?

15 **MR TONY WRIGHT:** Yes.

16 **SIR BRIAN LANGSTAFF:** Then we come to Fiona.

17 So in a moment or two, I'm going to ask Mary to

18 invite you each to take the oath. In the case of you,

19 Tony, it will be the interpreter's oath because there

20 may be occasions when I understand your wife may not be

21 able to speak sufficiently well for us to be able to

22 understand what she's saying and you can help with that.

23 In a moment or two then, Ms Fraser Butlin will ask

24 the questions and you can see who you're speaking to

25 here.

1

1 pregnant with your son?

2 **MS FIONA ALLAN:** Yes.

3 **MS FRASER BUTLIN:** You were admitted to hospital at

4 27 weeks.

5 **MS FIONA ALLAN:** Yes.

6 **MS FRASER BUTLIN:** And why was that?

7 **MS FIONA ALLAN:** I had been bleeding quite a lot and I'd

8 been going for scans and it had been detected the

9 placenta was quite low, but I was told on occasions that

10 it -- as the birth -- develops, that the placenta can

11 move up, but I did go, one week, in. It had went

12 further down so they basically said, "This isn't looking

13 good, I think we're going to have to bring you in". So

14 I did go for a scan and I was told I couldn't go home it

15 was so -- grade 4 sort of thing.

16 **MS FRASER BUTLIN:** It was a placenta previa.

17 **MS FIONA ALLAN:** Yes.

18 **MS FRASER BUTLIN:** So the placenta was in the completely

19 wrong place and you were at high risk of haemorrhaging.

20 **MS FIONA ALLAN:** Yes.

21 **MS FRASER BUTLIN:** In fact, you did haemorrhage.

22 **MS FIONA ALLAN:** Yes.

23 **MS FRASER BUTLIN:** And you went into theatre for an

24 emergency caesarean.

25 **MS FIONA ALLAN:** Yes.

3

REDACTED VERSION

1 Mary.

2 **MS FIONA ALLAN (sworn)**

3 **MS DOROTHY WRIGHT (sworn)**

4 **MR PAUL ANTHONY WRIGHT (sworn)**

5 **MS LINDA ANN KITSON (sworn)**

6 **SIR BRIAN LANGSTAFF:** Yes.

7 **Questioned by MS FRASER BUTLIN**

8 **MS FRASER BUTLIN:** Fiona, when you were about 25 you had

9 severe abdominal pain and you were admitted into

10 hospital. What did they discover when you were

11 admitted?

12 **MS FIONA ALLAN:** They discovered a non-malignant tumour on

13 my fallopian tube which had strangulated and obviously

14 caused problems with my ovary.

15 **MS FRASER BUTLIN:** So you had the strangulated fallopian

16 tube removed and one of the ovaries?

17 **MS FIONA ALLAN:** Yes.

18 **MS FRASER BUTLIN:** At that point, what you were told about

19 your ability to have children?

20 **MS FIONA ALLAN:** Basically non-existent. We had been trying

21 for a family and I was told that my chances were slim to

22 nil.

23 **MS FRASER BUTLIN:** So in 1984 you adopted your daughter?

24 **MS FIONA ALLAN:** Yes.

25 **MS FRASER BUTLIN:** Then at Christmas you discovered you were

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1 **MS FRASER BUTLIN:** At that point, I think you were also

2 given three units of blood?

3 **MS FIONA ALLAN:** Yes. I think it was three or four.

4 I think it was -- I just erred on the cautious side.

5 **MS FRASER BUTLIN:** Can you tell us what your health was like

6 after the birth of your son?

7 **MS FIONA ALLAN:** It was actually horrendous and I did speak,

8 funnily enough, to my daughter about it to say

9 I couldn't believe how ill I felt after it. And I had

10 nothing to gauge against, so I did put it down to it

11 being an emergency traumatic caesarean. But I just felt

12 so ill and I couldn't explain and I didn't really have

13 an interest in the baby [... redacted ...]. It just

14 took me a long time to recover and I just didn't feel

15 good about it.

16 **MS FRASER BUTLIN:** Can you tell us in what way you didn't

17 feel good?

18 **MS FIONA ALLAN:** I just felt so sick, drained, fuzzy.

19 I just wanted to sleep all the time. I had family

20 coming up wanting to visit me and I just felt so ill and

21 I remembered thinking surely this just can't be down to

22 childbirth, yes.

23 **MS FRASER BUTLIN:** In fact, during that period, for the

24 first couple of weeks your son [... redacted ...]

25 **MS FIONA ALLAN:** Yes.

4

1 **MS FRASER BUTLIN:** And your GP encouraged you to have -- the
 2 childcare that you had for your daughter to continue,
 3 even though you were home?
 4 **MS FIONA ALLAN:** Because I was going to see him and I was so
 5 unwell. I think he had to come out at one point, yeah.
 6 **MS FRASER BUTLIN:** Nine years later you went to donate
 7 blood.
 8 **MS FIONA ALLAN:** Yes.
 9 **MS FRASER BUTLIN:** And what happened after that?
 10 **MS FIONA ALLAN:** I did -- I can't remember how long it took
 11 after but I did get a letter, I think it was from
 12 Law Hospital, just simply stating, "Thank you for coming
 13 to give blood. Unfortunately, we can't accept your
 14 blood. It's detected that you have blood infection.
 15 Please be reassured it is not hepatitis -- it is not HIV
 16 or AIDS". And then, "Don't share razors, toothbrushes
 17 and we'll see you at some point".
 18 Then I was -- it was a Friday night and we were
 19 going on holiday on the Saturday with young children,
 20 and I was absolutely devastated because I couldn't get
 21 in touch with anybody and I had to go away on holiday,
 22 totally ruined, thinking -- bearing in mind it was
 23 30-odd years ago -- "Oh my God, I'm infected", and
 24 I didn't want to drink, I didn't want to do anything.
 25 So it was pretty scary, yes.

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1 [... redacted ...].
 2 **MS FRASER BUTLIN:** So they could pin it down to the blood
 3 transfusion?
 4 **MS FIONA ALLAN:** Yes.
 5 **MS FRASER BUTLIN:** What advice did they give you at that
 6 point about hepatitis B?
 7 **MS FIONA ALLAN:** Nothing at all except for don't share
 8 razors, reduce your alcohol, just safety measures, don't
 9 share cups and that. But nothing else. Nothing else.
 10 **MS FRASER BUTLIN:** In your statement, you've said that you
 11 were advised it was unfortunate that you had hepatitis B
 12 but that you should be grateful that the transfusion
 13 after the birth saved your life?
 14 **MS FIONA ALLAN:** Yes, I was told that so many times by
 15 people. I just spoke about it this morning, saying how
 16 that was all I ever got was, "Oh, you should be
 17 grateful, it saved your life".
 18 **MS FRASER BUTLIN:** You were then referred to the Brownlee
 19 Infectious Diseases Centre.
 20 **MS FIONA ALLAN:** Yes.
 21 **MS FRASER BUTLIN:** What were you advised there?
 22 **MS FIONA ALLAN:** I spoke to a lovely consultant there and
 23 I went on a couple of occasions to see him. He was very
 24 nice, just explained what hepatitis B was, that the
 25 cells were still replicating at that point. So it gave

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1 **MS FRASER BUTLIN:** Because you'd received that letter
 2 effectively late on a Friday?
 3 **MS FIONA ALLAN:** Yes, yes.
 4 **MS FRASER BUTLIN:** So although the letter had a number to
 5 call, you couldn't ring it?
 6 **MS FIONA ALLAN:** No.
 7 **MS FRASER BUTLIN:** When you got back, you then had an
 8 appointment with doctors at the Blood Transfusion
 9 Service.
 10 **MS FIONA ALLAN:** Yes.
 11 **MS FRASER BUTLIN:** What did they ask you about?
 12 **MS FIONA ALLAN:** They asked me if I had ever dealt with
 13 drugs, which I quite emphatically haven't, and if we'd
 14 ever had any kind of promiscuous relationships, which we
 15 hadn't either, so, yeah.
 16 **MS FRASER BUTLIN:** You then had a discussion with the
 17 doctors and it was discussed that the hepatitis B had
 18 probably arisen from the blood transfusions?
 19 **MS FIONA ALLAN:** Yes, yes.
 20 **MS FRASER BUTLIN:** What did they say in relation to that?
 21 **MS FIONA ALLAN:** They had said that the likelihood of me
 22 being infected before my childbirth was quite remote due
 23 to the fact that I had taken blood tests, et cetera,
 24 nothing had ever, ever shown up, and that most likely my
 25 child would be -- my baby would be infected as well,

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1 me a -- really, really just re-endorsed what precautions
 2 I should be taking, which were generally what I'd
 3 already been told.
 4 **MS FRASER BUTLIN:** And he -- after seeing him a few times,
 5 he then encouraged you to be checked every six months by
 6 the GP.
 7 **MS FIONA ALLAN:** Yes.
 8 **MS FRASER BUTLIN:** But at that point were you offered any
 9 treatment of any sort?
 10 **MS FIONA ALLAN:** No, nothing at all. Nothing at all.
 11 **MS FRASER BUTLIN:** What's your physical health been like
 12 since then?
 13 **MS FIONA ALLAN:** I don't have the best health. When I was
 14 born, I had a condition called spina bifida occulta,
 15 which has given me back pain, which I really didn't know
 16 until after the birth, and then it was sort of
 17 exacerbated, and I now have to take slow-release
 18 tramadol on a daily basis for my spine. My immune
 19 system's poor enough, as in I do seem to keep taking
 20 different infections, but generally I would say my
 21 health, I'm quite lucky.
 22 **MS FRASER BUTLIN:** You've said in your statement that you've
 23 had consistent fatigue as well over the years.
 24 **MS FIONA ALLAN:** Yeah, yeah, yeah. I have been diagnosed
 25 with fibromyalgia, and I was always encouraged to --

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1 I had to give my children to their grandparents every
2 week because -- every weekend just because I was just
3 constantly exhausted all the time and, again, I had lots
4 of brain fog.

5 I went through a very early change of life and all
6 my illnesses and conditions I put down to the change of
7 life, but back then I was only 37 at the time. But it's
8 on reflection, just when I think about it, I think -- of
9 course I don't know what I don't know -- yeah, it was
10 a bit of a horrendous time for me then as well because
11 I was walking on, like, cotton wool all the time, you
12 know?

13 **MS FRASER BUTLIN:** You've talked in your statement that you
14 had significant fatigue but you kept being told that you
15 were fine.

16 **MS FIONA ALLAN:** Yes.

17 **MS FRASER BUTLIN:** Then you had the early menopause.

18 **MS FIONA ALLAN:** Yes.

19 **MS FRASER BUTLIN:** And you were told that was the reason for
20 your fatigue and your brain fog?

21 **MS FIONA ALLAN:** Yes.

22 **MS FRASER BUTLIN:** But now, looking back, you're left
23 questioning whether it's the hepatitis.

24 **MS FIONA ALLAN:** Yes, yes.

25 **MS FRASER BUTLIN:** In terms of the impact on your mental

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1 **MS FIONA ALLAN:** I've never, ever been asked to go
2 specifically for these tests. I've just assumed that
3 every time I've had an illness or something that it has
4 been -- my liver's been checked but not to my knowledge
5 do I know anything, except that I'm always going to be
6 a hepatitis B carrier.

7 **MS FRASER BUTLIN:** And so there's no formal liver follow-up
8 for you that's in place at all?

9 **MS FIONA ALLAN:** No, no, no.

10 **MS FRASER BUTLIN:** In your statement, you've talked about
11 two experiences of interactions with clinicians about
12 your hepatitis B that you've described as difficult.

13 **MS FIONA ALLAN:** Yes.

14 **MS FRASER BUTLIN:** What can you tell us about those, first
15 of all, in relation to a varicose vein across the knee?

16 **MS FIONA ALLAN:** Yes, I don't suffer from varicose veins but
17 I did get one right across my knee, and I went to my
18 doctor and I was referred immediately to a vascular
19 surgeon who did it that week because he was a bit
20 concerned about it. Always stick -- on every
21 pre-assessment, I've always mentioned my hep B carrier
22 status and it was all down in writing, and I get down to
23 the theatre and we were just about to go in and the
24 surgeon came out and literally his voice was so loud
25 saying that I hadn't advised him that I had hepatitis B,

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1 well-being, what can you tell us about that?

2 **MS FIONA ALLAN:** I deal with it fine now but at the time, as
3 it was 30-odd years ago, I was absolutely scared to tell
4 anybody at all and I was worried that I would infect
5 people and I was worried if I was holding their
6 children. I was paranoid about everything in the house
7 with the children and -- yeah, it did -- and it affected
8 my personal relationship in the house quite badly.

9 **MS FRASER BUTLIN:** Your marriage broke down.

10 **MS FIONA ALLAN:** Yes.

11 **MS FRASER BUTLIN:** And you say in your statement it was
12 largely because of your infected status and your
13 fatigue.

14 **MS FIONA ALLAN:** Yeah, yeah.

15 **MS FRASER BUTLIN:** Since then, you've not had any
16 significant relationships?

17 **MS FIONA ALLAN:** I've been too scared to just because I'm
18 diagnosed as a hep B carrier with chronic hepatitis and
19 I'm frightened to tell anybody. You know? My friends
20 know, et cetera, but it's very difficult to put that
21 across to somebody, so I've avoided it.

22 **MS FRASER BUTLIN:** In terms of your medical treatment, you
23 went to the Brownlee for tests for a few years but then
24 what follow-up have you had since then of your
25 hepatitis B?

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1 I was in a vascular area and I should be more mindful to
2 tell people. And it was the most horrendous thing.
3 I went in crying my eyes out into theatre. It was
4 awful.

5 **MS FRASER BUTLIN:** And, secondly, you needed a biopsy of
6 your womb.

7 **MS FIONA ALLAN:** Yes.

8 **MS FRASER BUTLIN:** And what happened then?

9 **MS FIONA ALLAN:** Again, I came back from theatre and one of
10 the nurses came up to change a dressing and I had been
11 bleeding and she looked at my notes and again -- and
12 raised her voice and said, "You could have let me know",
13 and I said, "It's in my records", and she said, "I've
14 got children to think about. You could have given me
15 the opportunity to wear gloves". And I knew the lady in
16 the bed next to me and it was so traumatic because I was
17 so embarrassed.

18 **MS FRASER BUTLIN:** Throughout your interactions with
19 clinicians originally in relation to the hepatitis B,
20 but subsequently in relation to fibromyalgia and other
21 difficulties you've had, has anyone offered you any
22 psychological support?

23 **MS FIONA ALLAN:** No, never, never.

24 **MS FRASER BUTLIN:** In terms of your situation today, what's
25 your position in relation to your condition today?

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1 **MS FIONA ALLAN:** I'm a bit more open about it now because
 2 I'm not ashamed and, because of all the investigations,
 3 people know that these things happen now. I just get on
 4 with my life and -- financially, it's very difficult.
 5 Financially it's difficult because, as soon as you've
 6 got that on your records, when I got separated from my
 7 husband I had to change my mortgage, et cetera, and all
 8 my premiums -- I had to cancel my critical life
 9 insurance because everything shot up, all my travel
 10 insurances are expensive. So it is difficult when you
 11 have to recognise it, yeah.
 12 **MS FRASER BUTLIN:** Do you now not have life insurance?
 13 **MS FIONA ALLAN:** I do have life insurance, yes. I do.
 14 Because that was long before -- I took that out when --
 15 obviously when I was younger.
 16 **MS FRASER BUTLIN:** But the critical life --
 17 **MS FIONA ALLAN:** I don't have the critical life insurance.
 18 I had to cancel that.
 19 **MS FRASER BUTLIN:** Thank you.
 20 Dot, so that everyone understands your situation,
 21 you were diagnosed with cancer of the tongue relatively
 22 recently.
 23 **MS DOROTHY WRIGHT:** Two years.
 24 **MS FRASER BUTLIN:** Two years ago and so your speech has been
 25 significantly affected.

13

1 **MS DOROTHY WRIGHT:** At the Weston Park Hospital.
 2 **MS FRASER BUTLIN:** Sorry, I didn't quite catch that.
 3 **MR TONY WRIGHT:** The Weston Park, in Sheffield.
 4 **MS FRASER BUTLIN:** Thank you. And needed further
 5 transfusions?
 6 **MS DOROTHY WRIGHT:** I did.
 7 **MS FRASER BUTLIN:** And further surgery?
 8 **MS DOROTHY WRIGHT:** Yes, I had a growth in my tummy.
 9 **MS FRASER BUTLIN:** Sorry, I didn't catch it.
 10 **MR TONY WRIGHT:** She had a growth in her tummy.
 11 **MS FRASER BUTLIN:** Sir, do we want to just take a short
 12 break?
 13 **SIR BRIAN LANGSTAFF:** Let's just have a short break, just
 14 for a few minutes. I'm sorry about this but that's what
 15 we are going to do.
 16 **MS FRASER BUTLIN:** Absolutely, thank you.
 17 **SIR BRIAN LANGSTAFF:** Say five minutes. 10.30 am.
 18 (10.24 am)
 19 (A short break)
 20 (11.15 am)
 21 **SIR BRIAN LANGSTAFF:** Yes.
 22 **MS FRASER BUTLIN:** Thank you, sir.
 23 Dot, just before the break we were talking about
 24 your diagnosis of having a chorea carcinoma and the
 25 surgery and chemotherapy you had. The chemotherapy

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REDACTED VERSION

1 **MS DOROTHY WRIGHT:** It has.
 2 **MS FRASER BUTLIN:** So I'm going to ask questions as normal
 3 but if we're struggling, Tony, your husband is going to
 4 help us.
 5 **MS DOROTHY WRIGHT:** He will.
 6 **MS FRASER BUTLIN:** You gave birth to your daughter in 1976.
 7 **MS DOROTHY WRIGHT:** Yes.
 8 **MS FRASER BUTLIN:** And experienced heavy bleeding after
 9 that.
 10 **MS DOROTHY WRIGHT:** Very.
 11 **MS FRASER BUTLIN:** Requiring two dilation and curettage
 12 procedures.
 13 **MS DOROTHY WRIGHT:** Yes, absolutely.
 14 **MS FRASER BUTLIN:** You were also given blood transfusions?
 15 **MS DOROTHY WRIGHT:** Can't remember how many, but it was
 16 a lot -- a lot of blood.
 17 **MS FRASER BUTLIN:** You bled again a few weeks later and
 18 underwent a hysterectomy?
 19 **MS DOROTHY WRIGHT:** I did. I was rushed in because
 20 I couldn't support another baby, so (inaudible).
 21 **MS FRASER BUTLIN:** And at that point it was discovered you
 22 had a chorea carcinoma.
 23 **MS DOROTHY WRIGHT:** Yes.
 24 **MS FRASER BUTLIN:** You underwent chemotherapy and
 25 radiotherapy?

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1 continued for three years and by this time it was also
 2 being done in Charing Cross Hospital.
 3 **MS DOROTHY WRIGHT:** Yes.
 4 **MS FRASER BUTLIN:** And throughout that time you received
 5 fairly regular blood transfusions.
 6 **MS DOROTHY WRIGHT:** I did, yes.
 7 **MS FRASER BUTLIN:** At some point in the three years, at
 8 Charing Cross Hospital you were told you'd contracted
 9 hepatitis B?
 10 **MS DOROTHY WRIGHT:** I was. The doctor just came and he said
 11 you have to go in side ward, "You have hepatitis B".
 12 Well, I don't know nothing about it. "But we haven't
 13 given you it, it's from somewhere else". End of. That
 14 was it.
 15 **MS FRASER BUTLIN:** And you were put in a ward on your own,
 16 in a room on the ward on your own, and how did that make
 17 you feel to discover that you'd contracted hepatitis B?
 18 **MS DOROTHY WRIGHT:** Well, I have an infectious disease,
 19 we've got a little girl at home, it frightened me. It
 20 was -- I was so sad, so frightened, and nobody would
 21 tell me anything. Nobody.
 22 **MS FRASER BUTLIN:** You were monitored for a few years and
 23 your levels remained steady.
 24 **MS DOROTHY WRIGHT:** Yes.
 25 **MS FRASER BUTLIN:** And over time the monitoring changed from

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1 weekly to fortnightly to monthly.
 2 **MS DOROTHY WRIGHT:** Yes.
 3 **MS FRASER BUTLIN:** Then in the mid-80s you were told you
 4 didn't need to be monitored any further.
 5 **MS DOROTHY WRIGHT:** I was, yes.
 6 **MS FRASER BUTLIN:** And at this point you had not been given
 7 any treatment for the hepatitis B.
 8 **MS DOROTHY WRIGHT:** Nothing, nothing.
 9 **MS FRASER BUTLIN:** We then go forwards to 1999 and you
 10 started having some bowel problems. And you are
 11 nodding.
 12 **MS DOROTHY WRIGHT:** Yes.
 13 **MS FRASER BUTLIN:** And the consultant noticed red spots on
 14 your body.
 15 **MS DOROTHY WRIGHT:** All over the place.
 16 **MS FRASER BUTLIN:** Which he said were from severe liver
 17 damage.
 18 **MS DOROTHY WRIGHT:** Yes.
 19 **MS FRASER BUTLIN:** You ended up on a ward which was mixed
 20 sex.
 21 **MS DOROTHY WRIGHT:** Yes, horrendous.
 22 **MS FRASER BUTLIN:** You said it was terrifying.
 23 **MS DOROTHY WRIGHT:** It was. There were drug addicts,
 24 alcoholics. One night I rang up Tony and I said,
 25 "Please get me out of here". The man next door was

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1 **MS DOROTHY WRIGHT:** But it did.
 2 **MS FRASER BUTLIN:** But it did.
 3 You've described in your statement that the
 4 transplant was life changing and your health was very
 5 different after it.
 6 **MS DOROTHY WRIGHT:** Very.
 7 **MS FRASER BUTLIN:** Can you tell us in what way your health
 8 changed?
 9 **MS DOROTHY WRIGHT:** I've always been a very active person
 10 and it sort of frustrated me because I couldn't do
 11 everything I wanted to. And I was frightened if I did
 12 do too much, it would affect my liver. Now, would it?
 13 So -- but you have to get on with it. I've been given
 14 a chance, I'm taking it.
 15 **MS FRASER BUTLIN:** And after the transplant you then
 16 received lamivudine, medication for the hepatitis B.
 17 **MS DOROTHY WRIGHT:** I did.
 18 **MS FRASER BUTLIN:** But after six years that was changed to
 19 tenofovir.
 20 **MS DOROTHY WRIGHT:** It was.
 21 **MS FRASER BUTLIN:** Because the lamivudine was causing damage
 22 to your kidney.
 23 **MS DOROTHY WRIGHT:** Yes.
 24 **MS FRASER BUTLIN:** And you've had to have stents fitted in
 25 your left kidney on three occasions, and the right

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1 weeing all over, swearing, shouting. That's no place to
 2 stay when you're ill.
 3 **MS FRASER BUTLIN:** And you were told in September or
 4 October 1999 that your liver was very seriously damaged?
 5 **MS DOROTHY WRIGHT:** I was, even more frightening.
 6 **MS FRASER BUTLIN:** And you went onto the waiting list for
 7 a transplant in January 2000.
 8 **MS DOROTHY WRIGHT:** No, I went on the list at Christmas time
 9 the year before.
 10 **MR TONY WRIGHT:** '99.
 11 **MS DOROTHY WRIGHT:** 1999. And wonderful doctors, wonderful.
 12 March?
 13 **MR TONY WRIGHT:** March '20.
 14 **MS DOROTHY WRIGHT:** March 20 -- 20 I got the call.
 15 **MS FRASER BUTLIN:** And you had the transplant in March 2000.
 16 **MS DOROTHY WRIGHT:** I did.
 17 **MS FRASER BUTLIN:** What were your feelings about having the
 18 transplant?
 19 **MS DOROTHY WRIGHT:** No choice: life or death. I just had to
 20 live. I have a child at home, who my parents had
 21 brought up really, and (inaudible) love her. I never
 22 knew if the transplant would work.
 23 **MS FRASER BUTLIN:** Sorry, I missed that.
 24 **MR TONY WRIGHT:** She says she never knew if the transplant
 25 would work, so that made her a lot worse.

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1 kidney had already been damaged by the radiotherapy and
 2 the chemotherapy --
 3 **MS DOROTHY WRIGHT:** It had.
 4 **MS FRASER BUTLIN:** And you continue, I think, to have liver
 5 checks every six months, and then you developed the
 6 tongue cancer two years ago.
 7 **MS DOROTHY WRIGHT:** Yes.
 8 **MS FRASER BUTLIN:** Has there been any discussion with your
 9 treating clinicians about any connection between the
 10 tongue cancer and the hepatitis B?
 11 **MS DOROTHY WRIGHT:** Well, I've never asked because they were
 12 trying their best to get me better and it does feel very
 13 mean of me to start saying, is it hep B because if it
 14 is, I want evidence. But I do think my kidneys have
 15 been affected by it. Whether this *[indicates]* has,
 16 I don't know.
 17 **MS FRASER BUTLIN:** You've also tried to obtain your medical
 18 records, but Charing Cross Hospital have said they don't
 19 have any for you?
 20 **MS DOROTHY WRIGHT:** There's no record of my ever being
 21 there, which is strange because every six months I sent
 22 a urine sample there to test my chorea carcinoma has not
 23 come back.
 24 **MS FRASER BUTLIN:** Thank you.
 25 Linda, you had a heart operation in April 1979 and

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1 it was a closed mitral valvotomy.
 2 **MS LINDA KITSON:** Yes.
 3 **MS FRASER BUTLIN:** And you needed a transfusion during the
 4 operation.
 5 **MS LINDA KITSON:** Yes, I did.
 6 **MS FRASER BUTLIN:** How did you come to find out that you had
 7 contracted hepatitis B?
 8 **MS LINDA KITSON:** That -- oh dear.
 9 I had a back operation done, a lot later on, and
 10 I didn't know it at the time but Mr Milner took blood
 11 samples and he sent it off for, apparently, hepatitis B,
 12 and the way I found out was I got a letter in the post.
 13 I didn't even know he had done it for hepatitis B.
 14 I didn't know what hepatitis B was.
 15 **MS FRASER BUTLIN:** And that was September 2017?
 16 **MS LINDA KITSON:** Yes.
 17 **MS FRASER BUTLIN:** So 38 years later.
 18 **MS LINDA KITSON:** Yes.
 19 **MS FRASER BUTLIN:** If we can just put the letter up that
 20 went to your GP, just so we can see what was said.
 21 It is WITN2641003, please, and it is page 3.
 22 We see in the middle of the letter, the main body of
 23 the letter:
 24 "Just to let you know that I have received the blood
 25 results back from Linda's blood tests that were

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1 **MS FRASER BUTLIN:** What were you told about the hepatitis B
 2 by them?
 3 **MS LINDA KITSON:** Not a great deal that somebody like me can
 4 understand. It is like that [*indicates*]. You know, you
 5 don't really understand it. But it just meant that
 6 I would have to have tests done every six months, scans
 7 on my liver and my kidneys. So that's what I do every
 8 six months. I have follow-ups.
 9 **MS FRASER BUTLIN:** I think you said in your statement that
 10 you were told that it wasn't affecting the liver but
 11 that it could do at a later stage.
 12 **MS LINDA KITSON:** Well, it is doing now. Apparently I have
 13 cysts on my liver, two cysts on my liver. And at first
 14 they thought I had a blockage in my kidney, but on the
 15 last scan they did they said it wasn't a blockage, it is
 16 cysts as well.
 17 **MS FRASER BUTLIN:** Just staying in the 2017 and those first
 18 appointments with the hepatologists, what were you
 19 advised to do in relation to precautions to take? Were
 20 you advised about anything in relation to contraceptions
 21 or toothbrushes or anything of that sort?
 22 **MS LINDA KITSON:** No, nothing.
 23 **MS FRASER BUTLIN:** What understanding were you given about
 24 the long-term impact of the hepatitis B?
 25 **MS LINDA KITSON:** It wasn't supposed to affect you. You

23

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1 performed when she came to see me in clinic on
 2 11 September. To my surprise, she had positive results
 3 for hepatitis B surface antigen, hepatitis B core
 4 antibody and hepatitis B e antibody. The hepatitis B
 5 core IGM antibody, the hepatitis B e antigen and the
 6 hepatitis C antibodies were not detected. She had also
 7 no evidence of HIV antibody or antigen. Our laboratory
 8 told me that the results are consistent with chronic
 9 Hepatitis B infection but that we need to perform
 10 confirmatory tests."
 11 Lots of medical language, but indicating you had
 12 chronic hepatitis B. Then this:
 13 "Interestingly enough, Linda's U&E's [urea and
 14 electrolytes], full blood count, liver function test,
 15 bone chemistry and Victim D levels were all largely
 16 normal although her urea was slightly raised at 8.1."
 17 There's then a recommendation for further tests to
 18 be undertaken.
 19 The letter that you received from the consultant,
 20 obviously that was to your GP but you received a letter,
 21 came as a complete surprise to you, is that right?
 22 **MS LINDA KITSON:** Yes, yes.
 23 **MS FRASER BUTLIN:** You went to see your GP and then you were
 24 referred to a hepatologist.
 25 **MS LINDA KITSON:** Yes, that's right.

22

1 know, you were supposed to be okay, but apparently you
 2 are not, are you, because all of a sudden, there are
 3 these cysts appearing, which -- are they connected?
 4 Because nobody has told me. Nobody has actually said to
 5 me, "Linda, you have got these cysts because of your
 6 hepatitis B". It is just, "You have got the cysts and
 7 you have got the cysts on your kidneys", but no reason
 8 why they are there.
 9 **MS FRASER BUTLIN:** At the initial stage of when you were
 10 being told about the hepatitis B, what was the message?
 11 That it was okay?
 12 **MS LINDA KITSON:** Yeah, you could live with it. "You can
 13 live with it". You can't, but, according to them
 14 because they haven't got it, "It's all right because
 15 I haven't got it, but you can live with it, it is fine".
 16 **MS FRASER BUTLIN:** And just thinking about the time between
 17 the heart operation in 1979 and the diagnosis in 2017,
 18 what's your physical health been like?
 19 **MS LINDA KITSON:** Normal I would say. You know, I try and
 20 keep active as I can. I'm on a lot of tablets for my
 21 back now and everything, but, yeah, I try to keep
 22 active.
 23 **MS FRASER BUTLIN:** In your statement you have talked about
 24 having fatigue.
 25 **MS LINDA KITSON:** Yes.

24

1 **MS FRASER BUTLIN:** And aches and pains that are fairly
2 unexplained.
3 **MS LINDA KITSON:** Yes.
4 **MS FRASER BUTLIN:** What can you tell us about those?
5 **MS LINDA KITSON:** They are just that, they are pains that --
6 and tiredness is an awful thing, but, you know, people
7 go, "Well, you are 70, Linda, you are going to get
8 tired", you know, "You are 65". Whenever, you know, you
9 say you are tired, "Well, you are going to get tired
10 because you are old".
11 **MS FRASER BUTLIN:** And when you were younger, post-heart
12 operation, were you feeling that fatigue then as well?
13 **MS LINDA KITSON:** Yes, and breathlessness and everything,
14 yeah.
15 **MS FRASER BUTLIN:** And in 1988 you were investigated for
16 some aches and pains and they said at that point it was
17 all psychological?
18 **MS LINDA KITSON:** Yes.
19 **MS FRASER BUTLIN:** June 1998 you were seen by the
20 cardiologists because you had unexplained tiredness and
21 weight loss, is that right?
22 **MS LINDA KITSON:** Yes, that's right.
23 **MS FRASER BUTLIN:** And 1996 you saw a haematologist because
24 you had some unexplained bruising.
25 **MS LINDA KITSON:** Yes.

25

1 **MS FRASER BUTLIN:** And in your statement you say that you
2 are very worried about what happened in those years?
3 **MS LINDA KITSON:** Very much so. Very much so. Yeah. As
4 I say, it is the operations that you've had that nobody
5 would have known about. I've had my toes done and, you
6 know, all such silly things -- like the hysterectomy.
7 Did I have that done afterwards? Yeah. Stuff like
8 that, that you just wonder how many more people have you
9 passed it on to? You know, does it just go on in
10 a vicious circle? Yes, it is hepatitis B but it is
11 still -- it is not nice. It is really not nice.
12 **MS FRASER BUTLIN:** You have continued to have follow-up at
13 the hepatology clinic every six months.
14 **MS LINDA KITSON:** Yes.
15 **MS FRASER BUTLIN:** You have just said now that there are
16 cysts on the liver and on the kidneys.
17 **MS LINDA KITSON:** That's right.
18 **MS FRASER BUTLIN:** Throughout that time that you have been
19 monitored, what have the hepatitis B levels been doing?
20 **MS LINDA KITSON:** Reasonably staying the same, yes. They
21 are quite pleased with the levels, as far as I know.
22 You don't get to see anybody. You don't get to talk
23 to a doctor. You don't actually -- you know, you can't
24 talk to a doctor and say, "What is this?" You just get
25 an appointment, you go get your scan done and then that

27

1 **MS FRASER BUTLIN:** But again nothing was found?
2 **MS LINDA KITSON:** Nothing, no.
3 **MS FRASER BUTLIN:** Would it be fair that since 1979 until
4 now, there has been an ongoing difficulty with fatigue?
5 **MS LINDA KITSON:** Yes.
6 **MS FRASER BUTLIN:** You have said in your statement as well
7 that you have been very worried about infecting others
8 **MS LINDA KITSON:** That's right.
9 **MS FRASER BUTLIN:** Can you tell us anything about that?
10 What do you feel?
11 **MS LINDA KITSON:** Well, you feel like, I wonder how many
12 times I have cut myself and somebody has come to help
13 me? Have I infected that person? I have had quite
14 a few operations after the heart operation. Have
15 I infected anybody in theatre? You know, just -- you
16 don't know. Have you passed -- well, I couldn't have
17 gone and given blood but often I did think about giving
18 blood, but at least I know that they would not have
19 taken the blood and probably I would have found out
20 sooner. Yes, if I'd have gone and given blood I might
21 have found out sooner. But, yeah, it's just, I don't
22 know, hard. Very hard.
23 **MS FRASER BUTLIN:** Because there was 38 years where you
24 didn't know that you were infected?
25 **MS LINDA KITSON:** No.

26

1 scan gets sent back to whoever, but whoever gets the
2 scan doesn't ring you.
3 **MS FRASER BUTLIN:** So how do you find out the information
4 from your scan?
5 **MS LINDA KITSON:** Actually the lady that did my scan told
6 me. She was really chatty about it and she said that,
7 "They said before they thought you had a blockage in
8 your kidney but I'm 99% certain that it is cysts that's
9 growing on your kidney", so that's how I found out.
10 **MS FRASER BUTLIN:** Have you had a discussion at all with the
11 clinicians about what those cysts mean?
12 **MS LINDA KITSON:** No. They just say it is nothing to worry
13 about.
14 **MS FRASER BUTLIN:** In terms of understanding your infection,
15 you asked for further information to be sought to
16 understand the connection between your infection and the
17 transfusion that you were given; is that right?
18 **MS LINDA KITSON:** Yes.
19 **MS FRASER BUTLIN:** I want to just look at some of the
20 documents that deal with that. If we could go to
21 WITN2641011, and it's page 2, please. It's a letter
22 from the gastroenterologist to the haematologist at
23 Leeds General Infirmary and it simply says this:
24 "I write regarding the above lady. She has
25 presented with the hepatology services here in Bradford

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1 with abnormal LFTs and has gone on to have a liver
 2 screen which has suggested she has hepatitis B virus."
 3 That's not quite how it happened, is it, Linda?
 4 **MS LINDA KITSON:** No, it's not.
 5 **MS FRASER BUTLIN:** "She doesn't have any clear risk factors
 6 for contracting this, other than having a blood
 7 transfusion in 1979 at Leeds General Infirmary when she
 8 had a valvuloplasty for mitral stenosis. The
 9 haematologist here in Bradford, Dr Adrian Williams, who
 10 I believe is the transfusion lead, has suggested that
 11 I get in touch with you to see if we can investigate
 12 this matter a little further. Mrs Kitson is keen to be
 13 kept informed of any investigation into whether her
 14 hepatitis B she received at this time."
 15 You were wanting to track the transfusion you had
 16 received and your hepatitis B; is that right?
 17 **MS LINDA KITSON:** Yes, that's right.
 18 **MS FRASER BUTLIN:** The registrar was then told to contact
 19 the NHS Blood and Transplant and then we have a letter
 20 from the specialist nurse asking for it to be followed
 21 up. WITN2641014, please. Again, it's page 2. Just the
 22 last paragraph. It's a letter to you:
 23 "I have spoken to the doctor that you saw and he has
 24 confirmed that he remains investigating LGI and your
 25 blood transfusion and we will see you back in clinic in

29

1 **MS DOROTHY WRIGHT:** I made myself an appointment with an
 2 infectious diseases' consultant, and when I asked at my
 3 appointment, "What's happening to me? What will happen?
 4 And he was very good and told me more or less what I may
 5 need to know. But life was difficult because with the
 6 littlest scratch or graze on me, on everyone else, I'm
 7 covering it up and cover it up straightaway, but so that
 8 I never passed it on. I felt like a leper at times.
 9 But my family got used to it and my daughter and son
 10 would say, "I've got a scratch", and I'd say, "We'll put
 11 something on that".
 12 **MS FRASER BUTLIN:** You described feeling like a leper
 13 sometimes, and both Linda and Fiona, you both nodded.
 14 Do you want to tell us more about that?
 15 **MS LINDA KITSON:** It is just, people actually, when they
 16 find out, because there's not a lot of education about
 17 hepatitis B, they just presume that you are either
 18 taking drugs or you are a prostitute.
 19 **MS DOROTHY WRIGHT:** Yes.
 20 **MS LINDA KITSON:** You are either one or the other. You just
 21 can't be a family, you know, or a mistake, you are
 22 either -- "Oh, I didn't know you took drugs, Linda?"
 23 "Well, I don't, love, no. I'm sorry to disappoint
 24 you, but I don't take drugs. It's not my fault I've got
 25 this disease."

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1 6 months' time."
 2 After that letter, did you hear anything further
 3 about any investigations in relation to the transfusion
 4 you'd received?
 5 **MS LINDA KITSON:** No, nothing.
 6 **MS FRASER BUTLIN:** Have you had any further discussion with
 7 anyone about what work they're doing to trace the
 8 transfusion?
 9 **MS LINDA KITSON:** No, nothing at all.
 10 **MS FRASER BUTLIN:** Thank you.
 11 I want to move to a more thematic discussion, if
 12 I may, with the three of you. All of you have discussed
 13 periods of physical ill health after receiving your
 14 transfusions or as an ongoing issue. What discussions
 15 have you had with doctors about the connection between
 16 those bouts of ill health, the ongoing fatigue for two
 17 of you, and your hepatitis B?
 18 **MS FIONA ALLAN:** Nothing, no. My daughter's often said
 19 should you never have had a liver scan or -- and I've
 20 just never been offered anything like that and it's
 21 always just been put down to you take tramadol for
 22 a spine condition; I have osteoporosis; I have
 23 osteoarthritis, and it's always my medication that's put
 24 down to tiredness and "maybe you need to have a break"
 25 but never anything about hepatitis B.

30

1 **MS FIONA ALLAN:** And because I did find out years ago, and,
 2 again, every liver complaint was down to hepatitis --
 3 sorry, to AIDS or HIV, I was just so scared to even talk
 4 about it to anybody. And like Linda was saying, it was
 5 just constant -- I still, to this day -- I could bring
 6 out my bag -- I've always got a pack of plasters with
 7 me, because I'm terrified in case I get a little scratch
 8 or anything, yeah.
 9 **MS FRASER BUTLIN:** And what's the effect of that been, that
 10 hepatitis B been on your mental well-being?
 11 **MS LINDA KITSON:** It hasn't helped at all, no.
 12 It is just another load to bear because you just --
 13 yeah, you agree.
 14 **MS DOROTHY WRIGHT:** Absolutely (inaudible) to describe it
 15 **MS FRASER BUTLIN:** Sorry, I didn't catch that?
 16 **MR TONY WRIGHT:** She said it's a good way to describe it.
 17 **MS DOROTHY WRIGHT:** Another load to bear.
 18 **MS LINDA KITSON:** Personally speaking, I don't know about
 19 these two, but I feel like hepatitis B is put at the
 20 bottom of the pile. We are under HIV, we're under
 21 hep C. We are there, we're not anybody. When it is on
 22 the telly it is always HIV and hep C that's mentioned.
 23 B is never mentioned. And I don't understand why,
 24 because people are suffering with it. You know, we are
 25 suffering.

32

1 And can I go back to a point about, I never knew
2 that there was tablets. Nobody has ever said to me
3 there is medication you can take for it. I know I'm
4 skipping back to something but I've just remembered. So
5 I didn't even know that you could take tablets for it.
6 I don't know whether I don't need to take them but it is
7 still important that I didn't know it until somebody
8 mentioned it earlier on.

9 **MS FRASER BUTLIN:** Fiona, you are nodding to that.

10 **MS FIONA ALLAN:** Yeah. I mean, I was just saying at the
11 break, I can't believe that there could have been
12 counselling available. I feel my life would have been
13 a lot more different, just in terms of lifestyle and
14 knowing it is okay to meet -- I mean, I'm just
15 constantly being asked why I have never moved on in
16 a relationship or -- and you don't want to explain to
17 anybody, you know, so ... But, again, at the time, it
18 was a big taboo and I thought I can't tell anybody.

19 **MS FRASER BUTLIN:** And you are reflecting there on the lack
20 of psychological support or even information perhaps?

21 **MS FIONA ALLAN:** Yes. Everything was all, "You are lucky
22 you are still here", and that was all you ever got.
23 So ...

24 **MS FRASER BUTLIN:** And that question of being lucky, is that
25 something, Linda and Dot, that you also --

33

1 **MS LINDA KITSON:** No.

2 **MS FRASER BUTLIN:** Or any offer of psychological support in
3 relation to hepatitis B?

4 **MS FIONA ALLAN:** No.

5 **MS LINDA KITSON:** No.

6 **MS FRASER BUTLIN:** We picked up, Fiona, with you about
7 insurance and the costs of insurance. Is that
8 an experience, Linda and Dot, that you've had as well?

9 **MS LINDA KITSON:** Well, I can't get insurance anyway. It is
10 very difficult for me to get insurance because I have
11 a heart condition, and God forbid I might drop dead
12 soon. You know, like, you could get run over by a bus
13 but because I've got a heart condition I can't get
14 insurance. So it really, really is difficult. Now on
15 top of that I have got hep B as well so I suppose no.
16 And I'm old.

17 **MS DOROTHY WRIGHT:** No. I bought a life insurance but
18 because Tony was with the post office at this time, we
19 do have travel insurance with them. They are very good
20 and still use them. A bit more expensive, but at least
21 I can go places. So I'm fortunate in that way.

22 **MS FRASER BUTLIN:** As hepatitis B sufferers, you are
23 ineligible for the financial assistance schemes that the
24 Inquiry has spoken about in relation to HIV and
25 hepatitis C. What impact has that had on you?

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1 **MS DOROTHY WRIGHT:** I got told the same. "Lucky". I don't
2 think so. Maybe "lucky" that I have a liver
3 transplant -- "lucky" that I have got hep B. Why? Why
4 lucky? It is very, very unfortunate. No life is
5 straightforward, it was never going there, it was round
6 like that and I'm just (inaudible) and I have to get on
7 with it, otherwise I would be a recluse. And that's not
8 nice. That's not me.

9 **MS LINDA KITSON:** Yes, am I lucky that somebody didn't do
10 their job right and didn't bother to look and check
11 everything, and "Oh, it is okay"? Is that why? They
12 mean you are lucky you are alive? No. I'm lucky
13 that -- somebody should have done their job right in the
14 first place. And why, when I had my heart operation
15 done in 1979 and I go back every year for checkups does
16 nobody ever think then, two years later, "Oh, maybe this
17 lady needs a blood test because it was '79, it was when
18 the infected blood was coming through"? I have been
19 going to the LGI since 1979 every year and nobody ever
20 thought about doing a blood test on me. I could have
21 known years ago. But it is all down to, "Well, it's not
22 my fault, it is not me".

23 **MS FRASER BUTLIN:** And since you have all been diagnosed
24 none of you have received psychological support in
25 relation to the hepatitis B?

34

1 **MS FIONA ALLAN:** Quite demoralising, actually. I never
2 really ever thought about financial impact at all or --
3 I always did make a joke that if it ever did come to
4 fruition, somebody would inherit it because it --
5 I wouldn't be here to tell the tale. But it is a bit
6 demoralising because it -- as Linda said, it makes you
7 feel like it wasn't that important what's happened to
8 you. So, yeah.

9 **MS LINDA KITSON:** Yeah, I agree.

10 **MS FRASER BUTLIN:** Dot, do you want to add anything on that?

11 **MS DOROTHY WRIGHT:** No, thank you.

12 **MS FRASER BUTLIN:** Linda, anything else you want to add to
13 that?

14 **MS LINDA KITSON:** No. I have never gone down the route of
15 looking into help or anything. Just -- like it is
16 supposed to be, you just get on with it.

17 **MS DOROTHY WRIGHT:** That's so. You have to get on with it.
18 Whatever happens (inaudible) I have thought that I want
19 to live, even though it is very difficult sometimes.
20 But we are here, telling our stories out there.

21 **MR TONY WRIGHT:** I don't know whether I'm allowed to say,
22 but when Dot was in London, I was travelling from
23 Nottingham to London on a regular basis, and never ever
24 has anybody ever called and say you can apply for this
25 or apply for that. It was all out of our own pocket all

36

1 the time.

2 **MS FRASER BUTLIN:** Sir, those are the questions I have for
3 the panel. I don't know if you have any questions you
4 would like to ask them?

5 **SIR BRIAN LANGSTAFF:** Well, just this, two of you had the
6 initial transfusions most probably which caused your
7 hepatitis B round about the time of childbirth or
8 associated with childbirth. Each of you has described
9 being very tired, and you have described how conditions
10 and health professionals have dealt with that over the
11 years. So I'm going to ask you, do you think this is
12 particularly because you happen to be women, because you
13 have been told it is because you have got a child, you
14 have been told it is because of the menopause, you have
15 been told because it is your age; is there something
16 about being women that you think is reflected in this or
17 do you think it just happens to be what the doctor will
18 say to anyone, "You've got children, you are going to be
19 tired"? That may be said more to a woman than a man?

20 **MS LINDA KITSON:** I can't imagine them saying it to Peter,
21 no. No, I can't imagine them saying it -- no, I think
22 it is because you are women. Yeah. Definitely. That's
23 my opinion anyway.

24 **MS FIONA ALLAN:** I have never even thought about it that way
25 until you've just stated all the different things and

37

1 I just don't like being put at the bottom of the pile.
2 I think -- I know it is not as bad as hep C and I know
3 it is not as bad as HIV, but it is still bad to me. And
4 I don't like being put at the bottom of the pile.
5 I like -- I want to be on an equal footing.

6 **MS DOROTHY WRIGHT:** Yes, it's life changing.

7 **MS FRASER BUTLIN:** I didn't catch --

8 **MR TONY WRIGHT:** It is life changing.

9 **MS LINDA KITSON:** It is life changing. It's something that
10 you -- you know, you've gone from being a normal person
11 to all of a sudden you have got this rotten disease
12 inside of you and it changes your life. It really does
13 change your life. You know? And it is not fair. We
14 didn't ask for it. And it is somebody's incompetence.
15 And somebody should be made to answer. Somebody should
16 be made to say, "It was me, it was my fault, and I'm
17 sorry". But he's not got it or she's not got it, so it
18 doesn't matter, and "You are only hepatitis B, don't
19 worry about it". I'm getting on my soap box, sorry.

20 **SIR BRIAN LANGSTAFF:** You don't need to apologise.

21 **MS LINDA KITSON:** I'm sorry.

22 **SIR BRIAN LANGSTAFF:** No, it is your chance to say what you
23 really think, and it is important to hear what you
24 really think.

25 **MS LINDA KITSON:** I do think that we are put to the bottom.

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1 thought, yeah, it possibly could be.

2 **MS DOROTHY WRIGHT:** What was I going to say? I have spoken
3 to the doctors about it, but they tend to say, "Well,
4 we're at where we're at at the moment, here (inaudible),
5 you may as well just go home and sort yourself out".
6 That's what happened.

7 **SIR BRIAN LANGSTAFF:** I didn't quite catch that.

8 **MR TONY WRIGHT:** When she went to the doctors, when she's
9 felt tired and not very well, they've just said, "Go
10 home, you know, sort it out yourself and come back in
11 a fortnight".

12 **SIR BRIAN LANGSTAFF:** Yes.

13 **MR TONY WRIGHT:** A lot of the time they hadn't known what it
14 was that was wrong with her.

15 **SIR BRIAN LANGSTAFF:** That's all that I ask.

16 **MS FRASER BUTLIN:** Linda, is there anything else you would
17 like to say?

18 **MS LINDA KITSON:** No, I don't think so. I just -- I just
19 don't like being at the bottom of the pile. I would
20 like us all to be equal. We are all in this together,
21 HIV, C and B are all affected. We shouldn't be at the
22 bottom of the pile. I feel really, really dirty. I can
23 go -- if I'm dirty from running outside, I can go get
24 a shower. I cannot get rid of this blood, it is there,
25 it is there to stay until I die, and I feel dirty. And

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1 As I say, it is mentioned on TV about -- they will
2 mention HIV, they will mention hepatitis C, but they
3 will never ever add -- like, mention B. And it is
4 a disease, it should be mentioned -- we should be all
5 together. Definitely.

6 **MS FRASER BUTLIN:** Dot, is there anything you'd like to add?

7 **MS DOROTHY WRIGHT:** About that, no.

8 What I would like to say is a massive thank you to
9 Sir Brian and all the team for working so hard for so
10 long to get us here and now our voices are getting heard
11 at long last. Whether it's -- I'm sorry. It is too
12 late for a lot of people but we're here, we're fighting
13 our corner and we're given that space to do that. So
14 thank you to everybody. Thank you.

15 **MS LINDA KITSON:** Totally agree.

16 **MS FIONA ALLAN:** I was just going to add to what Linda had
17 said as well about feeling at the bottom of the heap and
18 you don't matter.

19 [... redacted ...]

20 I've still got the stigma. I feel I've have still
21 got the -- I can't clear it out my head now. So much as
22 hepatitis C I do agree was very serious, this has still
23 impacted on me in a bigger scale.

24 **SIR BRIAN LANGSTAFF:** Can I thank you all, but let me start
25 by thanking you, Trish, for being here to support Linda.

40

1 Thank you, Tony, for being here to support Dot and to
 2 interpret as you have done on occasions. The fact that
 3 you had to interpret but Dot is here to give her
 4 evidence -- the difficulties of giving evidence are
 5 plain to all of us who have done it, who have seen it,
 6 it may not be appreciated by all but I do believe it is
 7 never easy to give evidence, and perhaps it is a timely
 8 reminder that we took a slight delay this morning,
 9 because it isn't easy, and I want to really say how much
 10 I admire your courage in being here to say to everyone
 11 what is plainly deeply personal and a chance to say what
 12 you really feel about what has happened to you. It is
 13 very valuable. Thank you very much indeed.

14 Now, you are free to stay or go. If you stay, you
 15 will have to wait until 2.00 when we have our next
 16 witness, Sally Davies, if she's well enough to be here.

17 **MS FRASER BUTLIN:** I've had a message to say she is well
 18 enough and she will be joining us at 2.00.

19 **SIR BRIAN LANGSTAFF:** One of the reasons she was put to this
 20 afternoon because she needs perhaps the morning. So,
 21 you are very welcome to stay if you wish. You are
 22 absolutely free to go. Thank you once again. It will
 23 be, of course, 2.00 that we start again.

24 (11.53 am)

(The short adjournment)

41

1 were unwell after that. What can you tell us about your
 2 health at that point?

3 **MS SALLY DAVIS:** At that point, it was clear that I had
 4 health issues, but it wasn't clear that there was any
 5 real lasting strength in them. There was a sort of
 6 pedal to get well again kind of feel. And, being young,
 7 I think one was more optimistic that you could throw it
 8 off.

9 **MS FRASER BUTLIN:** And in terms of how you felt, you've
 10 described in your statement feeling extremely broken.
 11 You weren't sure if you were ill or depressed or what
 12 was happening; is that right?

13 **MS SALLY DAVIS:** Yes, it is.

14 **MS FRASER BUTLIN:** Can you tell us any more of how you were
 15 feeling at that point?

16 **MS SALLY DAVIS:** I think the most difficult thing was
 17 literally finding the energy that I could use to get
 18 better and look after children and have miscarriages and
 19 all of the things that were compacted together -- so
 20 possibly even masked how difficult it really was.

21 **MS FRASER BUTLIN:** You became pregnant again and at that
 22 point your gynaecologist did a blood test, and what did
 23 he tell you about those results?

24 **MS SALLY DAVIS:** He said there were -- there was good news
 25 and bad news. And the good news was that I was

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1 (2.00 pm)

2 **SIR BRIAN LANGSTAFF:** Good afternoon, Sally. Thank you for
 3 being here with us. In a moment, Ms Fraser Butlin will
 4 ask you the questions but first Mary will ask you to
 5 take the affirmation.

6 Mary.

7 **MS SALLY JANINE DAVIS (affirmed)**

8 **Questioned by MS FRASER BUTLIN**

9 **MS FRASER BUTLIN:** Sally, I want to start by asking you some
 10 questions about how you came to be infected with
 11 hepatitis B.

12 **MS SALLY DAVIS:** Right.

13 **MS FRASER BUTLIN:** You were pregnant and started to bleed at
 14 16 weeks' gestation; is that right?

15 **MS SALLY DAVIS:** Yes.

16 **MS FRASER BUTLIN:** And when you were admitted into hospital,
 17 the foetal heartbeat couldn't be found and so you needed
 18 to have an evacuation of your uterus?

19 **MS SALLY DAVIS:** Yes, that's true.

20 **MS FRASER BUTLIN:** And you haemorrhaged and required
 21 a transfusion?

22 **MS SALLY DAVIS:** Yes.

23 **MS FRASER BUTLIN:** That was in November 1978?

24 **MS SALLY DAVIS:** Yes.

25 **MS FRASER BUTLIN:** And your statement describes that you

42

1 pregnant, because I had had a few pregnancies that were
 2 sad, but the bad news was that I had taken on a disease,
 3 which in those days was very serious but wasn't
 4 necessarily serious enough to reach me through a GP.

5 **MS FRASER BUTLIN:** And that was the hepatitis B?

6 **MS SALLY DAVIS:** Yes.

7 **MS FRASER BUTLIN:** Was he able to tell you anything of what
 8 he understood the source of the infection to be?

9 **MS SALLY DAVIS:** No, there was nothing given, as far as
 10 I know, that included any real information, or even soft
 11 information, because people weren't asking the
 12 questions. I didn't ask them until later when
 13 I realised things weren't quite right. But I think the
 14 dearth of information, the time of life in which it
 15 occurred, probably dictated the way it is now.

16 **MS FRASER BUTLIN:** You were pregnant in 1981 with your
 17 daughter and at 32 weeks of that pregnancy you were
 18 admitted to hospital. When you were admitted, how did
 19 the staff treat you?

20 **MS SALLY DAVIS:** Well, that's an interesting question
 21 because it's connected to how it all works and, I must
 22 say, it was very, very difficult to put it together when
 23 I went in because it looked as if I was taking my
 24 daughter to a prison rather than a hospital. It was
 25 genuinely quite frightening. But the fear probably fell

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1 on me because she was too young to note.

2 **MS FRASER BUTLIN:** And you've described in your statement

3 that when she was born all the medical professionals

4 were suited up in gowns?

5 **MS SALLY DAVIS:** Yes, yes, which indicated, I think, that

6 they knew there was an issue, but we didn't know there

7 was an issue, so automatically you have less chance of

8 creating a good outcome or even hassling anyone into

9 trying to work out what's wrong with you.

10 **MS FRASER BUTLIN:** You also had a son, and after having the

11 children you then trained as a barrister?

12 **MS SALLY DAVIS:** Yes.

13 **MS FRASER BUTLIN:** What was your health like at that time?

14 **MS SALLY DAVIS:** Well, probably worse than I thought because

15 [... redacted ...]. And that was obviously -- experts

16 know better than I -- it is quite -- quite a frightening

17 outcome.

18 **MS FRASER BUTLIN:** [... redacted ...]

19 **MS SALLY DAVIS:** Yes, it was really quite tough. But I kind

20 of removed all my bedding and anything I could find and

21 took them off to the hospital and sat in there for

22 two weeks, so we did it together really.

23 **MS FRASER BUTLIN:** After having the children you trained as

24 a barrister, and what happened after a couple of years

25 of working as a barrister, in terms of your health?

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1 **MS SALLY DAVIS:** Well, there was more -- there was obviously

2 more reason to look at what was going on, because it

3 didn't change. When something doesn't change, you

4 really have to look and see why. And I suppose this was

5 an extreme case of me worrying. Again, it created huge

6 amounts of worry.

7 **MS FRASER BUTLIN:** When you say your health didn't change,

8 is that because you were continuing to feel unwell --

9 **MS SALLY DAVIS:** Yes.

10 **MS FRASER BUTLIN:** -- and fatigued and not really picking

11 up?

12 **MS SALLY DAVIS:** It didn't -- it just was an issue that you

13 couldn't put right yourself. And there were no obvious

14 outcomes in the environment that could help you to

15 identify or go towards the right -- possibly -- person.

16 **MS FRASER BUTLIN:** After two years in practice you decided

17 that the physical demands of being a barrister, carrying

18 files and travelling the country, were too much for you?

19 **MS SALLY DAVIS:** It was very hard. And having had

20 a difficult baby route, it was hard to not recognise

21 that actually I was doing damage.

22 **MS FRASER BUTLIN:** So you transferred into the Civil

23 Service.

24 **MS SALLY DAVIS:** Yes, which was a really good and happy

25 move.

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1 **MS FRASER BUTLIN:** But during your time at the Civil Service

2 you continued to have absences from work?

3 **MS SALLY DAVIS:** There were enormous times of exhaustion and

4 semi-illness. I don't really know how you describe it,

5 but it's not got its own slot but it has got its own

6 sense of being fragile and not quite making the mark

7 which you think you could do. That was also quite

8 irritating actually. You had to accept a different

9 sense of what would be considered successful. And it

10 was obviously the children that won, I'm happy to say.

11 **MS FRASER BUTLIN:** You speak in your statement of not being

12 able to reach your full potential in your career. What

13 can you tell us of how that felt and what you faced?

14 **MS SALLY DAVIS:** That really was a dominant daily feeling,

15 because it had been so hard to actually do ten exams in

16 five days, over three hours each, and I really did put

17 heart and soul in it because I felt lucky that I had the

18 two children I did have and so easily could not have

19 had, that I almost felt that this was more of a sort of

20 gift and I wouldn't give this up because this was

21 a thank you. But it was a problem to me to have to do

22 what seemed like double the work other people had to do

23 to keep it straight and on the road. And I felt --

24 I feel that I did more or less manage it.

25 **MS FRASER BUTLIN:** And your ill health has continued.

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1 **MS SALLY DAVIS:** It has been a saga that just every time you

2 think you might be all right, you are not. And I hadn't

3 even, until recently, until all of you wonderful people

4 had set into your work, I hadn't really looked at what

5 it was doing to me in the long-term. And these things

6 really don't come out straightaway, and the fact that

7 I was re-diagnosed and re-diagnosed, and diagnosed

8 again, and again, was also a complicated aspect of how

9 you feel about yourself.

10 **MS FRASER BUTLIN:** If we just unpack those diagnoses. In

11 the 2000s you developed skin problems. What can you

12 tell us about those?

13 **MS SALLY DAVIS:** Well, only that I had skin problems, both

14 in having Henry and afterwards, and they were random and

15 extreme, which is not an easy situation either. No one

16 could find a cause. It wasn't as if everyone was

17 solving it and I was running a different body, we were

18 all running the same problem.

19 **MS FRASER BUTLIN:** And you were diagnosed or misdiagnosed

20 with rheumatoid arthritis.

21 **MS SALLY DAVIS:** That was almost as shocking as having it,

22 just being told about it, because I had arranged my life

23 around the fact that it wasn't going to be easy. I was

24 divorced, I didn't have spare energy and I needed to do

25 X, Y and Z to even begin, and then suddenly it was as

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1 if, after the three years or more that I'd carefully
2 done the diet, and the child, and things that we all do,
3 but somehow this seemed a bit more difficult, and then
4 in one night I was told, "Well, actually, you know, you
5 don't have it." I can see it in the eyes. "You have
6 Parkinson's disease".

7 Which, then I had to quite carefully pick at it,
8 that I didn't say I didn't like it because I didn't like
9 it, it was actually a worry that they might be right.

10 **MS FRASER BUTLIN:** So initially the diagnosis was rheumatoid
11 arthritis and you were given very strong medication for
12 that.

13 **MS SALLY DAVIS:** Yes, for many years. Fortunately I don't
14 take easily to drugs and I'm always refusing them and
15 upsetting everyone, but had I taken genuinely their
16 rheumatoid arthritis drugs I would be in trouble by now.

17 **MS FRASER BUTLIN:** Then in the mid-2010s you were
18 re-diagnosed and told it was fibromyalgia you were
19 suffering from.

20 **MS SALLY DAVIS:** Which I didn't listen to at all, I have no
21 idea whether I've got fibromyalgia. I'm not treated for
22 it or anything.

23 **MS FRASER BUTLIN:** Then you were diagnosed with Parkinson's
24 disease.

25 **MS SALLY DAVIS:** Yes. And then I had to lift my head

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1 **MS FRASER BUTLIN:** And you've then had relatively regular
2 blood tests, liver function tests, and an ultrasound
3 every year?

4 **MS SALLY DAVIS:** Yes.

5 **MS FRASER BUTLIN:** And I think that --

6 **MS SALLY DAVIS:** But they're quite serious investigations.
7 I don't think they just stand up as being a bit of
8 a nuisance.

9 **MS FRASER BUTLIN:** And what is the condition of your liver?

10 **MS SALLY DAVIS:** Well, you will know more than I but it's
11 done on a step basis and I'm carefully monitoring the
12 steps clearly and it started to go up. I did all
13 I could, you know, the no drink and the no food and sit
14 back and it will be all right. But I think the worry
15 with that was mostly that I got another one. I'm very
16 suspicious, I'm afraid.

17 **MS FRASER BUTLIN:** And the liver what you've been told,
18 I think, from your statement, is that your liver is
19 cirrhotic, there is cirrhosis.

20 **MS SALLY DAVIS:** I think the cirrhosis bit is a little bit
21 over-diagnosed and it's had two diagnoses, one of each.
22 So it's obviously not a happy liver but it's not
23 totally, you know, lost as a cause yet.

24 **MS FRASER BUTLIN:** In terms of the interaction between your
25 liver and the hepatitis B, and your Parkinson's disease,

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1 a little bit and recognise that there was a problem but
2 did we really know what it was. After a whole lifetime
3 of misdiagnosis and illness and running, as it were, to
4 catch up, I wasn't quite sure what I should sit down and
5 quietly research because -- and in the end I haven't
6 done a huge amount, by choice.

7 **MS FRASER BUTLIN:** And that's your current diagnosis, that
8 it is of Parkinson's?

9 **MS SALLY DAVIS:** Yes, and it is quite seriously made by
10 serious and good people. But they are comfortable and
11 happy enough to occasionally wander off the scale and
12 find another way of not having the illness.

13 **MS FRASER BUTLIN:** In terms of hepatology, in terms of liver
14 care, what follow-up have you had?

15 **MS SALLY DAVIS:** Quite a lot, but not at the beginning.
16 I started to get more and more worried that I hadn't
17 really taken it as seriously as I should, and so my GP,
18 who is a very splendid and helpful person, sent me to
19 somebody who was, in those days, clearly significant,
20 but I can't tell you who they are without -- it was
21 a lady, and I can't remember her name.

22 **MS FRASER BUTLIN:** And that was in about 2010, I think, that
23 you were referred into hepatology --

24 **MS SALLY DAVIS:** It was about that actually, yes. That is
25 probably about right.

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1 what are the difficulties you've had, particularly with
2 medication, in that regard?

3 **MS SALLY DAVIS:** Medication's been really, really hard and
4 I think it is for most people because you try to tie it
5 up alongside everyone else and you can't. You try and
6 do it yourself just for you and you can't, and people
7 don't let you. In all good nature, they sometimes
8 create a difficult path.

9 **MS FRASER BUTLIN:** You said in your statement that a lot of
10 the medication for Parkinson's is old.

11 **MS SALLY DAVIS:** It's 60 years old. It's outrageous. It
12 should not be 60 years old.

13 **MS FRASER BUTLIN:** And there's not a very -- it can be
14 difficult to find the right medication that then doesn't
15 affect your liver?

16 **MS SALLY DAVIS:** That's also true but then when you've found
17 it you almost -- immediately it feels as if you've got
18 to find something else because it's working all the time
19 and mostly in a negative direction.

20 **MS FRASER BUTLIN:** And so with somebody who doesn't have the
21 liver difficulties, with the Parkinson's disease they
22 might change the medication very regularly.

23 **MS SALLY DAVIS:** Yes, and it might be quite a good thing to
24 do. But if you're very allergic, because I'm really
25 allergic to medicines, you have to decide what you're

52

1 going to do without.

2 **MS FRASER BUTLIN:** And I think you've said in your statement

3 that the doctors have struggled with that, finding the

4 combination that works that also does n't impact on your

5 liver condition.

6 **MS SALLY DAVIS:** Well, it almost always does now but it's

7 a slightly different weight in the summation of it.

8 **MS FRASER BUTLIN:** In trying to balance the liver function

9 versus the Parkinson's.

10 **MS SALLY DAVIS:** Yes, and you know that you're on a loser

11 right from the start until there's another situation in

12 which people can find their way to a positive research

13 set up.

14 **MS FRASER BUTLIN:** This morning with the panel we talked

15 about the connection between ill health and the

16 hepatitis B. For you, how much discussion has there

17 been with your clinicians throughout these bouts of

18 physical ill health about any connection with the

19 hepatitis B?

20 **MS SALLY DAVIS:** It's been a constant similar nightmare

21 really, and I don't normally talk in those ways but

22 I would say it's so put a brake on what you do, and even

23 what you think and what other people think, and what

24 your family thinks and what your children think, and how

25 far should you go with this person not to be deprived of

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1 to be interested. And it is -- you have to make

2 decisions about whether you actually see your friends

3 and say, "Sorry, I can't do that today, had a really bad

4 test for liver". But a lot of people of my age,

5 backwards as opposed to forwards, would never talk about

6 it, on the basis that, you know, schools, social lives

7 and other health issues would be a problem to them, and

8 there was no information just around that you could pick

9 up and use to build your own sense of what's going on.

10 **MS FRASER BUTLIN:** So you were lacking information about the

11 hepatitis B?

12 **MS SALLY DAVIS:** Completely.

13 **MS FRASER BUTLIN:** And it wasn't discussed within your peer

14 group or your friends?

15 **MS SALLY DAVIS:** It wasn't my peer group or even in

16 hospital. I had no idea I had had "anything", but

17 presumably they must have had some indication that I had

18 had something, and whether that kept them quiet or

19 whether they didn't get the right answers, how would

20 I ever know? I do know that we were lucky to keep the

21 children.

22 **MS FRASER BUTLIN:** Another discussion we had this morning

23 was about difficulties with insurance and -- life

24 insurance and travel insurance. Was that something that

25 you faced with the hepatitis B?

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1 dentistry, or how much do you go this far not to be

2 deprived of tests that you think are more relevant than

3 they do. You can go on forever, which is the most

4 extraordinary thing about this, because it's so, so

5 wrapped in tiny, tiny things that don't work.

6 **MS FRASER BUTLIN:** How many discussions have you had or how

7 often have you talked with clinicians about whether

8 there is a connection between what you faced and the

9 hepatitis B?

10 **MS SALLY DAVIS:** There clearly isn't an answer to that in

11 whole. But I found it extremely difficult to worry more

12 than to take the pills. Other people do it the other

13 way.

14 **MS FRASER BUTLIN:** And what's the impact of the infection

15 been on your mental well-being?

16 **MS SALLY DAVIS:** Well, again, it puts you into a high risk

17 area of thought and care and love and everything and you

18 really cannot serve yourself up any better than you do,

19 but it doesn't feel like that. And as -- [... redacted

20 ...] and I have to worry about how much of that was me.

21 **MS FRASER BUTLIN:** Earlier, the panel talked about feeling

22 like they were a leper, that they were infectious. Is

23 that something that you have any reflections on?

24 **MS SALLY DAVIS:** Yes, indeed, because you can't describe it.

25 If there's no words, it is very difficult to get people

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1 **MS SALLY DAVIS:** Yes, I did, but nobody was quite as into it

2 as they are now, and so it really was up to you at what

3 level you would put yourself in and feel that you really

4 had some kind of integrity. But it was very much

5 a single situation determined by you, and then assessed

6 as being possibly a bit dodgy if you weren't really

7 careful about the detail. But that in itself leads to

8 a moment when you know you have got to go in and say to

9 your dentist, "I'm awfully sorry but I'm carrying

10 something that might kill you and you might need to

11 know", and not many people who are -- actually put

12 forward the strength of the possibility of not being

13 here for ages. And I find that really odd.

14 **MS FRASER BUTLIN:** From a financial perspective, obviously

15 with hepatitis B you are not eligible for the financial

16 assistance schemes that we have talked about in the

17 Inquiry that there is available for the HIV and

18 hepatitis C sufferers, or for some of them. That

19 ineligibility, how has that made you feel? Have you

20 been aware of the schemes and not being able to apply

21 for them?

22 **MS SALLY DAVIS:** Yes, but I think I'd come to terms with

23 sorting my own structure out so that I didn't have to

24 worry every time anything came round that I had actually

25 done what I needed. In those days it was easier. I'm

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1 never quite sure why it was. Just maybe it was that you
 2 were still running -- mostly -- around. Now I find it
 3 quite difficult.

4 **MS FRASER BUTLIN:** Because at that point you were still able
 5 to work within the Civil Service, albeit that you
 6 retired perhaps earlier than you would have done?

7 **MS SALLY DAVIS:** Sorry, I didn't quite catch that.

8 **MS FRASER BUTLIN:** No, that's okay. You said that you'd
 9 managed to arrange your own affairs, in terms of
 10 financial affairs, early on in the time. Is that
 11 because you were able to keep working for quite a long
 12 time in the Civil Service?

13 **MS SALLY DAVIS:** Well, I did work for a long number of years
 14 in terms of the amount of work, but I didn't do so much
 15 work as I would have expected to do, and I was lucky
 16 because I was well treated by the Civil Service in terms
 17 of what I could do and that was really appreciated
 18 because the flexibility was given.

19 **MS FRASER BUTLIN:** And so, perhaps because the Civil Service
 20 were able to support you, you worked longer than you
 21 might have done in another role?

22 **MS SALLY DAVIS:** That's definitely true and also because of
 23 the effort made to get there. It's a question of have
 24 I managed to roll up the hill and is it okay to keep
 25 going for a bit longer? But it has pretty much made

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1 from Susan Hallwood and Elaine Read.

2 **SIR BRIAN LANGSTAFF:** Thank you. So 10.00 tomorrow.
 3 (2.27 pm)

4 (The Inquiry adjourned until 10.00 am on Thursday,
 5 29 September 2020)

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1 itself impossible now.

2 **MS FRASER BUTLIN:** And you retired early --

3 **MS SALLY DAVIS:** I retired early but I kept on working for
 4 -- I sat on ethics committees and other things that
 5 I really enjoyed, so I was really lucky.

6 **MS FRASER BUTLIN:** They're the topics we talked about as
 7 a panel this morning. Sir Brian, do you have anything
 8 else you would like to ask?

9 **SIR BRIAN LANGSTAFF:** No, I don't. Thank you.

10 **MS FRASER BUTLIN:** Sally, is there anything else you would
 11 like to add before we finish?

12 **MS SALLY DAVIS:** No, I don't think so, thank you, because
 13 you've given me a chance to know much more than I would
 14 have ever known in any other way. So my sense is of
 15 gratitude and keep on going.

16 **SIR BRIAN LANGSTAFF:** Can I thank you for being in a good
 17 place today enough to be here and keep on going, as you
 18 said. It has been important to listen to what you have
 19 had to say, so thank you very much.

20 **MS SALLY DAVIS:** Thank you.

21 **SIR BRIAN LANGSTAFF:** Ms Fraser Butlin, tomorrow?

22 **MS FRASER BUTLIN:** Sir, give me one moment. I'm sorry,
 23 Ms Richards gave me the note. Apologies. We will be
 24 hearing from two witnesses in relation to Alder Hey.
 25 I have it here. Apologies, sir. We will be hearing

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