

Tuesday, 9 July 2019

(10.12 am)

**SIR BRIAN LANGSTAFF:** I am sorry that we've started late. Technological problems.

It's perhaps the case that technology is labour-saving. When you try and sort it out, it does take time. It is actually quite reassuring to know that we can manage without it and we're going to do that this morning until ordinary service is restored, and it won't affect what is happening.

The technological problem at the moment is in relation to the provision of document images and Ms Richards has agreed to work round that, so that's what we shall do.

Before we begin with my making an anonymity order for Mr W, let me just raise something with you, Ms Richards, arising out of yesterday's testimony.

Do we have something to report as to a response to what was being said?

**MS RICHARDS:** Yes, sir, sorry, it was my omission yesterday when Mr and Mrs V were giving their evidence I should have mentioned then that Dr Lowe has been asked to respond to the matters raised in their statements and is proposing to respond and once received that response will be published in due

1

With that introduction, may we have Mr W, please.

**MR W, affirmed**

**Questioned by MS RICHARDS**

**Q.** Mr W, you're here to talk about your late wife, [redacted].

**A.** Yes.

**Q.** And we're going to name [redacted] in the course of your evidence because it would not be easy for you to give your evidence about her without naming her. So those in the room will hear her name, but that name is not to be reported or published or disclosed in any respect.

And you've shown us two beautiful photographs of [redacted], one of you and [redacted] on your wedding day and another of you and [redacted] in 1986 which the Chair has seen and which I have seen but which, because of the anonymity order, we won't be showing more generally. But thank you for sharing those photographs with us.

You met in 1976 and married in 1978.

**A.** Yes.

**Q.** And [redacted] was a civil servant --

**A.** Yes, that's right.

**Q.** -- at the Department of Health?

3

course.

**SIR BRIAN LANGSTAFF:** Thank you very much.

So back to Mr W, again it's a restriction order to preserve anonymity. Now, because it will be very difficult for Mr W to avoid mentioning some names, family names, in the course of his evidence, there will be no live-streaming. The transcript will be edited to avoid any conflict, any compromising of his anonymity later, and so you will hear it and hear it here, but the world out there won't for the moment.

The order is as follows: the name and address of witness W2781, that's Mr W to you and me, the name of his wife who died, and the name of any other member of the witness's family and any other identifying information, such as the witness's image or a description of their appearance, cannot be disclosed or published in any form unless express permission is given by me, or by the Secretary to the Inquiry acting on my behalf -- the Solicitor to the Inquiry, sorry, acting on my behalf.

Witness W2781 must be referred to only as Mr W. The order remains in force for the duration of the Inquiry and at all times thereafter unless otherwise ordered, and I may vary or revoke the order by making a further order during the course of the Inquiry.

2

**A.** Yes.

**Q.** What was she like as a person?

**A.** Outgoing, lovely. (Pause)

Beautiful, a very, very nice person.

**Q.** She had kidney problems for some years.

**A.** Yes, since she was in her teen years.

**Q.** And that gradually got worse and worse?

**A.** Yes.

**Q.** Although she didn't let that stop her from living her life to the full?

**A.** Oh, no, not at all, no, no.

**Q.** But around May of 1984 she started to require regular dialysis?

**A.** Yes.

**Q.** And what did that entail?

**A.** Well, it entailed her having to go down to the hospital at least three or four times a week and that was a round trip of 120 miles, and then they decided they were going to put a unit in the back garden and they were just actually in the process of doing that, putting a unit in the back garden, and I was getting trained up to use the dialysis machine to look after her and, obviously, then a kidney became available.

**Q.** Because she'd been put on the transplant list?

**A.** Straightaway, yeah.

4

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

5

1 actually come with the kidney, and they would treat it  
2 as such and, of course, you're just thinking flu-type  
3 virus, that's a couple of Anadin and go to bed, you  
4 will be okay. You know, you're not thinking anything,  
5 because you don't know anything else.  
6 Q. But she didn't get better, she --  
7 A. No.  
8 Q. -- was starting to experience lethargy and fatigue,  
9 loss of weight, loss of appetite.  
10 A. Massive loss of weight, yeah, her arms and her legs  
11 got very, very thin and she started coming out in  
12 spots and the spots turned into blisters. She was  
13 just a complete mess, just an entirely different lady  
14 whatsoever.  
15 Q. And she started to get repeat infections?  
16 A. All the time, yeah. It was back and forwards to the  
17 hospital all the time. We didn't seem to be away from  
18 Manchester at all.  
19 Q. And then there was an occasion in July of 1986, the  
20 end of July, when [redacted]'s brother had taken her  
21 into the hospital for an appointment.  
22 A. Yeah, the reason that happened was because I worked a  
23 three-shift seven-day system on -- where I was  
24 working, and it happened to be that day. We just  
25 thought it was a check-up she was going for.

7

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

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1 I couldn't possibly have been there so her brother, he  
2 volunteered to take her down. He took her down to the  
3 hospital. And when she came back it was about, I'd  
4 just actually got into bed in the afternoon and she  
5 came upstairs, breaking her heart.  
6 Q. What did she tell you?  
7 A. Sorry. (Pause)  
8 Q. Take as much time as you need and I can take it from  
9 your statement, if that would be easier. (Pause)  
10 A. Her actual words were "[redacted], you're never going  
11 to believe this, but I've got HIV". "HIV?" I was  
12 sort of half awake. "HIV, what are you talking about,  
13 you've got HIV? Because how is that possible?"  
14 Because all we knew about HIV at the end was it a gay  
15 plague. That's what we were told. That's what  
16 everybody was told.  
17 Of course, when you're not thinking -- "No, no",  
18 she says, it's -- "No, it's not -- I've got HIV and  
19 we've got to phone Dr Ackrill straightaway and you've  
20 got to down there and he's going to explain things  
21 further".  
22 Of course, we phone Dr Ackrill and he said,  
23 "Could you come down" -- I was actually due back in my  
24 work to do another shift, and I phoned my boss and  
25 they covered it and said, "Just go, [redacted]".

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

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

**Q.** And at this stage you and she still did not know how she had become infected with HIV?

**A.** No.

**Q.** Can you recall what, if any, advice or information the doctors were able to give you about the condition?

**A.** All we were told was -- the first thing we were told was, "For your own good, don't tell anybody. Because of the stigma that's attached to this, we don't want

9

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

**Q.** You've said in your statement that you and [redacted] didn't understand what the HIV meant, little was -- seemed to be known about it apart from what you'd picked up from gay plague and tombstone adverts on TV and the like.

**A.** That wasn't then. The adverts weren't out then, they were just in the throes of coming out.

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

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

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

11

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

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

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

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

**A.** Yeah.

**Q.** I'm going to see if our systems will allow it to be displayed on the screen now, because we've had some problems but if not I'll read it out.

**A.** So, Paul, the number is 2781002.

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

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

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

"She received the right kidney from ..."

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

**A.** No.

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

And then another virus we don't need to concern

12

ourselves with for the purposes of your evidence:  
 "... and was found to be negative for all three.  
 The transplant took place on 20 September. The match  
 was almost perfect with only one measured mismatch at A3  
 on the HLA locus."

Then it says:  
 "[redacted] was also tested for hepatitis and  
 HIV and was negative."

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

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

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

13

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

15

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

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

A. Yes.

Q. And that the recipients of a number of the organs that  
 were donated converted to HIV?

A. Yes.

SIR BRIAN LANGSTAFF: It amounts to five people given HIV  
 from one blood transfusion, plus the donor.

MS RICHARDS: Including the donor.

SIR BRIAN LANGSTAFF: Six.

A. Six people, yeah.

MS RICHARDS: Well, I think we have liver and heart, two  
 kidneys and then the donor, and one of the kidney  
 recipients was [redacted].

A. Yes.

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

14

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

Q. The observation you've made in your witness statement  
 is:

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

A. Definitely, yeah, yeah.

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

Q. [redacted]'s health continued to deteriorate?

A. Yeah, greatly, yeah.

16

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

17

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

19

1 that I showed you today, that was the last photograph  
2 of us two together and she's so happy in it because  
3 I was actually holding her up, because her legs were  
4 like that and her arms were like that, and she was so  
5 sore with the lumps, blisters, it was bad.  
6 Q. There was an inquest into [redacted]'s death.  
7 A. Yeah.  
8 Q. And you've explained in your statement that at the  
9 inquest you asked the doctor how long [redacted] might  
10 have survived with dialysis if she hadn't had the  
11 transplant.  
12 A. Yeah.  
13 Q. And the answer was she could have gone on for a few  
14 more years?  
15 A. Yes, yes.  
16 Q. You've explained to me that you have had a sense that  
17 the doctors were not telling you everything at this  
18 time.  
19 A. Yeah, it was like --  
20 Q. What did you mean by that?  
21 A. It was like a sixth sense. One particular doctor,  
22 whether you name him or not, he was sort of -- he  
23 would tell something he was sort of -- as if he was  
24 saying to you, "Look, don't believe what I'm saying"  
25 or -- and when you sort of asked him something --

18

1 I basically just didn't cope at all, I just didn't  
2 cope whatsoever.  
3 I lost everything, my job, my house. My health  
4 deteriorated. I ended up actually with post-traumatic  
5 stress disorder with regard to hospitals, which is  
6 very, very serious, inasmuch as I can't even go in  
7 a hospital. It's been recognised inasmuch as last  
8 November I had a massive heart attack, was taken to  
9 hospital and it was just into the second day, I got up  
10 out of bed and told them, "I'm leaving", because  
11 I just couldn't even hold up my head to look. I was  
12 getting dizzy.  
13 The consultant came. He'd already read my notes  
14 and he understood exactly what was going on. He said,  
15 "We're agreeing with you [redacted]. We're going take  
16 you in a side room now and we're going to treat you at  
17 home". And I got a fantastic care at home, doctors  
18 coming up and nurses coming up to my home. I was  
19 sorry to be such a burden, but this is what it's left  
20 me with, this post-traumatic stress disorder which  
21 I couldn't believe that I had.  
22 Q. In [redacted]'s lifetime, was she or you ever offered  
23 any psychological counselling or support?  
24 A. No, there was only the once and it was a few weeks  
25 after she was told. Whether it was psychological help

20

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

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

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

21 Q. And in the years since [redacted]'s death, have you  
 22 been offered any support or counselling?

23 A. My own doctors, yes, I went to see a couple of  
 24 psychologists but the treatment they were wanting to  
 25 give me, I just couldn't handle it at the time.

21

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

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

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

23

1 I felt like I'm not -- I wasn't quite ready for it,  
 2 and I just sort of just didn't go back and the doctors  
 3 understood and said, "That's okay, [redacted], we're  
 4 patient. We'll start it again when you're ready".  
 5 They've been absolutely marvellous because they knew  
 6 the full history.

7 Q. And you remarried. You have had a daughter.

8 A. Yes.

9 Q. And you say in your statement that they have been the  
 10 support that you needed.

11 A. Well, the lady that I married, she was actually --  
 12 worked in the medical profession for a few years.  
 13 When I first met her, she recognised -- I don't know  
 14 what she recognised, but we got married anyway and  
 15 I didn't think that would happen again, I really  
 16 didn't. And of course that was the silver lining and  
 17 this was the other silver lining.

18 Q. You've mentioned in your statement involvement in some  
 19 form of litigation in 1992 and having to sign  
 20 a waiver --

21 A. Yeah.

22 Q. -- in order to receive money?

23 A. The way that came about was I was in the car and I was  
 24 driving through -- the time it was in -- I just  
 25 flicked on Radio 4. I don't know what the programme

22

1 A. Yeah, yeah.

2 Q. Although you've made very clear in your statement how  
 3 you've rebuilt a life with your wife and your  
 4 daughter, you've said this, that you still have bad  
 5 dreams and nightmares --

6 A. Yeah.

7 Q. -- regularly, and you'll wake up crying, screaming and  
 8 sweating.

9 A. Oh yeah, that's three or four times a week. Even  
 10 today -- last night was not too bad, you just cope  
 11 with it, I got up, made myself a cup of tea. And I am  
 12 a smoker, I'm a heavy smoker and I shouldn't be,  
 13 I know that, but I got up last night at the hotel and  
 14 I went outside and had a cigarette and came back in  
 15 again, another cup of tea, went to bed and that's sort  
 16 of -- that helped.

17 Q. And you've also said in your statement that you  
 18 promised [redacted] that you would try and find out  
 19 what happened.

20 A. Yeah, and I didn't want that to be just a bare  
 21 promise. And I did try after it, I did try. There  
 22 was no Google in them days, there was nothing -- you  
 23 can just press a button and instantly there. You had  
 24 to go over libraries, you had to phone, you have to  
 25 see medical people and they could close ranks on you

24

and you wouldn't know, you just wouldn't know, so I sort of let it go and I always felt guilty about doing that and when this Inquiry came up -- the previous Inquiry, sorry, the Penrose Inquiry, I just didn't believe in it at all, and I didn't want to get involved. But when this Inquiry came up and I looked into it, and I seen what was involved, I totally believe in it because I think you're totally looking for the truth, and I totally, totally believe in what you are doing here. That's why I'm here.

**Q.** Thank you. I've got no further questions for you, but is there anything else that you would like to say?

**A.** No. I've wrote a little statement of sorts. It's, you might say, a bit hammy.

**Q.** If you want to say it, then, absolutely, this is your chance to do so.

**A.** Thank you. You'll have to forgive me. Can we just take a minute?

**Q.** Of course.

**A.** It's not a long statement.

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

25

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

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

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

27

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

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

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

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

26

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

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

Thank you.

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

No, nothing further.

Sir Brian?

**SIR BRIAN LANGSTAFF:** I'm not going to ask any questions, but just pick up on the word that you used in what you were saying at the end, which described what had happened when your wife was cruelly taken. We've heard some very disturbing tales in this Inquiry. I think few, if any, can be quite as cruel to the sufferer as the story of what happened to your wife, who went in for a life-saving treatment and came out with a death sentence, as you put it.

**A.** Yes.

28

1 **SIR BRIAN LANGSTAFF:** It has not been easy for you to tell  
 2 us but I think everyone listening will understand how  
 3 important it was that you did, so thank you.  
 4 **A.** I just thank you for giving me the opportunity to give  
 5 it and to get it off my chest.  
 6 **SIR BRIAN LANGSTAFF:** It's important.  
 7 **A.** And it should have been told.  
 8 **SIR BRIAN LANGSTAFF:** Thank you very much.  
 9 **A.** No. Thank you.  
 10 **SIR BRIAN LANGSTAFF:** We will take a break until 11.20 am.  
 11 **MS RICHARDS:** Thank you, sir.  
 12 **SIR BRIAN LANGSTAFF:** 11.20 am.  
 13 (10.51 am)  
 14 (A short break)  
 15 (11.25 am)  
 16 **SIR BRIAN LANGSTAFF:** Our next witness is Christine, is  
 17 it?  
 18 **MS RICHARDS:** It is, sir.  
 19 **SIR BRIAN LANGSTAFF:** Christine, please.  
 20 **CHRISTINE NORVAL, affirmed**  
 21 **Questioned by MS RICHARDS**  
 22 **MS RICHARDS:** Christine, you're here to talk about the  
 23 impact on you and your family of your husband Bruce's  
 24 infection.  
 25 **A.** Yes, that's correct.

29

1 haemophilia?  
 2 **A.** Well, he was very open. We went for lunch after our  
 3 shift and I burnt a pizza and he told me he was  
 4 a haemophiliac and I just blurted out, "Oh, have you  
 5 got AIDS then?" As a 20-year-old, I had, yes, foot in  
 6 mouth disease I would think, yes.  
 7 **Q.** Now, Bruce didn't know at that time that he had been  
 8 infected with hepatitis C?  
 9 **A.** No.  
 10 **Q.** But he was aware of being unwell?  
 11 **A.** Yes.  
 12 **Q.** What kind of symptoms was he experiencing at that  
 13 time?  
 14 **A.** Well, shortly after we got together he was struggling  
 15 to keep up his nursing studies. He was struggling to  
 16 keep up the extra shifts he was doing to pay the  
 17 bills. I remember one occasion we went to visit  
 18 a cousin and -- and we slept over at their house, and  
 19 I remember during the night that the bed was so wet  
 20 that I just thought he had wet the bed. It was so  
 21 wet, it was so -- I was absolutely just mortified.  
 22 I realised, you know, later that it wasn't urine but  
 23 we had soaked through the sheet or he had soaked  
 24 through the sheet and the mattress and, yes, I was  
 25 embarrassed by that.

31

1 **Q.** And we have a detailed witness statement from Bruce  
 2 and indeed from you and from each of your children,  
 3 and I'm not going to ask you to speak to their  
 4 statements.  
 5 **A.** Right.  
 6 **Q.** Although there may be a couple of passages from them  
 7 I refer to in the course of your evidence.  
 8 In terms of background, Bruce has, as his  
 9 statement explains to us, haemophilia B?  
 10 **A.** Yes.  
 11 **Q.** And he has over the course of many years been treated  
 12 with many Factor IX products?  
 13 **A.** Yes.  
 14 **Q.** And I'm going to ask you to start your testimony in  
 15 1988 when you and Bruce met.  
 16 **A.** Okay.  
 17 **Q.** That was in London?  
 18 **A.** That was in London. I'd gone down to London to be  
 19 a physiotherapy student and Bruce had moved down from  
 20 Inverness to London to do nursing. Eventually he went  
 21 to do nursing when he was down there, and we were  
 22 doing agency nursing to pay the bills and we met,  
 23 actually we were put on the same ward on the same day  
 24 and we met through work.  
 25 **Q.** And what was your response when Bruce told you he had

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1 **Q.** You describe in your statement he was experiencing  
 2 nausea, fatigue --  
 3 **A.** Yes, weight loss, yes.  
 4 **Q.** But doctors were telling him that it was all in the  
 5 head?  
 6 **A.** Yes.  
 7 **Q.** You said he was told it wasn't AIDS, so there was  
 8 nothing to worry about.  
 9 **A.** Yes.  
 10 **Q.** And you refer to him being described as an AIDS  
 11 wannabe?  
 12 **A.** Yes.  
 13 **Q.** It was in the course of 1990, when you were pregnant  
 14 with your first child --  
 15 **A.** Uh-huh.  
 16 **Q.** -- and you were due to get married --  
 17 **A.** Yes.  
 18 **Q.** -- that Bruce was told he had hepatitis C?  
 19 **A.** Yes. He'd moved centres to, gosh, the name's just  
 20 gone out of my head, the one in London.  
 21 **Q.** St Thomas's?  
 22 **A.** St Thomas's, thank you, and they were trialling the  
 23 new hep C tests, so he took part in the new hep C  
 24 test.  
 25 **Q.** And I'm just going to read a few lines from Bruce's

32



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

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

33

the baby.

**Q.** Now, you and Bruce and the baby moved to Lincolnshire in late 1991.

**A.** Yes.

**Q.** And how did Bruce's health develop over the following years?

**A.** He continued to have the night sweats. He vomited virtually every day, several times a day. He was prescribed build-up drinks by the GP. He was very emotional. He was very angry. He had massive amounts of fatigue, struggled to hold down a job, and sort of expressed feelings of feeling useless and being no use to us.

**Q.** And he did attempt various forms of work but he was unable because of his health to sustain those employments for very long?

**A.** Yes.

**Q.** You then had to go back to work full-time more quickly than you'd planned to.

**A.** Yes, I think my daughter was four months old when I went back to work full-time.

**Q.** And you've recalled in your witness statement one occasion on which your daughter called you Maureen, which was the childminder's name?

**A.** Yes, she was at the childminder all day while I was at

35

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

Now, Bruce came back and told you --

**A.** Yes.

**Q.** -- that he had been given this diagnosis of hepatitis C. What can you remember about that?

**A.** There was a mixture of emotions. Because he had been unwell and there didn't seem to be any reason for it, actually having a diagnosis almost made -- made it better because at least it was wasn't all in his head. At least there was some reason for him being unwell but he was really, really worried that either he'd infected me or the baby.

**Q.** And you've said in your statement that you weren't told or given any information about the risks of transmission to the baby?

**A.** No.

**Q.** And you weren't offered an HCV test?

**A.** No.

**Q.** And Bruce became very concerned about the risks of cross-infection following his diagnosis.

**A.** Yes, he was doing home treatment and I'd been helping -- I'd been putting the IV in for him and he stopped me from helping with that yes, and -- yes, he was just devastated that he was so worried for me and

34

work.

**Q.** And that you hadn't been your plan initially?

**A.** No, absolutely not. We'd always thought we were going to jointly parent the children and I wanted to have some time to be a mum and Bruce wanted some time to be a dad and this was our idea that we would do that.

**Q.** And during this period when you were living in Lincolnshire, how were things for you financially?

**A.** We were in a council house. We'd moved up to a council estate, and things were tough. To a pay a child minder, Bruce wasn't really earning very much. The benefit system was -- seemed to be against us. He was having to fight to be able to claim benefits that he should have had.

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

**Q.** Now, Bruce then went on a course of interferon for hepatitis C. You think it was I understand a trial.

**A.** I believe so. It was from -- the centre had moved to the Hallamshire in Sheffield at that time and I do remember going to see the doctor prior to him starting and the doctor saying, "Your liver enzymes are so bad, there's no question that you'll be taken on", and

36

1 I think he must have been quite late getting taken on,  
 2 because it seemed to be quite rushed that he started  
 3 the trial.  
 4 Q. And your statement says that in retrospect you suspect  
 5 that the dosage he was given may have been too high?  
 6 A. Again, I -- I'm not sure where I've got that  
 7 information from, but I'm sure that I've heard that  
 8 the initial trials, the dose, they were working with  
 9 the dosages and, subsequently, the doses were reduced.  
 10 Q. Bruce's description of the side effects of that course  
 11 of interferon are put in this way:  
 12 "Nobody had made me aware about the side effects of  
 13 treatment. I was told that interferon would give me  
 14 mild flu symptoms. If what I experienced is a mild flu,  
 15 I what would like to know what they think is a bad flu  
 16 is. Mentally and physically I've never recovered from  
 17 that experience."  
 18 A. Yes.  
 19 Q. What you can recall about the symptoms and side  
 20 effects that Bruce experienced during the interferon  
 21 trial?  
 22 A. I have visions of him with the needle waiting to stick  
 23 it into his stomach and him in tears, knowing that he  
 24 had to do it, but knowing that -- how poorly he was  
 25 going to feel after it. He was trying to continue to

37

1 hearing their stories, and I think having spoken to  
 2 each other and working with each other, they suddenly  
 3 realised, "Hang on, it's not just me. We're all  
 4 suffering with the same consequences".  
 5 Q. Now, you'd become pregnant with Robbie in 1996, having  
 6 been told that Bruce had become clear of hepatitis C.  
 7 A. Yes.  
 8 Q. It was seen I think by both of you, your statement  
 9 says, as a good moment to have a second child.  
 10 A. Yes, we'd -- there's six years between our children  
 11 and in that time, before Bruce had had treatment, we  
 12 had had difficulty coping and we'd been to Relate and  
 13 counselling and we'd sort of said, that's it, no more  
 14 children. That's it. It's not fair. But after being  
 15 told that you're clear of the virus, you will get  
 16 better, you'll be healthy, I'd always wanted a second  
 17 child, so this was a definite choice to have a second  
 18 child.  
 19 Q. But the symptoms never having gone away, what did it  
 20 feel like for you and for Bruce having made this  
 21 decision but nothing had got better?  
 22 A. It -- it was difficult. My pregnancy with my son was  
 23 very difficult. I had multiple threatened  
 24 miscarriages, and I do remember thinking maybe it  
 25 would be better if this child doesn't survive.

39

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

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

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

38

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

40

1 his physical health conditions at that time?  
 2 **A.** I think he -- he felt worthless but at the same time  
 3 he -- he was wanting to -- not campaign but to get to  
 4 the bottom of this, to find out exactly what had  
 5 happened and to find the truth out.  
 6 So as much as he was poorly, he was unwell, he  
 7 started devoting more and more and more of his  
 8 energies into researching what had happened, into  
 9 campaigning and going on the TV, newspaper articles,  
 10 this sort of thing to try and highlight the case.  
 11 **Q.** His statement describes depression and a sense of  
 12 social isolation at this time as well.  
 13 **A.** Yes. We don't -- we didn't socialise at all. Bruce  
 14 found it very difficult coping with crowds and also  
 15 it's that first question when you're introduced to  
 16 somebody new, it's, "Oh what do you do for a living?"  
 17 And if you say -- you don't want to tell people the  
 18 whole story, not that we hid it, I absolutely didn't  
 19 hide what had happened to us, but it was that  
 20 difficult question.  
 21 People really don't want to know the ins and  
 22 outs and if he said he was a house husband, which is  
 23 what he sort of started to say to people, again, a man  
 24 staying at home and his wife going to work, he felt  
 25 that that lessened him and took away his -- his

41

1 a case of trying to separate myself from the pain and  
 2 I moved out of the family home into a rental property  
 3 nearby, and took the children and had to take on huge  
 4 debt to furnish it and pay the first month's rent  
 5 and -- and I was still off sick at this time, so  
 6 I was -- was on sick leave, but it was -- it was just  
 7 my way of coping.  
 8 **Q.** In 2004 Bruce received a letter, we've seen a number  
 9 of such letters, about the potential risk of vCJD.  
 10 **A.** Yes.  
 11 **Q.** What can you recall about that?  
 12 **A.** Well, we have to almost go back a bit from that.  
 13 Bruce and I were watching the vCJD story in the press  
 14 and we just turned to each other one day and said,  
 15 "These are young people. I wonder how many of these  
 16 people have given blood?"  
 17 So we wrote to, I don't know, we asked our  
 18 doctors, we asked The Haemophilia Society could this  
 19 be an issue? And we were told we were scaremongering,  
 20 we were frightening people and we should shut up.  
 21 So when the letter out, it confirmed yet again  
 22 we that we had been lied to. That we had -- you know,  
 23 they tried to placate us by saying there's no problem  
 24 but actually, yeah, you don't -- you stop believing  
 25 people because time after time after time your

43

1 masculinity, I suppose.  
 2 **Q.** You went through a period in the late 1990s, early  
 3 2000s when you were both struggling and your own  
 4 mental health was suffering.  
 5 **A.** Yes. I -- Bruce was just so poorly, really,  
 6 I think -- just so ill all the time and I had two  
 7 young children. My son didn't sleep so we were all  
 8 sleep-deprived, and on one occasion a long-time  
 9 patient that I'd had -- I was a community physio by  
 10 this time -- had died and I went to her funeral and  
 11 I remember it was pouring rain and I got in the car  
 12 and I went to go to my next patient, which just  
 13 happened to be near a river and I drove the car up to  
 14 the edge of the river and I sat there thinking, "Do  
 15 you know, this would end everything, all the pain, if  
 16 I drove the car into the river".  
 17 And at that point, I had two young children and  
 18 I just think that always brings you back, and I rang  
 19 Bruce and he just said, "Come home now. Just come  
 20 home", and I did, I managed to drive our car and go  
 21 home and just then I saw my GP and got signed off work  
 22 and started antidepressants and counselling, trying to  
 23 cope with it.  
 24 **Q.** You and Bruce did separate for a while.  
 25 **A.** Just immediately after that, again -- again, it was

42

1 concerns and theories and thoughts are proved right.  
 2 **Q.** And Bruce says in relation to the fear of vCJD this:  
 3 "There's nothing that terrifies me more than CJD.  
 4 HIV was a scary disease but the idea of losing yourself,  
 5 having your personality and everything you are eaten  
 6 away by death of your brain cells and to end up being  
 7 completely dependent and unable to even intellectually  
 8 interact because of CJD terrifies the hell out of me and  
 9 always has done."  
 10 **A.** Yes.  
 11 **Q.** "But this is a real risk for people like me. People  
 12 need to sit up and take notice of that."  
 13 **A.** Yeah.  
 14 **Q.** Bruce is and has been for a number of years profoundly  
 15 distrustful of the medical profession and medical  
 16 treatments and hasn't wanted to try any further  
 17 treatments.  
 18 **A.** Yes. When the new treatments started to come out he  
 19 was asked over and over again, despite the fact that  
 20 he's PCR negative, that we thought he was, for want of  
 21 a better word, cured of hep C but they still feel that  
 22 he should have this treatment, but he sort of said,  
 23 "Do you know, actually, I've been there at the start  
 24 before. I've been a guinea pig, for the want of  
 25 a better phrase, before", and he just didn't trust

44

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

8 **Q.** And yourself as a physiotherapist, working as part of  
9 the health service, what's the impact been on you  
10 practising your profession of having in the background  
11 these questions and concerns and this lack of trust?

12 **A.** I suppose I've been caught in between it, really,  
13 because my training and everything I see, I see so  
14 much good work, but at the same time I see so much  
15 horrendous stories and I've -- when I was working,  
16 I used to take on the cases that were long-term,  
17 people who had maybe been written off by everybody  
18 else, and so I started to understand the needs of  
19 long-term conditions and people with long-term  
20 problems wasn't necessarily well catered for and so  
21 I moved my practice towards that.

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

45

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

7 **Q.** For many years, as many in this room will know, Bruce  
8 has been extensively involved in investigation,  
9 research and campaigning and you describe in your  
10 statement that that's effectively become his life.

11 **A.** Yes. Yes.

12 **Q.** What has the impact of that been on you?

13 **A.** He -- I've said this so many times. We -- it's the  
14 first thing that he will speak about in the morning  
15 and it's the last thing he will speak about before he  
16 goes to bed, and within the day, no matter what the  
17 conversation is, we don't go half an hour without him  
18 discussing it, without somebody phoning up, without  
19 him looking on Internet and no matter where we go,  
20 what we do, he's constantly speaking to people,  
21 looking at things, putting two and two together, and  
22 he's done this from his bed a lot of the time.

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

47

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

6 **Q.** You describe Bruce at this time being exhausted,  
7 unable to do many physical tasks. You used to go  
8 hillwalking together and he could no longer do that?

9 **A.** No. We didn't even go on holiday together. I -- when  
10 we lived in England, we would come up and visit his  
11 family and when we moved to Scotland, we would then go  
12 back down, but I would take the children myself  
13 because Bruce just couldn't cope with it. And even if  
14 we did go away, it would be a weekend in a caravan  
15 somewhere, collecting tokens from the newspaper, this  
16 sort of thing, because we couldn't afford anything  
17 more than that.

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

20 **Q.** And you've said in your statement that you think he  
21 has a form of post-traumatic stress disorder because  
22 of everything he's experienced?

23 **A.** Yeah, I don't know if that's the right term but I know  
24 the anxiety levels that he experiences when he has to  
25 go into hospital are such that we've actually walked

46

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

8 **Q.** You've described it in your statement in some respects  
9 as being toxic and damaging. What do you mean by  
10 that?

11 **A.** Yes, I mean we're talking about something that  
12 happened so many years ago and there have been so many  
13 opportunities that the state could have taken to  
14 reduce what -- the harm that this has done.

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

48

1 and you can only be knocked down so many times. So,  
 2 you know, you raise your level up and then you're  
 3 knocked down, and every single time, and it's just  
 4 gone on for so long and the evidence is there.  
 5 Q. You've explained in your statement that this has given  
 6 Bruce his purpose.  
 7 A. Yes.  
 8 Q. But he's also seen so many people die.  
 9 A. Yes, yes. Yes, over the years, you know, I've  
 10 attended so many events and, you know, there's so many  
 11 people. I mean, some stick in my mind because I met  
 12 them as well. I wasn't always there because I was  
 13 working and then meeting their loved ones after  
 14 they've died, knowing that they have died in the most  
 15 horrendous ways, bloated, yellow, attached to machines  
 16 in intensive care, having amputations. Losing  
 17 everything, and these people were Bruce's friends and  
 18 he would say to them and they would say to him, "Don't  
 19 give up the fight. Don't give up the fight. Keep  
 20 going", and he would say, "I am fighting for you.  
 21 I am continuing not just for my family, for  
 22 everybody's family", and it's -- we've often felt  
 23 within the family that we are second place to that  
 24 fight, but we understand why that has happened.  
 25 I don't think you would put up with it if you

49

1 A. Yes.  
 2 Q. And following that you've taken retirement.  
 3 A. Yes.  
 4 Q. And one of your passions now are ponies and carriage  
 5 riding, but what's the impact been on you over the  
 6 decades that we've briefly been talking about, those  
 7 decades? How has it taken its toll on you?  
 8 A. I mean, there's -- physically, because Bruce either  
 9 is -- has been physically unwell to do things and then  
 10 all his energy that he has had has been in campaigning  
 11 and I've had to be the breadwinner. I've had to do  
 12 the house work. I've had to do the gardening,  
 13 everything, so I've been a sole parent almost. That's  
 14 how it's felt.  
 15 I felt a huge burden to pay the bills to keep  
 16 working. I would have loved to have worked at a lower  
 17 level or worked part-time but I didn't have the  
 18 opportunity to do that, even with my wages coming in  
 19 money was tight. We were always juggling a credit  
 20 card or a loan or -- and there never seemed to be any  
 21 money for what we needed and how can you say save for  
 22 tomorrow when you don't know if you're going to have  
 23 a tomorrow?  
 24 So I had to -- I was trying to support the  
 25 children so that -- and we couldn't shield them. My

51

1 didn't know the pain and people's stories behind it.  
 2 I would have walked and left Bruce. I wouldn't have  
 3 got back together but just simply because it is ten  
 4 green bottles, you know. It's just less and less all  
 5 the time to shoulder that burden. Bruce says he  
 6 stands on the shoulders of dead men.  
 7 Well, there's nobody there to support him. He's  
 8 there doing it with -- he's not on his own by any  
 9 means, far from it, but there's just this small group  
 10 of people that are keeping on because of the  
 11 horrendous stories that we know, the horrendous deaths  
 12 that we've seen.  
 13 Q. Your daughter has described that in his way in her  
 14 statement:  
 15 "People he knew were dying and I recall he had this  
 16 black address book and when people died he would cross  
 17 out their names. I remember coming home and there was  
 18 a hallway connected to an office that he could use.  
 19 I could hear him crying. I would see the black book  
 20 open and he had the phone and you knew another person  
 21 had died."  
 22 A. Yes, yes.  
 23 Q. You had cancer --  
 24 A. Yes.  
 25 Q. -- in 2014.

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1 daughter was -- has said just last week that she knew  
 2 when we were trying to hide things and that made her  
 3 much more upset than ever. And it's also -- Bruce has  
 4 also been through so much that if you've got a cold or  
 5 anything, it's nothing, it's really nothing compared  
 6 to what he's going through, so you would feel I cannot  
 7 be poorly because I'm nothing like as poorly as he is,  
 8 and that -- and I went through chemotherapy and  
 9 radiotherapy and, apart from a few days after each  
 10 treatment, I would still say I was fitter going  
 11 through that than Bruce has had for nearly 30 years.  
 12 Q. Bruce has recognised in his statement this, he says:  
 13 "My infection has an absolutely and completely  
 14 devastating effect on my family. It has completely  
 15 changed the way their lives have gone from their  
 16 earliest point."  
 17 Do you agree with that?  
 18 A. Absolutely, yes, yes.  
 19 Q. I will ask just a little about the effect on your  
 20 children.  
 21 A. Yes.  
 22 Q. They've both given statements to the Inquiry. You've  
 23 described your daughter as a very gentle soul, who  
 24 holds everything in and she says in her statement  
 25 she's grown up acutely aware of her Dad being ill and

52

1 that's affected how she deals with people.

2 A. Yes, and she's never had that security of knowing that

3 her Dad was going to be there the next day or the next

4 day, so living with that insecurity she -- again, it's

5 just recently she admitted to me that she would go to

6 the library after school hoping that I would be in

7 from work before she got in because she was terribly

8 worried that she would find her Dad dead, as a -- and

9 this is as an 11/12-year-old, and she had episodes of

10 school where she ran away one day and we had the

11 police called from school, and she's been to

12 counselling through child services and has continued

13 to have severe mental health issues since then.

14 She's been hospitalised twice in a psychiatric

15 ward and she spent her 21st birthday on a psychiatric

16 ward. When we went in to see the consultant,

17 obviously she talked about her Dad and I was called in

18 to see the consultant psychiatrist and he turned round

19 and said, "You have to choose between your husband and

20 your daughter. Your husband's campaigning is so awful

21 that if he continues to campaign, your daughter will

22 never be well".

23 And at the time I was raging about that. I was

24 so angry. How dare he say that? And now my daughter

25 [redacted], and speaking with a different psychiatrist

53

1 relationship with his father, no.

2 Q. And he said in his statement he thought for a long

3 time that his Dad was going to die and that the idea

4 of coming home from school to find his father dead was

5 normal to him.

6 A. Yes, it's -- yes. I mean, however rational that is or

7 isn't, that's what's in their mind it is Russian

8 roulette. Somebody said that the other day. There is

9 no rhyme nor reason why, you know, one person has died

10 and another -- and nobody could tell us, so of course

11 when you're in the dark times your brain goes to that

12 dark place.

13 Q. And he has said in his statement he would like all the

14 campaigning and infected blood conversations to stop.

15 A. Yes. We all would. Let's face it, everybody here

16 would but by God we're not going to let it go until

17 this is sorted out and we -- and in spite of

18 everything, we are standing together because we want

19 to see this done properly. We want to see the people

20 that have contributed to this, for want of a better

21 phrase, being brought to task.

22 Q. And you've said this at the conclusion of your

23 statement, Christine:

24 "I think it's been a compromise between the campaign

25 being toxic and the fact that if Bruce did not take part

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1 I reflected on that and thought, "Actually, he was

2 right", but he went about it the wrong way. If he had

3 just said, "Look, this is very damaging, what's

4 happening, and do X, Y and Z", but expecting me to

5 leave my husband, I -- in no uncertain terms it was,

6 "Leave your husband or your daughter won't be well".

7 No, I went back to my daughter at that point and

8 said, "Please don't think I don't love you enough to

9 put you first, because I will always put you first,

10 but I cannot -- I cannot -- I just don't think it's

11 right. I don't think this is the right way. I don't

12 think this is going to help us", and indeed at that

13 point I think she -- I don't know if that helped her

14 but she did recover for a while. She went back to

15 college. She then went back to university.

16 In spite of everything, she's got a good degree,

17 and [redacted].

18 Q. Your son, you say and he says, struggled with the fact

19 he wasn't able to do with his Dad what other

20 children's fathers did. They couldn't kick a football

21 around in the garden because of Bruce's ill health?

22 A. Yes, yes. We didn't go out to theme parks for the day

23 or anything like that. He just wasn't fit for that,

24 so whenever we did that it was just me or my sister or

25 friends or whatever, but he didn't have that

54

1 in the campaign, then who would do it? He feels a sense

2 of responsibility."

3 And you say in your statement that you

4 understand that.

5 A. Yes, yes.

6 Q. Then you say this:

7 "I'd always known that Bruce might die from his

8 infections for the last 20-plus years. He is extremely

9 upset every time someone else dies. Age 54 is the

10 average age that other haemophiliacs who have been

11 infected passed away. I believe this means that Bruce

12 is hyper aware of his own mortality. It feels like we

13 live on a knife edge, forced to live today but planning

14 for a future that he might not have."

15 A. Yes. His 54th birthday, again, I know it's

16 an arbitrary date but it was very significant and he

17 was -- his mood was very low around that time, yes.

18 Q. Christine, those are the questions I had for you. But

19 is there anything further you would like to say?

20 A. I've just made up a couple of notes. (Pause)

21 I was asked to come here and speak about the

22 family and tell our story. I've shared secrets with

23 you that I've never -- that I've not told anybody

24 else. I've never told anybody that I almost committed

25 suicide but I don't want anybody to go away thinking,

56

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

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

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

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

57

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

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

**Q.** Thank you. I'm just going to ask Mr O'Neill if there's anything further.

59

Maybe a good starting point would be if they told the story, they came clean and they were absolutely honest, because I don't believe that they've told the story before.

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

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

58

Nothing further.

Sir?

**SIR BRIAN LANGSTAFF:** You've given us a remarkably clear and compelling account, in particular of a driven man. Don't answer this question unless you feel you can or would want to, but at some stage this Inquiry will have to end, whatever its conclusions may be, what -- have you had any discussion, the two of you, about how life will then be?

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

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

60

would say, "Right I'm going to test this. I'm going to be looking at this", and a lot of people, it might not bother them. They might not be worried about it, but for some of us we do want to know that -- that there's not a vial gone off for some new thing and that there's no -- you know, there's nothing new in the future.

My daughter is a carrier and after the evidence we heard last week, we had a tearful session and she said, "Do you know, my genetics mean that this will never go away. The infections -- we might get to the bottom of the infections but it's what's next".

And she -- to the point where she said she won't have children. And if she adopts, although we would love the child and she would love the child as much as a biological child, they would always be a reminder that she has adopted because of what has happened to us here.

But we would like a quiet life. We would like to, yeah, just get on with it and -- because of my cancer diagnosis and because of Bruce's diagnosis, we don't have that security. So we just -- we just have to live our lives to the best we possibly can, doing the things we'd like to do.

**SIR BRIAN LANGSTAFF:** Thank you --

61

treatment?

**A.** I think it varied. From speaking to my mother, as a sort of young child I was at the hospital maybe as a maximum frequency of once a week but it could be maybe once/twice a month.

**Q.** And what treatment did you receive?

**A.** Factor VIII.

**Q.** Did you ever receive cryoprecipitate?

**A.** No.

**Q.** You were treated in Dundee?

**A.** Yes.

**Q.** Was there a Haemophilia Centre there?

**A.** No, as I understand it, the haemophilia service in Dundee was largely quite disorganised during the 1980s. It wasn't until the arrival of Philip Cachia in 1991 that the centre was established. Prior to that, I believe then it was a paediatric, I just went to a general paediatric clinic.

**Q.** There was no specialist paediatric haemophilia clinic --

**A.** No.

**Q.** -- that you could attend?

**A.** No, I remember quite clearly going to the paediatric clinic. It was in a downstairs corridor in Ninewells and there was sort of cartoon characters and things on

63

**A.** Thank you very much.

**SIR BRIAN LANGSTAFF:** -- very, very much indeed and in particular for, as you said, telling us things that you've never told anyone before. We've been privileged. Thank you.

**A.** Thank you very much. Thank you, sir.

Thank you for having the opportunity. We really welcome the opportunity to tell the stories, as much as it's hard, it's really important.

**SIR BRIAN LANGSTAFF:** We'll take a break now until 1.30 pm.

**MS RICHARDS:** Thank you, sir.

**SIR BRIAN LANGSTAFF:** 1.30 pm.

(12.15 pm)

(The luncheon adjournment)

(1.30 pm)

**SIR BRIAN LANGSTAFF:** Our next witness wishes to be known as Graeme, does he?

**MS FRASER BUTLIN:** That's right.

**SIR BRIAN LANGSTAFF:** Graeme, please.

**GRAEME MALLOCH, sworn**

**Questioned by MS FRASER BUTLIN**

**Q.** Graeme, you have severe haemophilia A.

**A.** That's correct.

**Q.** And when you were young, how often did you need

62

the walls, and I quite enjoyed going because there was a play room and there was a games console and things like that. But I remember my Mum sort of sitting in the waiting room talking to other parents of children who had other conditions, not necessarily haemophilia.

**Q.** And your understanding is that throughout your childhood, you only ever received Scottish factor products?

**A.** That's correct.

**Q.** Why is that?

**A.** Well, again I believe largely because Tayside or Dundee was quite disorganised in terms of its haemophilia service, that there was no oversight from a director in terms of procurement, so all supplies by default came from SNBTS lab in Dundee.

**Q.** And that's what you've been told subsequently, that that's what was happening.

**A.** Yeah, I think we'd established that previously but I've also been told that again recently.

**Q.** In 1985 you now understand you were tested for HIV?

**A.** Yeah.

**Q.** Can we have 2192006, please, Paul.

It's a letter from January 1985 which says that you attended a special clinic for haemophiliacs on 11 January arranged along with another doctor so that

64



the problem of AIDS could be explained:

"A sample of blood was removed from Graeme for antibodies to the AIDS virus (HTLV-III), and the sample will be sent to Edinburgh along with others obtained at the same time from other haemophiliacs."

Then there's some discussion about hepatitis B. As far as you're aware, did your Mum attend such an appointment?

A. I obviously don't remember it as I would only have been five years at the time, but I've spoken to my Mum and my Dad about it. They have no recollection at all of this special clinic. They believe if this did happen, it would have been dressed as a standard haemophilia check-up, but they have no recollection of it whatsoever.

As a parent myself, I think if I was asked to come in and have my child tested for AIDS I would remember it, and my parents have no recollection of this whatsoever.

Q. Do they have any recollection of being told the result of that test?

A. No.

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

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

65

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

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

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

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

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

67

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

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

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

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

A. Well, we understood it to be that they were just going to be checking my inhibitor levels and the effectiveness of the treatment. We didn't expect there to be any sort of virology checks as a result of changing over to the new treatment.

Q. In late 1994/early 1995, when you were about 15, your

66

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

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

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

A. I believe she contacted Dr Wilkie the very same day and arranged a meeting.

Q. And what was she told?

A. I think she was -- was invited to come in for a meeting with my Dad. I don't think I was invited or I was excluded in some way, so she did attend a meeting, possibly it was about a couple of weeks later.

Q. We've got a letter from February 1995. It's 2192002. We can see that the purpose of the meeting was to discuss the fact that you were hepatitis C-positive, and the letter says in the second paragraph:

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

68

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

8 And if we carry on down the page it says:

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

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

15 A. They certainly were not relieved. When I received my  
16 notes and saw this letter, I showed it to my parents  
17 and I think they -- it's not funny, but they were  
18 almost rolling about the floor laughing at the way it  
19 was worded. They were not relieved in the slightest.  
20 After having had that meeting they were scared for the  
21 future and they didn't know really what it meant for  
22 me.

23 Q. What were you told about the hepatitis C?

24 A. From my parents I was told not to worry, that things  
25 would get sorted. I think they tried to calm me and

69

1 Q. When you were told about the diagnosis and you were  
2 told not to tell anyone what did you understand the  
3 diagnosis to mean for you?

4 A. That I was at the beginning of the end of my life.  
5 You know, I felt that I had just been given a death  
6 sentence and, you know, that I was only 15. I didn't  
7 really know what to do with it, if I'm honest. I was  
8 very scared, but outwardly I was trying to be brave  
9 because I didn't want my parents to see me upset.  
10 I wanted them to be -- they had been through the mill  
11 enough with my haemophilia. I didn't want them to  
12 sort of think that I was scared for my future.  
13 I wanted them to see me still as a positive teenager  
14 with a bright future, so I bottled it up and I put it  
15 away, and tried to carry on regardless.

16 Q. And did you talk to your parents much at all about it,  
17 or is it something that you --

18 A. Very little. I talked to them if they asked me  
19 anything, but I didn't go to them about anything.

20 Q. And you've said that you had been told not to tell  
21 anyone about it. What was the impact of that at  
22 school and with your friends?

23 A. Yeah. So nobody during my school days found out. It  
24 was a closely guarded secret. If you don't mind I'm  
25 just going to refer to some of my notes, because I'm

71

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

8 Q. Did you have any discussion with the doctors about it?

9 A. I don't recall at that stage, no.

10 Q. And how do you feel now about that delay in telling  
11 you or your Mum?

12 A. So that's from the test in 1992 until --

13 Q. 1995.

14 A. -- the letter I've received in 1995. I'm very angry  
15 about it. You know, if they knew in 1992 why didn't  
16 they tell us in 1992? It either means somebody  
17 withheld that information from us or somebody wasn't  
18 checking my results. Either way, it shouldn't have  
19 happened, you know, and if they hadn't checked my  
20 results why were testing me in the first place? So it  
21 does point to the fact that they probably withheld the  
22 information from me.

23 Q. And subsequently you've been concerned that if your  
24 Mum hadn't asked in 1995 when you were told --

25 A. When she was eventually told, yeah, yeah, exactly.

70

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

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

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

16 Q. What was the impact on your schooling, on your  
17 academic progression?

18 A. I think I did okay. I got enough -- you know, I was  
19 a fairly diligent kid. I did enough to get through  
20 all my exams. I got some decent higher results and  
21 managed to get to university and I got through  
22 university as well, probably didn't do as well as what  
23 I should have done either at school or university but  
24 that's because I think my mind wasn't really into it  
25 as I should have been.

72

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

73

1 sort of waiting for funding to come through, but  
2 I also wonder if it was perhaps to let me get past my  
3 school days. I don't really know the ins and outs of  
4 why it was held off until that point but I do remember  
5 hearing about funding issues.  
6 Q. So you had your first round of combination therapy in  
7 about 1998/1999.  
8 A. Yeah.  
9 Q. What impact did that have on you?  
10 A. I remember all the flu-like symptoms. It was pretty  
11 awful, waking up every day feeling like you had the  
12 flu and nothing you could do would shake it. I was  
13 tired and I remember things like headaches quite  
14 regular as well, but mainly the flu-like symptoms and  
15 tiredness.  
16 Q. And at that time you were at university?  
17 A. Yeah.  
18 Q. What effect did this have on your studies?  
19 A. It didn't stop me from attending, thankfully, because  
20 it was quite important that I got through the course  
21 but, again, I don't think I applied myself as well as  
22 I could have done if I hadn't been on the treatment.  
23 Q. That first round of treatment was unsuccessful.  
24 A. Correct.  
25 Q. And then you had a second round in 2001.

75

1 were first informed about you being hepatitis C positive  
2 in a letter ... on 16 January 1995. The first  
3 identification of hepatitis C antibody was in  
4 November 1992 as part of a general virological screen  
5 when you were changing Factor VIII products."  
6 Had you been told or your parents been told in  
7 1992 that you were having a general virological  
8 screen?  
9 A. Yes, that was part of changing the product but -- no,  
10 sorry, they weren't told that there was a general  
11 virological screen. They were told that they were  
12 doing routine bloods.  
13 Q. That was the careful monitoring bit?  
14 A. Yes.  
15 Q. But nothing about viruses?  
16 A. No.  
17 Q. And so I take it from that you weren't aware that you  
18 were being tested for hepatitis C in 1992?  
19 A. Not at all, no.  
20 Q. Once treatment options were discussed with you after  
21 your diagnosis, you had to wait for your first round  
22 of treatment.  
23 A. Yeah.  
24 Q. Why was that?  
25 A. I think there was a mixture of -- I did hear about

74

1 A. Hmm.  
2 Q. Why did that come to an end?  
3 A. It wasn't working, so I was on the treatment for six  
4 months and I was told, "It's not working. It's very  
5 unlikely to work at this stage", and given that I was  
6 suffering from the side effects that it was probably  
7 best to stop.  
8 Q. By then you were still at university. You were  
9 towards the end of your university course?  
10 A. Yeah.  
11 Q. Again, what was the impact of having the treatment on  
12 you?  
13 A. Similar. I was unwell again. Probably struggled  
14 a little more the second time round. I lost a lot of  
15 weight. I remember having to go on nutritional milk  
16 shakes and things to try and keep my weight up. It  
17 was pretty tough but, again, I was able to just about  
18 do enough at university to get through.  
19 It was doubly fortunate that the course I was  
20 doing was geography, and it's something that I  
21 actually have a background interest in any way, so as  
22 much as I wasn't applying myself to the course in the  
23 way that I would have liked, I was probably able to  
24 infer enough with my own background knowledge just to  
25 pad out what I was learning on the course.

76

1 Q. I think at that point you'd also moved home again to  
 2 have a bit of extra support during the treatment.  
 3 A. Yeah, I think I'd gone back home to live with my  
 4 parents, yeah, yeah.  
 5 Q. After university, you were offered a media job.  
 6 A. Hmm.  
 7 Q. What can you tell us about that?  
 8 A. Yeah, after I graduated I was obviously looking for  
 9 a career and one of the things that had interested me  
 10 was this media job. I attended for an interview. The  
 11 interview went very well, so well in fact that it was  
 12 more or less concluded that, "We just need to send you  
 13 for a medical but that's a formality and an offer will  
 14 come out in the post afterwards".  
 15 So I went for the medical, I think it was  
 16 a couple of days later. I hadn't disclosed my  
 17 haemophilia or hepatitis at the interview or in my  
 18 application, but I didn't think it was going to be  
 19 an issue but I went for the medical and when I was  
 20 lying on the table the doctor who was doing the  
 21 medical happened to notice I had three small scars in  
 22 my stomach area which were from the liver biopsy that  
 23 I'd had when I was I think 16, possibly, and obviously  
 24 enquired as to what those scars were, and that's when  
 25 I disclosed obviously that I'd had hepatitis C as

77

1 and they thought I would be a good fit because they  
 2 knew me for four years and they knew I had a degree  
 3 and was looking for a proper career and felt I'd be  
 4 a good fit for them.  
 5 So they made me an offer and that's where  
 6 I stayed then for I think it was 12 years.  
 7 Q. By -- or not long after that you met your wife and you  
 8 married.  
 9 A. We married in 2007 but we met not long after, 2001,  
 10 yeah.  
 11 Q. 2007 you got married and your wife was very keen to  
 12 have children?  
 13 A. Yes.  
 14 Q. As were you?  
 15 A. Mmm-hmm.  
 16 Q. But you waited for some time.  
 17 A. Yeah.  
 18 Q. Can you tell us why?  
 19 A. Ultimately, I was the one who kind of held off more  
 20 than my wife because of my hepatitis C status.  
 21 I didn't want to risk the possible transmission of  
 22 hep C to my wife, but we sort of -- you know, I was  
 23 absolutely petrified of actually passing it on and  
 24 that's why we sort of held off and we held off and we  
 25 held off, and it was ultimately sort of in 2011/12

79

1 a result of my haemophilia.  
 2 A week or so passed and the letter never came to  
 3 offer the job and I eventually got fed up waiting and  
 4 phoned up and was told that the job had been filled by  
 5 somebody else.  
 6 Q. How did you feel that point?  
 7 A. Devastated. You know, I was really keen on the job  
 8 and I'd been more or less told that I had it. I was  
 9 really looking forward to it, so I think I kind of  
 10 knew after the medical that there might have been  
 11 issues but I kind of still hoped that I was going to  
 12 get it, but it never happened so I was really upset.  
 13 Q. So what did you do after that, in terms of work?  
 14 A. Luckily whilst I'd been at university I'd had a summer  
 15 job working in a shoe warehouse. When I had finished  
 16 university, they actually gave me a permanent  
 17 part-time position working in the warehouse and they  
 18 knew that I was looking for a proper career to fall on  
 19 from that.  
 20 Luckily, I think it wasn't long after the  
 21 rejection from the media job, they invited me to come  
 22 through to the office and had a chat with me about  
 23 possibly moving into a management position. The stock  
 24 controller of that company was due to retire in  
 25 a year's time and they needed somebody to replace her,

78

1 that we kind of felt we can't really wait any longer.  
 2 Q. You were offered a third round of treatment and you  
 3 deferred that --  
 4 A. Yes.  
 5 Q. -- in order to start a family?  
 6 A. Yes. It was sort of coincidental that around about  
 7 the time when my wife and I decided we couldn't wait  
 8 any longer to start a family that the next sort of  
 9 round of treatment was made available.  
 10 We felt because of the length of time that  
 11 I would be on the treatment and the time you have to  
 12 wait afterwards for getting pregnant that it would be  
 13 best that I deferred the treatment.  
 14 At this stage I wasn't unwell from the  
 15 hepatitis C, not noticeable anyway, so the advice was  
 16 that there was no rush to get started so that there  
 17 was time for us to start a family, if that's what we  
 18 wished to do. So the agreement was we would defer the  
 19 treatment for a year to allow us to start trying for  
 20 a family.  
 21 It was getting touch and go, so much so that we  
 22 decided that actually we got involved with freezing my  
 23 sperm because we were getting worried that we weren't  
 24 going to fall pregnant before I was due to start the  
 25 treatment and in case of any complications we wanted

80

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

81

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

83

1 **Q.** Why is that?  
 2 **A.** That was actually through the Scottish  
 3 Infected Blood Support Scheme. Some of the  
 4 information that was -- that I found when I was doing  
 5 the application suggested that interferon can  
 6 exacerbate arthritis and that's why I kind of wonder  
 7 whether that might have been the case with me.  
 8 My arthritis in my ankles has primarily been  
 9 caused by bleeds from my haemophilia, but I don't  
 10 really remember the arthritis kicking in until sort of  
 11 the early 2000s, which was not long after the two  
 12 courses of interferon treatment. It may be  
 13 coincidental but it may not be.  
 14 **Q.** For you the timing is pretty close to having started  
 15 that interferon and the arthritis getting worse?  
 16 **A.** Correct, yes, yeah.  
 17 **Q.** What's the situation now with your liver?  
 18 **A.** I believe I have minimal or no fibrosis based on the  
 19 last sets of ultrasound scans that I had before the  
 20 treatment, so I'm hopeful that's still the case.  
 21 **Q.** Have you had any monitoring since completing the  
 22 treatment?  
 23 **A.** I've had liver function tests done for a about a year  
 24 afterwards, which were all normal.  
 25 **Q.** Anything since then?

82

1 It's kind of difficult to say, because I don't  
 2 know what I was like before other than I was a quite  
 3 an outgoing kid. I feel like I became more reserved  
 4 after the treatment came and more secretive.  
 5 One of the things that kind of sticks out for me  
 6 is that my haemophilia was actually something I wore  
 7 very proudly as a child. I was very outgoing and  
 8 I talked about it all the time. I did demonstrations  
 9 in a classroom. I did talks in the classroom about  
 10 it, I even did a treatment demonstration but a couple  
 11 of kids fainted in the class, so my haemophilia was  
 12 something I was very proud of, strangely. You know,  
 13 it was a big part of who I was.  
 14 When I got the hepatitis C diagnosis it felt  
 15 like almost a part of me kind of died because by  
 16 association the haemophilia became a dirty word and it  
 17 was something I then had to hide away. Where I had  
 18 been very open about my haemophilia, it was now  
 19 something I hid away because I didn't want people to  
 20 make the connection between haemophilia and  
 21 hepatitis C. So, yeah, that did affect me quite a lot  
 22 and it still does. You know, to this day I'm not very  
 23 open with people about anything, to be honest. I keep  
 24 a lot to myself.  
 25 **Q.** You describe in your statement being a closed door

84

1 emotionally.

2 A. Yeah.

3 Q. And often feeling emotionally detached from reality

4 and kind of flat line.

5 A. Yeah, yeah, I don't get upset the way I should get

6 upset about things which are distressing or upsetting.

7 I don't get the elation maybe that I should do when

8 something really good happens. I do feel like I'm

9 just kind on a level all the time.

10 Q. What has been the impact of the infection of your

11 family life?

12 A. I'm not as affectionate as I should be, I don't think.

13 You know, kisses and cuddles with my kids and my wife

14 don't come naturally. I really do have to work hard

15 at it and remind myself that it's okay to do these

16 things, and I think that's partly as well that, you

17 know, for many years I actually felt dirty and

18 infectious. You know, I didn't want to touch people.

19 I used to think, you know, that my sweat would

20 be infectious and I would be worried about touching

21 light switches in case somebody came along and touched

22 it after me and got hep C, you know, so it's

23 definitely affected me.

24 Don't get me wrong, I love my kids dearly and

25 I think they know that as well but, you know, I think

85

1 that I've sort of thought about for this is, you know,

2 if you're not hungry you're not hungry, but if you

3 pass a fish and chip shop you'll all of a sudden be

4 very hungry. The same with counselling. If it's

5 there right in front of you and somebody starts

6 a conversation, even if you didn't want that

7 conversation, it might happen and it might start the

8 outpouring of what you need to talk about.

9 Q. You've reflected in your statement that you think you

10 probably would have benefited from counselling,

11 certainly in the early days --

12 A. Yeah.

13 Q. -- even if you hadn't really wanted it?

14 A. Correct, yeah, if it had been given to me and almost

15 made compulsory I think it would have helped.

16 Q. In terms of your working life, during that third round

17 of treatment your daughter was born and you were made

18 redundant.

19 A. Yeah.

20 Q. And you said the side effects were awful.

21 A. Yeah.

22 Q. But the impact of that situation with work was also

23 very difficult.

24 A. Yeah, I was -- as you say, I was right in the midst of

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

87

1 I would have been a more affectionate and sort of

2 cuddly kind of Dad if that was the -- if I hadn't had

3 the hep C.

4 Q. And how has it affected your marriage.

5 A. I'm very lucky in a way that Laura has known me since

6 2001 and she was one of the first people I actually

7 probably really confided in about the hep C so she's

8 always known about it so it's been a part of our

9 relationship all the way through, but I don't think it

10 has helped. You know, I've -- as I say, I'm probably

11 not as physically affectionate as what I should be.

12 It is something I have to work as hard at and it's

13 probably not as natural a physical relationship as it

14 should be.

15 Q. Throughout this time have you been offered any

16 counselling or psychological support?

17 A. No, other than attending the usual haemophilia

18 clinics, "Are you okay? Is there anything you want to

19 talk about?" There's not been any sort of specialist

20 counselling offered.

21 Q. Do you think if there had been some offered you would

22 have taken it up?

23 A. I'm probably a typical guy in that, no, I probably

24 wouldn't have. That's not to say that it shouldn't

25 have been sort of pushed on me. One of the things

86

1 born on 26 December and I'd actually taken two weeks

2 off work with the idea that I would have paternity

3 leave to follow on after that. So I was off work over

4 Christmas and New Year and I think it was on -- my

5 daughter still hadn't been born but it was around

6 about 5 January I got a phone call from work to say

7 that the business was closing down and you know that

8 obviously they had started the consultation process

9 about redundancy, and then my daughter was born on

10 10 January, five days later. It was very difficult.

11 I was in a bit of a mess, but I had to put a brave

12 face on it because my wife had been very unwell during

13 her pregnancy as well, so she needed my support and,

14 you know, I wasn't well enough to really give as much

15 as I would have liked to have done.

16 The redundancy thing, I kind of really just put

17 that to the back of my mind because I had bigger

18 things to deal with. I could worry about work later

19 but it was still a considerable thing to have to deal

20 with.

21 Q. When you did come to worry about work, what did you go

22 on to do?

23 A. I was fortunate that whilst I'd been working at the

24 shoe factory I'd also kind of had some promotions and

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

88

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

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

9 Q. And where you're working now, you've said it's been  
10 much easier health-wise because it's a family  
11 business?

12 A. Yeah, I didn't last long in the sort of media world  
13 and I'm now in the family business, which is easier  
14 because most people there do know my situation. It's  
15 a difficult job. It's quite long hours and quite  
16 a bit of stress because I'm essentially running the  
17 company but, as I say, people do know my circumstances  
18 so there's a bit of flexibility for me to come and go.

19 Q. In terms of financial effects can you tell us what the  
20 impact has been financially?

21 A. Yeah, going back again to sort of when I was first  
22 told about the hep C, there was that carefree  
23 attitude, you're a bit -- I didn't think I was going  
24 to be around long, so similar to where I wasn't too  
25 worried about my studies I wasn't really worried about

89

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

10 Q. And that is your ongoing major worry?

11 A. Yeah, it's looking after my family for the future.

12 Q. And that something might happen to you --

13 A. Yeah.

14 Q. -- even though you've cleared the virus --

15 A. Yeah.

16 Q. -- you continue to be worried about what your health  
17 will be in the future?

18 A. Yes, as I say, I'm worried that the foundation stones  
19 for future ill health haven't already been laid. You  
20 know, I had hep C for 30 years, so who knows? And  
21 I don't think there's anybody who -- nobody can tell  
22 you what the future holds for somebody who has had  
23 hepatitis C for 30 years because it's not happened  
24 yet.

25 Q. Those are the questions I have for you. Is there

91

1 money either. I had the sort of feeling I was going  
2 to be dead in a few years anyway so I might as well  
3 enjoy things while I was around, so I was very  
4 carefree with money. I just spent it, spent it, spent  
5 it, spent it, got into a lot of debt trying to enjoy  
6 myself while I still could. I was immature and silly,  
7 but that was the way I was.

8 Q. And then subsequently you've had difficulties with  
9 life insurance.

10 A. I don't have life insurance. I think I tried once and  
11 was rejected, so I've never tried again.

12 Q. And you've struggled with travel insurance.

13 A. I do get travel insurance but it's much more expensive  
14 than normal life -- travel insurance.

15 Q. You've received a Skipton Fund payment and some  
16 payments from the Scottish scheme.

17 A. Yes.

18 Q. What are your views of the scheme?

19 A. They're helpful but they're a long way short of what  
20 I think should be available. I've not had any  
21 difficulties getting those payments. I think my case  
22 has probably been quite cut and dry but, you know, the  
23 money has helped but it's a long way short of giving  
24 sort of financial security should I ever become  
25 unwell.

90

1 anything else you would like to say?

2 A. I've got a short statement which I would like to read.

3 Q. Please do.

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

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

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

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

92

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

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

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

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

93

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

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

13 Q. When you were diagnosed you were very concerned about  
14 passing on hepatitis C?

15 A. Yes.

16 Q. And washing your hands and being very scrupulous in  
17 that regard.

18 A. Mmm-hmm.

19 Q. You were also worried in case you had passed it on to  
20 your Mum.

21 A. Yeah.

22 Q. And she was subsequently tested as well and was clear?

23 A. Yeah, she was tested because there was a concern that  
24 it could have been passed on. My Mum was my  
25 treatment-giver up until when I started doing it

95

1 and ensuring that nothing like this could ever happen  
2 again.

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

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

8 A. Yeah.

9 Q. When you changed over to the higher purity Factor VIII  
10 from -- higher purity Factor VIII from 1992, were your  
11 parents told of any risks involved in any of the  
12 products, whether that was the higher purity or before  
13 that?

14 A. No, they had no awareness at all of any risks.

15 Q. Can you tell us about the emotional impact this has  
16 had on your parents.

17 A. Yeah. I mean, as I mentioned, I've not really spoken  
18 to them over the years about it because I've tried to  
19 let them feel that I'm okay.

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

94

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

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

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

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

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

96



1 records, there's almost nothing from your childhood,  
 2 hospital records. In fact, there are no childhood  
 3 hospital records only the GP bits that we've seen.  
 4 **A.** Yeah, they seem to be missing or omitted in some way.  
 5 There was numerous admissions as a child through the  
 6 1980s, which I can remember various examples, and  
 7 there was nothing I could find in the records that  
 8 relate to those.  
 9 **MS FRASER BUTLIN:** Sir?  
 10 **SIR BRIAN LANGSTAFF:** Thank you for what has been a very  
 11 clear and frank account of your story and for giving  
 12 us, amongst other things, amongst the whole of your  
 13 story, the insight into being a 15-year-old diagnosed  
 14 with hepatitis C and seeking to protect your parents,  
 15 whilst your parents were seeking to protect you. It's  
 16 reflective of some other testimony we've heard. It's  
 17 not all the same but it gives us a very useful and  
 18 interesting insight. Thank you.  
 19 **A.** Thank you. Thank you again.  
 20 **SIR BRIAN LANGSTAFF:** Well, that concludes the evidence  
 21 for today. Now, tell us what we may expect tomorrow.  
 22 **MS FRASER BUTLIN:** Tomorrow we have two separate anonymous  
 23 witnesses, followed by Pauline Reid and followed by  
 24 a further anonymous witness.  
 25 **SIR BRIAN LANGSTAFF:** Thank you. 10 o'clock tomorrow.

97

1 10 o'clock.  
 2 (2.18 pm)  
 3 (Adjourned until 10.00 am the following day)  
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98

## I N D E X

1		
2		
3		
4	MR W, affirmed .....	3
5	Questioned by MS RICHARDS .....	3
6	CHRISTINE NORVAL, affirmed .....	29
7	Questioned by MS RICHARDS .....	29
8	GRAEME MALLOCH, sworn .....	62
9	Questioned by MS FRASER BUTLIN .....	62
10		
11		
12		
13		
14		
15		
16		
17		
18		
19		
20		
21		
22		
23		
24		
25		

99

<p><b>MS FRASER BUTLIN:</b> [3] 62/19 97/9 97/22</p> <p><b>MS RICHARDS:</b> [8] 1/20 14/16 14/19 28/12 29/11 29/18 29/22 62/12</p> <p><b>SIR BRIAN LANGSTAFF:</b> [22] 1/3 2/2 14/14 14/17 28/16 29/1 29/6 29/8 29/10 29/12 29/16 29/19 60/3 61/25 62/2 62/10 62/13 62/17 62/20 97/10 97/20 97/25</p> <p>'</p> <p><b>'90s</b> [1] 93/2</p> <p><b>'a</b> [1] 33/20</p> <p><b>'a mild</b> [1] 33/20</p> <p><b>'s</b> [11] 6/13 7/20 13/22 14/2 14/24 15/14 16/24 18/6 19/23 20/22 21/21</p> <p>.</p> <p><b>...</b> [1] 13/2</p> <p><b>... and</b> [1] 13/2</p> <p><b>1</b></p> <p><b>1.30 pm</b> [3] 62/11 62/13 62/16</p> <p><b>10</b> [1] 96/1</p> <p><b>10 January</b> [1] 88/10</p> <p><b>10 o'clock</b> [2] 97/25 98/1</p> <p><b>10.00 am</b> [1] 98/3</p> <p><b>10.12 am</b> [1] 1/2</p> <p><b>10.51 am</b> [1] 29/13</p> <p><b>11</b> [1] 96/1</p> <p><b>11 January</b> [1] 64/25</p> <p><b>11.20 am</b> [2] 29/10 29/12</p> <p><b>11.25 am</b> [1] 29/15</p> <p><b>12</b> [2] 79/6 79/25</p> <p><b>12.15 pm</b> [1] 62/14</p> <p><b>120 miles</b> [2] 4/18 21/6</p> <p><b>13</b> [1] 12/14</p> <p><b>15</b> [3] 13/19 66/25 71/6</p> <p><b>16</b> [1] 77/23</p> <p><b>16 January 1995</b> [1] 74/2</p> <p><b>19 September</b> [1] 12/22</p> <p><b>1948</b> [1] 27/6</p> <p><b>1976</b> [1] 3/21</p> <p><b>1978</b> [1] 3/21</p> <p><b>1980s</b> [5] 26/12 27/9 63/15 93/2 97/6</p>	<p><b>1984</b> [4] 4/12 5/1 12/12 12/23</p> <p><b>1985</b> [2] 64/20 64/23</p> <p><b>1986</b> [2] 3/16 7/19</p> <p><b>1987</b> [1] 17/19</p> <p><b>1988</b> [1] 30/15</p> <p><b>1990</b> [1] 32/13</p> <p><b>1990s</b> [1] 42/2</p> <p><b>1991</b> [2] 35/3 63/16</p> <p><b>1992</b> [13] 12/2 15/1 22/19 65/23 66/7 70/12 70/15 70/16 73/17 74/4 74/7 74/18 94/10</p> <p><b>1994</b> [1] 67/14</p> <p><b>1994/early 1995</b> [1] 66/25</p> <p><b>1995</b> [8] 66/25 68/1 68/20 70/13 70/14 70/24 72/4 74/2</p> <p><b>1996</b> [1] 39/5</p> <p><b>1999</b> [3] 73/10 73/24 75/7</p> <p><b>2</b></p> <p><b>2.18 pm</b> [1] 98/2</p> <p><b>20</b> [1] 12/12</p> <p><b>20 September</b> [1] 13/3</p> <p><b>20-plus</b> [1] 56/8</p> <p><b>2000s</b> [2] 42/3 82/11</p> <p><b>2001</b> [3] 75/25 79/9 86/6</p> <p><b>2004</b> [1] 43/8</p> <p><b>2007</b> [2] 79/9 79/11</p> <p><b>2011/12</b> [1] 79/25</p> <p><b>2014</b> [1] 50/25</p> <p><b>2019</b> [1] 1/1</p> <p><b>2192002</b> [1] 68/20</p> <p><b>2192004</b> [1] 66/6</p> <p><b>2192006</b> [1] 64/22</p> <p><b>2192007</b> [1] 73/23</p> <p><b>2192008</b> [1] 67/25</p> <p><b>21st</b> [1] 53/15</p> <p><b>23</b> [1] 12/21</p> <p><b>26 December</b> [1] 88/1</p> <p><b>2781002</b> [1] 12/7</p> <p><b>3</b></p> <p><b>30</b> [5] 25/25 52/11 91/20 91/23 93/10</p> <p><b>30 years</b> [1] 83/10</p> <p><b>33</b> [1] 17/19</p> <p><b>5</b></p> <p><b>5 January</b> [1] 88/6</p> <p><b>54</b> [1] 56/9</p> <p><b>54th</b> [1] 56/15</p> <p><b>9</b></p> <p><b>9 July</b> [1] 1/1</p>	<p><b>A</b></p> <p><b>A3</b> [1] 13/4</p> <p><b>able</b> [14] 6/4 9/22 19/4 36/13 40/5 40/19 54/19 57/23 76/17 76/23 81/1 81/1 89/4 91/7</p> <p><b>about</b> [116]</p> <p><b>about 1998/1999</b> [1] 75/7</p> <p><b>above</b> [1] 93/17</p> <p><b>abroad</b> [1] 26/20</p> <p><b>absolutely</b> [16] 5/24 6/10 14/1 22/5 23/7 25/15 31/21 36/3 38/20 41/18 52/13 52/18 58/3 59/22 73/5 79/23</p> <p><b>academic</b> [1] 72/17</p> <p><b>accepted</b> [1] 6/8</p> <p><b>accident</b> [3] 12/22 13/20 14/9</p> <p><b>accord</b> [2] 27/15 69/13</p> <p><b>account</b> [2] 60/4 97/11</p> <p><b>Ackrill</b> [5] 8/19 8/22 9/1 10/8 19/6</p> <p><b>acquainted</b> [1] 92/19</p> <p><b>across</b> [2] 19/3 19/4</p> <p><b>act</b> [1] 95/2</p> <p><b>acting</b> [2] 2/18 2/20</p> <p><b>action</b> [4] 27/11 27/12 73/11 92/11</p> <p><b>active</b> [1] 69/7</p> <p><b>activity</b> [1] 69/1</p> <p><b>actual</b> [4] 8/10 19/17 69/1 72/3</p> <p><b>actually</b> [38] 1/7 4/20 7/1 8/4 8/23 11/14 11/18 11/24 15/9 15/16 18/3 20/4 22/11 30/23 33/3 33/19 34/9 43/24 44/23 45/2 46/25 54/1 59/20 60/18 67/8 72/4 76/21 78/16 79/23 80/22 82/2 84/6 85/17 86/6 88/1 95/2 95/6 96/12</p> <p><b>acutely</b> [1] 52/25</p> <p><b>add</b> [1] 59/13</p> <p><b>added</b> [1] 93/14</p> <p><b>address</b> [2] 2/11 50/16</p> <p><b>Adjourned</b> [1] 98/3</p> <p><b>adjournment</b> [1] 62/15</p> <p><b>admissions</b> [1] 97/5</p> <p><b>admitted</b> [2] 12/11 53/5</p> <p><b>adopted</b> [2] 61/17</p>	<p>73/6</p> <p><b>adopts</b> [1] 61/14</p> <p><b>adult</b> [1] 96/14</p> <p><b>adverts</b> [4] 11/6 11/8 17/7 27/17</p> <p><b>advice</b> [2] 9/21 80/15</p> <p><b>affect</b> [2] 1/10 84/21</p> <p><b>affected</b> [9] 26/10 27/23 53/1 58/11 67/18 67/22 85/23 86/4 92/17</p> <p><b>affectionate</b> [3] 85/12 86/1 86/11</p> <p><b>affirmed</b> [4] 3/3 29/20 99/3 99/5</p> <p><b>afford</b> [2] 46/16 60/11</p> <p><b>after</b> [43] 4/22 5/24 6/9 10/7 10/14 11/23 16/7 16/8 17/22 19/5 19/11 19/16 19/22 20/25 24/21 31/2 31/14 37/25 39/14 40/20 42/25 43/25 43/25 49/13 52/9 53/6 58/6 61/8 69/20 74/20 77/5 77/8 78/10 78/13 78/20 79/7 79/9 82/11 84/4 85/22 88/3 91/5 91/11</p> <p><b>afternoon</b> [1] 8/4</p> <p><b>afterwards</b> [4] 58/14 77/14 80/12 82/24</p> <p><b>again</b> [31] 2/3 10/8 22/4 22/15 23/16 24/15 37/6 38/1 40/1 41/23 42/25 42/25 43/21 44/19 48/25 53/4 56/15 57/24 64/11 64/19 75/21 76/11 76/13 76/17 77/1 81/11 81/13 89/21 90/11 94/2 97/19</p> <p><b>against</b> [2] 33/16 36/12</p> <p><b>age</b> [3] 56/9 56/10 96/1</p> <p><b>Age 54</b> [1] 56/9</p> <p><b>aged</b> [1] 12/21</p> <p><b>agency</b> [1] 30/22</p> <p><b>aggressive</b> [1] 38/3</p> <p><b>ago</b> [7] 6/15 19/18 19/20 25/25 26/3 48/12 93/9</p> <p><b>agree</b> [1] 52/17</p> <p><b>agreed</b> [3] 1/13 5/10 96/24</p> <p><b>agreeing</b> [1] 20/15</p> <p><b>agreement</b> [2] 23/2 80/18</p> <p><b>ahead</b> [4] 27/22 92/14 93/8 93/18</p>	<p><b>AIDS</b> [10] 26/13 27/10 27/14 31/5 32/7 32/10 65/1 65/3 65/17 70/5</p> <p><b>albeit</b> [1] 92/14</p> <p><b>all</b> [51] 2/23 4/11 5/11 6/23 7/16 7/17 7/18 8/14 9/23 11/22 13/2 17/14 20/1 21/13 21/20 25/5 26/2 26/5 27/1 32/4 33/24 34/10 35/25 39/3 41/13 42/6 42/7 42/15 45/5 50/4 51/10 55/13 55/15 64/14 65/11 66/12 67/10 70/6 71/16 72/20 74/19 75/10 82/24 84/8 85/9 86/9 87/3 92/13 93/25 94/14 97/17</p> <p><b>allow</b> [2] 12/4 80/19</p> <p><b>allowed</b> [3] 15/23 26/7 59/23</p> <p><b>almost</b> [9] 13/4 34/9 43/12 51/13 56/24 69/18 84/15 87/14 97/1</p> <p><b>along</b> [3] 64/25 65/4 85/21</p> <p><b>already</b> [5] 6/11 20/13 27/20 83/11 91/19</p> <p><b>also</b> [22] 13/7 13/23 13/25 15/15 24/17 27/24 41/14 49/8 52/3 52/4 64/19 66/9 70/2 73/22 75/2 77/1 81/23 87/22 88/24 93/12 94/22 95/19</p> <p><b>altered</b> [1] 93/5</p> <p><b>alternative</b> [1] 69/6</p> <p><b>although</b> [4] 4/9 24/2 30/6 61/14</p> <p><b>always</b> [16] 11/11 25/2 26/12 27/4 27/6 36/3 39/16 42/18 44/9 49/12 51/19 54/9 56/7 61/16 83/7 86/8</p> <p><b>am</b> [18] 1/2 1/3 24/11 25/24 29/10 29/12 29/13 29/15 49/20 49/21 57/3 57/3 57/11 59/22 81/16 93/11 93/12 98/3</p> <p><b>America</b> [1] 26/23</p> <p><b>amongst</b> [2] 97/12 97/12</p> <p><b>amounts</b> [2] 14/14 35/10</p> <p><b>amputations</b> [1] 49/16</p> <p><b>an 11/12-year-old</b> [1] 53/9</p> <p><b>an absolutely</b> [1]</p>	<p>52/13</p> <p><b>an adult</b> [1] 96/14</p> <p><b>an agreement</b> [1] 23/2</p> <p><b>an AIDS</b> [1] 32/10</p> <p><b>an alternative</b> [1] 69/6</p> <p><b>an anonymity</b> [1] 1/15</p> <p><b>an appointment</b> [1] 7/21</p> <p><b>an arbitrary</b> [1] 56/16</p> <p><b>an awkward</b> [1] 60/22</p> <p><b>an easy</b> [1] 21/6</p> <p><b>an end</b> [3] 57/17 58/23 76/2</p> <p><b>an English</b> [1] 67/13</p> <p><b>an entirely</b> [2] 5/22 7/13</p> <p><b>an eviction</b> [1] 36/15</p> <p><b>an HCV</b> [1] 34/18</p> <p><b>an HIV</b> [1] 9/9</p> <p><b>an HIV-positive</b> [1] 13/18</p> <p><b>an hour</b> [3] 9/8 47/17 59/1</p> <p><b>an important</b> [1] 12/8</p> <p><b>an inquest</b> [1] 18/6</p> <p><b>an intern</b> [1] 21/9</p> <p><b>an interview</b> [1] 77/10</p> <p><b>an issue</b> [2] 43/19 77/19</p> <p><b>an MP</b> [1] 57/11</p> <p><b>an occasion</b> [1] 7/19</p> <p><b>an offer</b> [2] 77/13 79/5</p> <p><b>an offhand</b> [1] 67/21</p> <p><b>an office</b> [1] 50/18</p> <p><b>an outgoing</b> [1] 84/3</p> <p><b>an ultrasound</b> [1] 69/2</p> <p><b>Anadin</b> [1] 7/3</p> <p><b>angry</b> [13] 11/15 35/10 38/3 38/4 48/6 53/24 57/3 57/3 57/11 58/12 59/21 59/22 70/14</p> <p><b>ankle</b> [1] 81/24</p> <p><b>ankles</b> [1] 82/8</p> <p><b>anonymity</b> [4] 1/15 2/4 2/9 3/18</p> <p><b>anonymous</b> [2] 97/22 97/24</p> <p><b>another</b> [12] 3/16 8/24 12/25 24/15 38/7 38/13 48/5 50/20 55/10 64/25 89/1 95/9</p> <p><b>answer</b> [2] 18/13 60/5</p> <p><b>answered</b> [1] 5/5</p> <p><b>answers</b> [1] 93/25</p> <p><b>anti</b> [1] 6/8</p> <p><b>anti-rejection</b> [1] 6/8</p> <p><b>antibodies</b> [1] 65/3</p> <p><b>antibody</b> [2] 68/5 74/3</p> <p><b>antidepressants</b> [1]</p>
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(26) MS FRASER BUTLIN: - antidepressants

<b>A</b> <b>antidepressants...</b> [1] 42/22 <b>anxiety</b> [3] 46/24 47/5 57/19 <b>anxious</b> [1] 57/20 <b>any</b> [46] 2/8 2/8 2/13 2/14 2/17 3/12 9/21 10/15 11/21 12/10 15/24 20/23 21/11 21/22 23/12 23/25 27/11 28/16 28/21 34/8 34/15 44/16 50/8 51/20 58/19 60/8 65/20 66/23 70/8 72/7 73/14 73/19 76/21 80/1 80/8 80/25 82/21 86/15 86/19 90/20 92/15 92/16 92/17 94/11 94/11 94/14 <b>anybody</b> [10] 9/24 10/10 10/11 10/12 11/11 56/23 56/24 56/25 91/21 92/18 <b>anyone</b> [4] 62/4 70/3 71/2 71/21 <b>anything</b> [23] 6/19 7/4 7/5 10/14 17/10 23/5 25/12 28/2 28/13 46/16 52/5 54/23 56/19 57/15 59/25 71/19 71/19 82/25 84/23 86/18 89/4 92/1 94/4 <b>anyway</b> [4] 6/9 22/14 80/15 90/2 <b>apart</b> [2] 11/5 52/9 <b>appearance</b> [1] 2/16 <b>appears</b> [1] 27/15 <b>appetite</b> [1] 7/9 <b>application</b> [2] 77/18 82/5 <b>applied</b> [1] 75/21 <b>applying</b> [3] 73/3 73/8 76/22 <b>appointment</b> [2] 7/21 65/8 <b>appreciate</b> [1] 59/17 <b>approach</b> [1] 73/13 <b>approached</b> [1] 67/19 <b>appropriately</b> [1] 93/1 <b>approximately</b> [1] 12/14 <b>arbitrary</b> [1] 56/16 <b>are</b> [36] 8/12 12/19 16/1 19/6 25/10 36/24 37/11 43/15 44/1 44/5 46/3 46/25 49/23 50/10 51/4 55/18 56/18 57/5 57/6 57/7 57/12 57/19 57/23	58/16 59/8 59/9 60/23 66/10 66/15 81/19 85/6 86/18 90/18 91/25 93/22 97/2 <b>area</b> [2] 67/15 77/22 <b>arising</b> [1] 1/17 <b>arms</b> [2] 7/10 18/4 <b>arose</b> [1] 93/2 <b>around</b> [11] 4/12 19/17 47/24 54/21 56/17 73/4 80/6 83/9 88/5 89/24 90/3 <b>arranged</b> [3] 58/14 64/25 68/13 <b>arrival</b> [1] 63/15 <b>arrived</b> [1] 72/4 <b>art</b> [1] 60/15 <b>arthritis</b> [5] 81/24 82/6 82/8 82/10 82/15 <b>articles</b> [1] 41/9 <b>arts</b> [1] 59/5 <b>as</b> [119] <b>ask</b> [12] 16/4 19/22 28/12 28/16 30/3 30/14 52/19 59/24 89/4 94/3 94/4 94/7 <b>asked</b> [18] 1/23 11/11 15/21 15/21 18/9 18/25 33/8 33/20 43/17 43/18 44/19 48/20 56/21 65/16 67/21 70/24 71/18 73/13 <b>asking</b> [1] 73/20 <b>asleep</b> [2] 38/12 38/14 <b>association</b> [1] 84/16 <b>assumed</b> [1] 16/5 <b>attached</b> [3] 9/25 49/15 70/5 <b>attack</b> [1] 20/8 <b>attempt</b> [1] 35/14 <b>attempts</b> [1] 14/8 <b>attend</b> [3] 63/22 65/7 68/17 <b>attended</b> [4] 49/10 64/24 67/16 77/10 86/17 <b>attending</b> [2] 75/19 <b>attention</b> [1] 25/22 <b>attitude</b> [4] 27/9 73/2 73/6 89/23 <b>August</b> [1] 66/7 <b>August 1992</b> [1] 66/7 <b>automatically</b> [1] 11/20 <b>available</b> [7] 4/23 5/2 5/8 23/15 27/25 80/9 90/20 <b>average</b> [1] 56/10 <b>avoid</b> [2] 2/5 2/8 <b>avoided</b> [1] 26/15	<b>awake</b> [1] 8/12 <b>aware</b> [9] 31/10 37/12 52/25 56/12 65/7 67/6 74/17 83/1 92/16 <b>awareness</b> [1] 94/14 <b>away</b> [19] 7/17 9/3 23/3 27/15 39/19 41/25 44/6 45/24 46/14 46/18 48/24 53/10 56/11 56/25 61/11 71/15 83/23 84/17 84/19 <b>awful</b> [5] 36/18 53/20 75/11 87/20 96/4 <b>awkward</b> [1] 60/22 <b>B</b> <b>baby</b> [4] 34/13 34/16 35/1 35/2 <b>back</b> [48] 2/3 4/19 4/21 5/21 5/22 6/15 7/16 8/3 8/23 9/10 10/8 10/17 13/13 17/7 21/18 22/2 23/6 23/11 23/19 23/21 23/23 24/14 33/8 33/14 34/3 35/18 35/21 38/8 40/1 42/18 43/12 46/12 48/25 50/3 54/7 54/14 54/15 58/8 58/9 58/10 58/24 58/25 77/3 83/20 88/17 89/21 91/8 96/5 <b>background</b> [5] 30/8 45/10 46/5 76/21 76/24 <b>bad</b> [6] 18/5 24/4 24/10 36/24 37/15 59/15 <b>badly</b> [1] 26/10 <b>banging</b> [1] 38/11 <b>bare</b> [1] 24/20 <b>based</b> [1] 82/18 <b>basically</b> [1] 20/1 <b>basis</b> [1] 69/3 <b>be</b> [123] <b>bear</b> [1] 93/20 <b>beautiful</b> [2] 3/14 4/4 <b>became</b> [6] 4/23 34/20 67/1 73/10 84/3 84/16 <b>because</b> [94] 2/4 3/9 3/18 4/24 6/16 7/5 7/22 8/13 8/14 9/12 9/13 9/24 11/14 11/22 12/5 12/8 15/17 16/3 17/17 18/2 18/3 19/1 20/10 21/1 22/5 23/6 25/8 27/6 33/10 34/7 34/10 35/15 36/16 37/2 40/4 43/25 44/8 45/5 45/13 45/25 46/2	46/13 46/16 46/21 48/3 49/11 49/12 50/3 50/10 51/8 52/7 53/7 54/9 54/21 55/18 57/19 58/3 58/11 61/17 61/20 61/21 64/1 64/11 66/13 67/8 70/3 71/9 71/25 72/7 72/9 72/10 72/24 73/2 73/21 75/19 79/1 79/20 80/10 80/23 84/1 84/15 84/19 88/12 88/17 89/10 89/14 89/16 91/23 93/19 94/18 94/21 95/23 96/9 96/11 <b>become</b> [10] 5/2 9/19 39/5 39/6 47/10 83/8 88/25 90/24 91/3 91/6 <b>becoming</b> [1] 13/11 <b>bed</b> [9] 7/3 8/4 20/10 24/15 31/19 31/20 38/9 47/16 47/22 <b>been</b> [126] <b>before</b> [17] 1/15 15/9 15/10 27/3 39/11 44/24 44/25 47/1 47/15 53/7 58/4 62/4 80/24 81/3 82/19 84/2 94/12 <b>began</b> [2] 6/13 27/11 <b>begin</b> [2] 1/15 6/14 <b>beginning</b> [1] 71/4 <b>behalf</b> [2] 2/19 2/20 <b>behind</b> [1] 50/1 <b>being</b> [26] 1/19 27/3 31/10 32/10 33/1 34/11 35/12 39/14 40/18 44/6 46/6 48/9 52/25 55/21 55/25 65/20 66/15 66/18 73/15 74/1 74/18 83/15 84/25 91/7 95/16 97/13 <b>believe</b> [20] 8/11 15/6 18/24 20/21 25/5 25/8 25/9 25/23 25/25 36/21 56/11 58/3 59/9 63/17 64/11 65/12 66/2 68/12 73/21 82/18 <b>believed</b> [4] 11/23 15/12 26/13 27/24 <b>believing</b> [1] 43/24 <b>below</b> [1] 81/19 <b>benefit</b> [2] 36/12 66/5 <b>benefited</b> [1] 87/10 <b>benefits</b> [1] 36/13 <b>best</b> [6] 16/1 46/4 61/23 76/7 80/13 96/23 <b>better</b> [13] 7/6 34/10	38/5 39/16 39/21 39/25 44/21 44/25 47/3 55/20 58/17 66/2 66/3 <b>between</b> [6] 39/10 45/12 53/19 55/24 73/14 84/20 <b>big</b> [1] 84/13 <b>bigger</b> [1] 88/17 <b>Bill</b> [1] 58/8 <b>billboards</b> [2] 17/8 27/18 <b>bills</b> [4] 30/22 31/17 51/15 91/9 <b>biological</b> [1] 61/16 <b>biopsy</b> [2] 69/6 77/22 <b>birthday</b> [2] 53/15 56/15 <b>bit</b> [13] 23/21 25/14 38/25 43/12 57/9 72/1 74/13 77/2 83/24 88/11 89/16 89/18 89/23 <b>bits</b> [2] 46/4 97/3 <b>black</b> [2] 50/16 50/19 <b>blame</b> [1] 26/17 <b>bleeding</b> [1] 33/11 <b>bleeds</b> [1] 82/9 <b>blighted</b> [1] 57/8 <b>blisters</b> [2] 7/12 18/5 <b>bloated</b> [1] 49/15 <b>blood</b> [24] 9/2 9/6 13/16 13/18 13/19 14/4 14/8 14/15 26/16 26/19 26/22 27/12 27/13 27/24 28/3 28/7 43/16 55/14 60/22 65/2 66/10 67/3 82/3 96/2 <b>bloods</b> [1] 74/12 <b>blurted</b> [1] 31/4 <b>body</b> [1] 81/14 <b>bomb</b> [1] 83/6 <b>book</b> [3] 26/1 50/16 50/19 <b>books</b> [1] 59/6 <b>born</b> [5] 27/7 87/17 88/1 88/5 88/9 <b>boss</b> [1] 8/24 <b>both</b> [7] 6/2 10/23 39/8 42/3 52/22 92/11 95/6 <b>bother</b> [2] 23/16 61/3 <b>bottled</b> [1] 71/14 <b>bottles</b> [1] 50/4 <b>bottom</b> [2] 41/4 61/12 <b>boys</b> [1] 72/12 <b>brain</b> [3] 38/2 44/6 55/11 <b>brave</b> [2] 71/8 88/11 <b>breadwinner</b> [1] 51/11	<b>break</b> [4] 17/12 29/10 29/14 62/10 <b>breaking</b> [1] 8/5 <b>breaks</b> [1] 59/19 <b>Brian</b> [2] 28/8 28/15 <b>briefly</b> [1] 51/6 <b>bright</b> [1] 71/14 <b>brilliant</b> [5] 6/1 6/1 6/10 6/12 26/25 <b>brings</b> [1] 42/18 <b>British</b> [1] 26/18 <b>brother</b> [3] 7/20 8/1 10/21 <b>brought</b> [1] 55/21 <b>Bruce</b> [41] 30/1 30/8 30/15 30/19 30/25 31/7 32/18 34/3 34/20 35/2 36/5 36/11 36/19 37/20 38/12 38/21 39/6 39/11 39/20 40/25 41/13 42/5 42/19 42/24 43/8 43/13 44/2 44/14 46/6 46/13 47/7 49/6 50/2 50/5 51/8 52/3 52/11 52/12 55/25 56/7 56/11 <b>Bruce's</b> [9] 29/23 32/25 35/5 37/10 38/18 40/4 49/17 54/21 61/21 <b>bruises</b> [1] 96/3 <b>bruising</b> [1] 95/8 <b>bugger</b> [1] 60/22 <b>build</b> [1] 35/9 <b>build-up</b> [1] 35/9 <b>burden</b> [5] 20/19 50/5 51/15 93/15 93/20 <b>burnt</b> [2] 31/3 38/14 <b>business</b> [3] 88/7 89/11 89/13 <b>busy</b> [2] 23/20 48/3 <b>but</b> [148] <b>BUTLIN</b> [2] 62/22 99/8 <b>button</b> [1] 24/23 <b>buying</b> [1] 26/20 <b>by</b> [49] 2/18 2/18 2/24 3/4 9/8 11/25 13/19 18/20 19/13 26/10 26/15 27/13 29/21 31/25 33/20 35/9 39/8 42/9 43/23 44/6 45/17 48/9 48/23 50/8 55/16 58/14 58/19 59/5 62/22 64/14 66/18 67/22 73/12 76/8 78/4 79/7 82/9 84/15 92/4 92/7 92/17 92/17 93/24 94/24 97/23 97/23 99/4 99/6 99/8
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<p><b>C</b></p> <p><b>cadaver</b> [2] 11/19 12/12</p> <p><b>call</b> [3] 5/1 88/6 89/3</p> <p><b>called</b> [4] 27/17 35/23 53/11 53/17</p> <p><b>calm</b> [1] 69/25</p> <p><b>came</b> [28] 5/19 5/21 5/22 8/3 8/5 9/10 11/18 11/19 11/19 16/11 16/11 20/13 22/23 23/10 23/22 24/14 25/3 25/6 28/23 33/14 34/3 58/2 64/15 67/11 78/2 84/4 85/21 96/11</p> <p><b>campaign</b> [4] 41/3 53/21 55/24 56/1</p> <p><b>campaigning</b> [7] 38/22 41/9 47/9 51/10 53/20 55/14 59/4</p> <p><b>can</b> [39] 1/8 5/2 8/8 9/21 16/3 17/16 19/22 21/14 23/5 23/18 23/19 24/23 25/17 26/10 28/3 28/21 34/6 37/19 43/11 47/3 48/15 49/1 51/21 57/18 60/5 61/23 64/22 66/6 67/25 68/1 68/21 73/8 77/7 79/18 82/5 89/19 91/21 94/15 97/6</p> <p><b>can't</b> [10] 6/19 20/6 23/12 46/2 47/5 59/9 60/13 80/1 81/21 91/4</p> <p><b>cancer</b> [8] 10/16 10/20 10/21 33/22 34/1 50/23 60/12 61/21</p> <p><b>cannot</b> [5] 2/16 25/23 52/6 54/10 54/10</p> <p><b>car</b> [7] 5/11 22/23 40/16 42/11 42/13 42/16 42/20</p> <p><b>caravan</b> [1] 46/14</p> <p><b>card</b> [1] 51/20</p> <p><b>care</b> [8] 9/5 12/1 12/11 19/9 20/17 25/21 49/16 66/3</p> <p><b>career</b> [3] 77/9 78/18 79/3</p> <p><b>carefree</b> [3] 73/1 89/22 90/4</p> <p><b>careful</b> [1] 74/13</p> <p><b>carefully</b> [2] 66/15 66/19</p> <p><b>carer</b> [1] 94/22</p> <p><b>carers</b> [2] 26/9 27/23</p> <p><b>carriage</b> [1] 51/4</p> <p><b>carrier</b> [1] 61/8</p>	<p><b>carry</b> [2] 69/8 71/15</p> <p><b>cartoon</b> [1] 63/25</p> <p><b>case</b> [13] 1/5 23/17 26/21 27/4 41/10 43/1 80/25 82/7 82/20 85/21 90/21 95/1 95/19</p> <p><b>cases</b> [1] 45/16</p> <p><b>catered</b> [1] 45/20</p> <p><b>caught</b> [1] 45/12</p> <p><b>caused</b> [4] 13/20 27/20 38/14 82/9</p> <p><b>cells</b> [1] 44/6</p> <p><b>Central</b> [1] 12/1</p> <p><b>centre</b> [3] 36/21 63/12 63/16</p> <p><b>centres</b> [1] 32/19</p> <p><b>certainly</b> [3] 67/12 69/15 87/11</p> <p><b>cetera</b> [3] 26/14 27/18 95/8</p> <p><b>Chair</b> [1] 3/17</p> <p><b>chance</b> [5] 23/5 25/16 67/22 89/5 96/19</p> <p><b>change</b> [1] 66/9</p> <p><b>changed</b> [5] 52/15 65/23 66/13 66/15 94/9</p> <p><b>changing</b> [5] 40/15 66/11 66/24 74/5 74/9</p> <p><b>characters</b> [1] 63/25</p> <p><b>charity</b> [1] 40/22</p> <p><b>chat</b> [1] 78/22</p> <p><b>chatting</b> [1] 69/9</p> <p><b>check</b> [4] 7/25 65/14 67/24 96/16</p> <p><b>check-up</b> [2] 65/14 67/24</p> <p><b>check-ups</b> [1] 96/16</p> <p><b>checked</b> [1] 70/19</p> <p><b>checking</b> [2] 66/21 70/18</p> <p><b>checks</b> [3] 26/19 27/2 66/23</p> <p><b>chemotherapy</b> [2] 52/8 58/6</p> <p><b>cheque</b> [1] 23/22</p> <p><b>cherry</b> [1] 46/4</p> <p><b>cherry-picking</b> [1] 46/4</p> <p><b>chest</b> [1] 29/5</p> <p><b>child</b> [15] 32/14 36/11 39/9 39/17 39/18 39/25 53/12 61/15 61/15 61/16 63/3 65/17 84/7 94/23 97/5</p> <p><b>childhood</b> [3] 64/7 97/1 97/2</p> <p><b>childminder</b> [1] 35/25</p> <p><b>childminder's</b> [1] 35/24</p> <p><b>children</b> [15] 30/2</p>	<p>36/4 39/10 39/14 42/7 42/17 43/3 46/12 46/19 51/25 52/20 61/14 64/4 66/12 79/12</p> <p><b>children's</b> [1] 54/20</p> <p><b>chip</b> [1] 87/3</p> <p><b>choice</b> [1] 39/17</p> <p><b>choose</b> [1] 53/19</p> <p><b>chose</b> [1] 27/10</p> <p><b>Christine</b> [7] 29/16 29/19 29/20 29/22 55/23 56/18 99/5</p> <p><b>CHRISTINE NORVAL</b> [2] 29/20 99/5</p> <p><b>Christmas</b> [1] 88/4</p> <p><b>chronic</b> [1] 12/13</p> <p><b>cigarette</b> [1] 24/14</p> <p><b>cinemas</b> [1] 27/18</p> <p><b>circulating</b> [1] 67/6</p> <p><b>circumstances</b> [3] 89/17 93/2 96/7</p> <p><b>cirrhosis</b> [2] 33/22 34/1</p> <p><b>civil</b> [1] 3/23</p> <p><b>CJD</b> [2] 44/3 44/8</p> <p><b>claim</b> [1] 36/13</p> <p><b>clamming</b> [1] 72/1</p> <p><b>class</b> [1] 84/11</p> <p><b>classroom</b> [2] 84/9 84/9</p> <p><b>clean</b> [1] 58/2</p> <p><b>clear</b> [7] 24/2 33/17 39/6 39/15 60/3 95/22 97/11</p> <p><b>cleared</b> [3] 38/17 91/14 93/8</p> <p><b>clearly</b> [2] 38/2 63/23</p> <p><b>clients</b> [1] 73/21</p> <p><b>clinic</b> [7] 33/9 63/18 63/20 63/24 64/24 65/12 68/9</p> <p><b>clinical</b> [1] 33/4</p> <p><b>clinics</b> [3] 33/6 60/20 86/18</p> <p><b>close</b> [3] 15/17 24/25 82/14</p> <p><b>closed</b> [1] 84/25</p> <p><b>closely</b> [3] 71/24 89/1 92/22</p> <p><b>closing</b> [1] 88/7</p> <p><b>coincidental</b> [2] 80/6 82/13</p> <p><b>cold</b> [1] 52/4</p> <p><b>collected</b> [1] 38/9</p> <p><b>collecting</b> [1] 46/15</p> <p><b>collective</b> [1] 59/11</p> <p><b>college</b> [1] 54/15</p> <p><b>colour</b> [1] 27/2</p> <p><b>combination</b> [1] 75/6</p> <p><b>come</b> [26] 6/16 7/1 8/23 10/23 13/17 17/3</p>	<p>19/4 28/4 33/5 33/8 42/19 42/19 44/18 46/10 47/25 56/21 65/17 68/15 75/1 76/2 77/14 78/21 85/14 88/21 89/18 91/3</p> <p><b>comes</b> [1] 68/9</p> <p><b>coming</b> [12] 7/11 11/9 19/3 19/12 20/18 20/18 21/18 38/8 50/17 51/18 55/4 96/20</p> <p><b>comment</b> [2] 16/14 26/11</p> <p><b>commerce</b> [1] 88/25</p> <p><b>commitment</b> [1] 92/7</p> <p><b>committed</b> [1] 56/24</p> <p><b>community</b> [3] 12/1 42/9 59/6</p> <p><b>companies</b> [2] 26/16 28/3</p> <p><b>company</b> [3] 78/24 89/2 89/17</p> <p><b>compared</b> [1] 52/5</p> <p><b>compelling</b> [1] 60/4</p> <p><b>compensation</b> [2] 23/4 23/14</p> <p><b>complacent</b> [1] 27/9</p> <p><b>complaint</b> [1] 96/13</p> <p><b>complete</b> [2] 7/13 21/16</p> <p><b>completely</b> [3] 44/7 52/13 52/14</p> <p><b>completing</b> [2] 82/21 96/18</p> <p><b>complications</b> [1] 80/25</p> <p><b>compromise</b> [1] 55/24</p> <p><b>compromising</b> [1] 2/8</p> <p><b>compulsory</b> [1] 87/15</p> <p><b>concern</b> [2] 12/25 95/23</p> <p><b>concerned</b> [7] 34/20 67/1 67/13 70/23 81/23 83/9 95/13</p> <p><b>concerns</b> [2] 44/1 45/11</p> <p><b>conclude</b> [1] 93/24</p> <p><b>concluded</b> [1] 77/12</p> <p><b>concludes</b> [1] 97/20</p> <p><b>conclusion</b> [2] 14/1 55/22</p> <p><b>conclusions</b> [1] 60/7</p> <p><b>condition</b> [1] 9/22</p> <p><b>conditions</b> [4] 40/25 41/1 45/19 64/5</p> <p><b>confided</b> [1] 86/7</p> <p><b>confidence</b> [1] 28/7</p> <p><b>confirm</b> [1] 73/25</p> <p><b>confirmed</b> [1] 43/21</p> <p><b>conflict</b> [1] 2/8</p>	<p><b>connected</b> [2] 33/13 50/18</p> <p><b>connection</b> [1] 84/20</p> <p><b>consequences</b> [1] 39/4</p> <p><b>considerable</b> [1] 88/19</p> <p><b>console</b> [1] 64/2</p> <p><b>constant</b> [2] 17/6 17/9</p> <p><b>constantly</b> [1] 47/20</p> <p><b>consultant</b> [3] 20/13 53/16 53/18</p> <p><b>consultation</b> [1] 88/8</p> <p><b>contacted</b> [1] 68/12</p> <p><b>continue</b> [2] 37/25 91/16</p> <p><b>continued</b> [3] 16/24 35/7 53/12</p> <p><b>continues</b> [3] 13/9 13/12 53/21</p> <p><b>continuing</b> [1] 49/21</p> <p><b>contrast</b> [1] 59/11</p> <p><b>contributed</b> [1] 55/20</p> <p><b>control</b> [1] 47/5</p> <p><b>controller</b> [1] 78/24</p> <p><b>conversation</b> [4] 19/5 47/17 87/6 87/7</p> <p><b>conversations</b> [1] 55/14</p> <p><b>converted</b> [3] 13/23 13/25 14/12</p> <p><b>cope</b> [6] 20/1 20/2 24/10 40/20 42/23 46/13</p> <p><b>coped</b> [1] 19/22</p> <p><b>coping</b> [4] 19/24 39/12 41/14 43/7</p> <p><b>correct</b> [7] 29/25 62/24 64/9 75/24 81/25 82/16 87/14</p> <p><b>corridor</b> [1] 63/24</p> <p><b>costs</b> [1] 93/16</p> <p><b>could</b> [31] 8/23 18/13 21/3 24/25 26/1 26/14 28/5 43/18 46/8 48/13 50/18 50/19 55/10 58/24 58/25 58/25 60/13 60/16 63/4 63/22 65/1 67/18 73/23 75/12 75/22 88/18 90/6 94/1 95/24 96/7 97/7</p> <p><b>couldn't</b> [16] 8/1 16/16 17/10 20/11 20/21 21/11 21/25 38/2 38/10 46/13 46/16 51/25 54/20 60/11 80/7 91/9</p> <p><b>council</b> [3] 36/9 36/10 36/16</p> <p><b>counselling</b> [9] 20/23 21/22 39/13 42/22</p>	<p>53/12 86/16 86/20 87/4 87/10</p> <p><b>country</b> [1] 26/24</p> <p><b>couple</b> [10] 7/3 9/15 10/7 21/23 30/6 56/20 68/18 77/16 84/10 94/6</p> <p><b>course</b> [33] 2/1 2/6 2/25 3/8 7/2 8/17 8/22 9/4 10/3 13/16 14/24 15/24 16/17 22/16 23/17 25/19 27/19 27/22 30/7 30/11 32/13 36/19 37/10 55/10 59/4 67/14 75/20 76/9 76/19 76/22 76/25 81/4 95/1</p> <p><b>courses</b> [2] 82/12 93/13</p> <p><b>cousin</b> [1] 31/18</p> <p><b>coverage</b> [1] 68/7</p> <p><b>covered</b> [1] 8/25</p> <p><b>creating</b> [1] 92/21</p> <p><b>credit</b> [1] 51/19</p> <p><b>creed</b> [1] 27/2</p> <p><b>cried</b> [1] 9/12</p> <p><b>cross</b> [2] 34/21 50/16</p> <p><b>cross-infection</b> [1] 34/21</p> <p><b>crowds</b> [1] 41/14</p> <p><b>cruel</b> [1] 28/21</p> <p><b>cruelly</b> [2] 26/2 28/19</p> <p><b>cry</b> [1] 59/17</p> <p><b>crying</b> [2] 24/7 50/19</p> <p><b>cryoprecipitate</b> [1] 63/8</p> <p><b>cuddles</b> [1] 85/13</p> <p><b>cuddly</b> [1] 86/2</p> <p><b>cumulation</b> [1] 95/10</p> <p><b>cup</b> [2] 24/11 24/15</p> <p><b>cured</b> [1] 44/21</p> <p><b>customers</b> [1] 26/17</p> <p><b>cut</b> [1] 90/22</p> <p><b>cuts</b> [1] 96/3</p> <p><b>D</b></p> <p><b>dad</b> [13] 36/6 40/18 52/25 53/3 53/8 53/17 54/19 55/3 65/11 68/2 68/16 72/10 86/2</p> <p><b>damage</b> [4] 38/15 83/10 93/12 93/17</p> <p><b>damaged</b> [2] 93/5 93/14</p> <p><b>damaging</b> [2] 48/9 54/3</p> <p><b>dare</b> [2] 53/24 57/22</p> <p><b>dark</b> [2] 55/11 55/12</p> <p><b>date</b> [1] 56/16</p> <p><b>daughter</b> [19] 22/7 24/4 35/20 35/23 38/8 40/16 50/13 52/1</p>
---	---	--	--	---	---

<b>D</b>	47/9 84/25 <b>daughter...</b> [11] 52/23 53/20 53/21 53/24 54/6 54/7 61/8 87/17 87/25 88/5 88/9 <b>Dawson</b> [1] 94/3 <b>day</b> [26] 3/16 5/4 7/23 7/24 17/12 20/9 30/23 33/17 35/8 35/8 35/25 36/15 40/23 43/14 46/19 47/16 53/3 53/4 53/10 54/22 55/8 68/12 72/3 75/11 84/22 98/3 <b>days</b> [11] 9/7 24/22 38/7 40/24 52/9 58/6 71/23 75/3 77/16 87/11 88/10 <b>dead</b> [7] 50/6 53/8 55/4 72/8 73/7 90/2 92/12 <b>deal</b> [4] 48/7 88/18 88/19 95/9 <b>deals</b> [1] 53/1 <b>dearly</b> [1] 85/24 <b>death</b> [7] 16/12 18/6 19/23 21/21 28/24 44/6 71/5 <b>deaths</b> [1] 50/11 <b>debt</b> [2] 43/4 90/5 <b>decades</b> [2] 51/6 51/7 <b>December</b> [1] 88/1 <b>decent</b> [1] 72/20 <b>decided</b> [3] 41/8 80/7 80/22 <b>decision</b> [4] 39/21 40/6 92/24 92/25 <b>decision-making</b> [1] 92/25 <b>decline</b> [1] 6/13 <b>declined</b> [1] 83/2 <b>default</b> [1] 64/15 <b>defer</b> [1] 80/18 <b>deferred</b> [2] 80/3 80/13 <b>definite</b> [1] 39/17 <b>definitely</b> [3] 16/13 81/20 85/23 <b>degree</b> [2] 54/16 79/2 <b>delay</b> [2] 70/10 73/22 <b>delivering</b> [1] 93/24 <b>demonstration</b> [1] 84/10 <b>demonstrations</b> [1] 84/8 <b>departed</b> [1] 93/21 <b>Department</b> [1] 3/25 <b>dependent</b> [1] 44/7 <b>depression</b> [1] 41/11 <b>deprived</b> [1] 42/8 <b>describe</b> [4] 32/1 46/6	28/18 32/10 48/8 50/13 52/23 <b>describes</b> [1] 41/11 <b>description</b> [3] 2/16 12/15 37/10 <b>despite</b> [2] 40/4 44/19 <b>detached</b> [1] 85/3 <b>detailed</b> [1] 30/1 <b>deteriorate</b> [1] 16/24 <b>deteriorated</b> [1] 20/4 <b>determine</b> [2] 69/1 69/7 <b>devastated</b> [2] 34/25 78/7 <b>devastating</b> [2] 52/14 81/11 <b>develop</b> [2] 33/25 35/5 <b>developed</b> [3] 17/2 73/1 89/2 <b>devoting</b> [1] 41/7 <b>diagnosed</b> [3] 95/5 95/13 97/13 <b>diagnosis</b> [10] 34/5 34/9 34/21 61/21 61/21 71/1 71/3 74/21 83/18 84/14 <b>dialysis</b> [4] 4/13 4/22 6/6 18/10 <b>did</b> [51] 4/15 6/14 8/6 9/18 11/12 11/17 16/4 17/24 18/20 23/21 24/21 24/21 26/8 26/23 29/3 35/5 35/14 39/19 42/20 42/24 46/14 54/14 54/20 54/24 55/25 62/25 63/6 63/8 65/7 65/12 67/3 68/10 68/17 70/8 71/2 71/16 72/18 72/19 74/25 75/9 75/18 76/2 78/6 78/13 81/3 84/8 84/9 84/10 84/21 88/21 88/21 <b>didn't</b> [48] 4/9 7/6 7/17 11/2 11/4 11/22 16/5 16/6 16/21 17/2 20/1 20/1 22/2 22/15 22/16 24/20 25/5 25/5 31/7 33/5 33/15 34/8 41/13 41/18 42/7 44/25 46/9 50/1 51/17 54/22 54/25 66/22 69/21 70/15 71/6 71/9 71/11 71/19 72/13 72/22 75/19 77/18 79/21 84/19 85/18 87/6 89/12 89/23 <b>die</b> [5] 17/5 17/16 49/8 55/3 56/7	<b>died</b> [11] 2/13 12/21 15/15 17/19 42/10 49/14 49/14 50/16 50/21 55/9 84/15 <b>dies</b> [1] 56/9 <b>different</b> [5] 5/22 7/13 53/25 83/23 93/14 <b>difficult</b> [10] 2/5 39/22 39/23 41/14 41/20 84/1 87/23 88/10 89/15 95/11 <b>difficulties</b> [2] 90/8 90/21 <b>difficulty</b> [2] 33/13 39/12 <b>dig</b> [1] 23/11 <b>diligent</b> [1] 72/19 <b>directed</b> [1] 27/18 <b>directly</b> [1] 16/4 <b>director</b> [1] 64/14 <b>dirty</b> [2] 84/16 85/17 <b>disclosed</b> [4] 2/16 3/12 77/16 77/25 <b>discovered</b> [2] 14/25 15/1 <b>discuss</b> [3] 15/24 68/22 69/5 <b>discussed</b> [1] 74/20 <b>discussing</b> [2] 47/18 59/1 <b>discussion</b> [4] 21/11 60/8 65/6 70/8 <b>disease</b> [6] 16/16 26/7 31/6 44/4 69/1 69/7 <b>diseases</b> [1] 70/6 <b>disorder</b> [4] 20/5 20/20 33/12 46/21 <b>disorganised</b> [2] 63/14 64/12 <b>displayed</b> [1] 12/5 <b>distressing</b> [1] 85/6 <b>distrust</b> [1] 45/23 <b>distrustful</b> [1] 44/15 <b>disturbing</b> [1] 28/20 <b>dizzy</b> [1] 20/12 <b>do</b> [79] 1/8 1/14 1/18 6/19 8/24 9/9 14/23 15/25 16/1 17/16 25/16 26/5 26/24 26/25 27/2 28/6 30/20 30/21 33/10 36/6 36/15 36/22 37/24 38/7 39/24 41/16 41/16 42/14 44/23 46/7 46/8 47/20 47/24 48/1 48/9 51/9 51/11 51/12 51/18 52/17 54/4 54/19 56/1 57/13 57/15 57/22 60/15 61/4 61/10 61/24 65/20 66/17 67/3	70/10 71/7 72/22 73/12 73/19 73/20 75/4 75/12 76/18 78/13 80/18 81/1 83/19 85/7 85/8 85/14 85/15 86/21 88/22 89/14 89/17 90/13 91/3 92/3 92/6 92/6 <b>doctor</b> [17] 6/18 10/9 18/9 18/21 19/6 21/8 21/9 33/3 33/7 33/14 36/23 36/24 57/24 60/25 64/25 67/20 77/20 <b>doctor's</b> [1] 11/13 <b>doctors</b> [10] 6/24 9/22 18/17 20/17 21/23 22/2 32/4 43/18 45/6 70/8 <b>document</b> [1] 1/12 <b>does</b> [8] 1/6 62/18 68/4 69/13 70/21 83/13 84/22 95/3 <b>doesn't</b> [2] 39/25 47/23 <b>doing</b> [16] 4/20 25/3 25/10 26/19 28/2 30/22 31/16 34/22 50/8 61/23 74/12 76/20 77/20 82/4 95/2 95/25 <b>don't</b> [63] 7/5 9/5 9/24 9/25 10/1 10/3 10/13 12/25 15/4 15/11 16/2 16/8 18/24 21/1 22/13 22/25 23/23 41/13 41/17 41/21 43/17 43/24 46/2 46/23 47/17 49/18 49/19 49/25 51/22 54/8 54/8 54/10 54/11 54/11 54/13 56/25 57/1 57/1 57/15 58/3 60/5 61/22 65/9 65/25 68/16 70/9 71/24 72/7 75/3 75/21 81/21 82/9 84/1 85/5 85/7 85/12 85/14 85/24 86/9 90/10 91/21 92/15 92/18 <b>donated</b> [1] 14/12 <b>done</b> [14] 6/12 19/12 23/8 44/9 47/22 48/14 55/19 69/3 72/23 75/22 82/23 83/11 88/15 93/12 <b>donor</b> [13] 5/2 12/18 12/23 13/14 13/16 13/18 13/22 14/3 14/6 14/15 14/16 14/20 15/8 <b>door</b> [5] 23/23 33/16 36/16 38/11 84/25	<b>doors</b> [1] 38/10 <b>doorway</b> [2] 33/4 33/16 <b>dosage</b> [1] 37/5 <b>dosages</b> [1] 37/9 <b>dose</b> [1] 37/8 <b>doses</b> [1] 37/9 <b>doubly</b> [1] 76/19 <b>doubt</b> [1] 14/1 <b>down</b> [29] 4/16 5/7 5/11 6/21 8/2 8/2 8/20 8/23 9/1 10/1 10/24 21/4 21/4 21/7 23/19 28/4 30/18 30/19 30/21 35/11 46/12 48/24 49/1 49/3 67/12 69/8 72/2 88/7 91/4 <b>downstairs</b> [1] 63/24 <b>Dr</b> [9] 1/22 8/19 8/22 9/1 10/8 19/6 67/19 68/10 68/12 <b>Dr Ackrill</b> [5] 8/19 8/22 9/1 10/8 19/6 <b>Dr Lowe</b> [1] 1/22 <b>Dr Wilkie</b> [3] 67/19 68/10 68/12 <b>dreams</b> [1] 24/5 <b>dressed</b> [2] 38/7 65/13 <b>drinks</b> [1] 35/9 <b>drive</b> [1] 42/20 <b>driven</b> [1] 60/4 <b>driving</b> [3] 22/24 38/24 40/17 <b>drop</b> [1] 40/15 <b>drove</b> [3] 5/11 42/13 42/16 <b>drugs</b> [2] 6/8 27/3 <b>dry</b> [1] 90/22 <b>due</b> [7] 1/25 8/23 32/16 78/24 80/24 81/3 87/25 <b>Dundee</b> [4] 63/10 63/14 64/12 64/15 <b>duration</b> [1] 2/22 <b>during</b> [15] 2/25 9/14 13/16 14/8 14/24 27/8 31/19 36/7 37/20 63/14 71/23 77/2 87/16 88/12 88/25 <b>dying</b> [1] 50/15	89/13 <b>easily</b> [1] 89/8 <b>easy</b> [3] 3/9 21/6 29/1 <b>eaten</b> [1] 44/5 <b>edge</b> [2] 42/14 56/13 <b>Edinburgh</b> [1] 65/4 <b>edited</b> [1] 2/8 <b>educate</b> [1] 21/13 <b>education</b> [1] 73/3 <b>effect</b> [5] 27/21 52/14 52/19 75/18 83/15 <b>effectively</b> [1] 47/10 <b>effectiveness</b> [1] 66/22 <b>effects</b> [9] 37/10 37/12 37/20 76/6 81/10 87/20 89/19 96/11 96/23 <b>eggshells</b> [1] 38/6 <b>eight</b> [2] 15/9 15/10 <b>either</b> [10] 34/12 48/5 51/8 66/17 70/16 70/18 72/23 90/1 92/24 93/3 <b>elation</b> [1] 85/7 <b>elevated</b> [1] 93/10 <b>else</b> [10] 7/5 25/12 28/13 45/18 56/9 56/24 57/10 66/3 78/5 92/1 <b>embarrassed</b> [1] 31/25 <b>emotional</b> [2] 35/10 94/15 <b>emotionally</b> [2] 85/1 85/3 <b>emotions</b> [1] 34/7 <b>emphasised</b> [1] 68/24 <b>employment</b> [1] 91/8 <b>employments</b> [1] 35/16 <b>encountered</b> [1] 73/22 <b>encouraged</b> [1] 67/17 <b>end</b> [14] 7/20 8/14 28/18 42/15 44/6 57/17 58/23 60/7 66/7 69/12 71/4 76/2 76/9 92/12 <b>ended</b> [4] 17/10 20/4 21/12 96/9 <b>energies</b> [1] 41/8 <b>energy</b> [4] 47/23 51/10 57/8 57/9 <b>England</b> [1] 46/10 <b>English</b> [1] 67/13 <b>enjoy</b> [3] 73/7 90/3 90/5 <b>enjoyed</b> [1] 64/1 <b>enough</b> [7] 54/8 71/11 72/18 72/19 76/18 76/24 88/14
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(29) daughter... - enough

<p><b>E</b></p> <p><b>enquired</b> [2] 67/8 77/24</p> <p><b>ensuring</b> [1] 94/1</p> <p><b>entail</b> [1] 4/15</p> <p><b>entailed</b> [1] 4/16</p> <p><b>enter</b> [1] 33/15</p> <p><b>entirely</b> [2] 5/22 7/13</p> <p><b>enzymes</b> [1] 36/24</p> <p><b>episodes</b> [1] 53/9</p> <p><b>essentially</b> [3] 38/19 66/1 89/16</p> <p><b>established</b> [2] 63/16 64/18</p> <p><b>estate</b> [1] 36/10</p> <p><b>et</b> [3] 26/14 27/18 95/8</p> <p><b>et cetera</b> [2] 26/14 95/8</p> <p><b>even</b> [18] 10/13 11/23 20/6 20/11 21/2 24/9 33/5 44/7 46/9 46/13 51/18 57/19 60/20 84/10 87/6 87/13 91/8 91/14</p> <p><b>event</b> [3] 12/10 23/25 58/14</p> <p><b>events</b> [4] 25/24 26/6 26/10 49/10</p> <p><b>eventually</b> [5] 30/20 40/24 70/2 70/25 78/3</p> <p><b>ever</b> [9] 20/22 26/7 52/3 57/23 63/8 64/7 83/20 90/24 94/1</p> <p><b>every</b> [12] 11/10 17/12 35/8 48/2 48/3 48/15 48/17 48/22 49/3 56/9 57/11 75/11</p> <p><b>everybody</b> [4] 8/16 45/17 55/15 57/10</p> <p><b>everybody's</b> [2] 49/22 59/17</p> <p><b>everyone</b> [1] 29/2</p> <p><b>everything</b> [18] 9/8 18/17 20/3 23/7 42/15 44/5 45/13 45/22 45/23 46/22 49/17 51/13 52/24 54/16 55/18 60/10 70/2 72/1</p> <p><b>eviction</b> [1] 36/15</p> <p><b>evidence</b> [12] 1/21 2/6 3/9 3/10 13/1 25/24 30/7 48/18 49/4 61/8 69/4 97/20</p> <p><b>exacerbate</b> [1] 82/6</p> <p><b>exact</b> [1] 19/18</p> <p><b>exactly</b> [4] 11/16 20/14 41/4 70/25</p> <p><b>exam</b> [1] 72/5</p> <p><b>examples</b> [1] 97/6</p> <p><b>exams</b> [2] 72/7 72/20</p>	<p><b>excluded</b> [1] 68/17</p> <p><b>excuse</b> [1] 48/23</p> <p><b>exhausted</b> [1] 46/6</p> <p><b>expect</b> [2] 66/22 97/21</p> <p><b>expecting</b> [1] 54/4</p> <p><b>expensive</b> [1] 90/13</p> <p><b>experience</b> [4] 6/14 7/8 26/11 37/17</p> <p><b>experienced</b> [3] 37/14 37/20 46/22</p> <p><b>experiences</b> [4] 46/24 47/2 47/3 92/23</p> <p><b>experiencing</b> [3] 31/12 32/1 40/10</p> <p><b>explain</b> [1] 8/20</p> <p><b>explained</b> [5] 18/8 18/16 49/5 65/1 66/16</p> <p><b>explains</b> [2] 30/9 38/18</p> <p><b>exposed</b> [1] 68/6</p> <p><b>express</b> [1] 2/17</p> <p><b>expressed</b> [1] 35/12</p> <p><b>extensively</b> [1] 47/8</p> <p><b>extra</b> [2] 31/16 77/2</p> <p><b>extremely</b> [1] 56/8</p> <p><b>F</b></p> <p><b>face</b> [2] 55/15 88/12</p> <p><b>fact</b> [12] 23/1 27/20 44/19 54/18 55/25 58/13 68/4 68/22 69/4 70/21 77/11 97/2</p> <p><b>factor</b> [10] 30/12 63/7 64/7 65/23 66/10 66/11 74/5 94/9 94/10 94/25</p> <p><b>Factor IX</b> [1] 30/12</p> <p><b>Factor VIII</b> [7] 63/7 66/10 66/11 74/5 94/9 94/10 94/25</p> <p><b>factors</b> [1] 95/11</p> <p><b>factory</b> [1] 88/24</p> <p><b>failure</b> [3] 12/14 69/12 93/1</p> <p><b>fainted</b> [1] 84/11</p> <p><b>fair</b> [2] 39/14 96/13</p> <p><b>fairly</b> [1] 72/19</p> <p><b>fall</b> [3] 78/18 80/24 81/3</p> <p><b>fallen</b> [1] 38/14</p> <p><b>false</b> [1] 19/25</p> <p><b>families</b> [1] 23/3</p> <p><b>family</b> [26] 2/6 2/14 10/13 10/15 10/15 10/19 11/1 11/12 25/23 29/23 43/2 46/11 49/21 49/22 49/23 52/14 56/22 80/5 80/8 80/17 80/20 85/11 89/10 89/13 91/2 91/11</p>	<p><b>fantastic</b> [4] 5/25 6/10 20/17 26/24</p> <p><b>far</b> [4] 5/15 5/16 50/9 65/7</p> <p><b>fast</b> [1] 38/12</p> <p><b>father</b> [2] 55/1 55/4</p> <p><b>fathers</b> [1] 54/20</p> <p><b>fatigue</b> [3] 7/8 32/2 35/11</p> <p><b>fatigued</b> [1] 81/16</p> <p><b>fatuous</b> [1] 57/14</p> <p><b>fault</b> [2] 10/5 10/19</p> <p><b>favourite</b> [1] 19/1</p> <p><b>fear</b> [3] 44/2 93/6 93/7</p> <p><b>fearful</b> [2] 83/4 83/13</p> <p><b>February</b> [1] 68/20</p> <p><b>February 1995</b> [1] 68/20</p> <p><b>fed</b> [1] 78/3</p> <p><b>feel</b> [17] 37/25 39/20 44/21 46/2 48/24 52/6 58/10 60/5 70/10 78/6 81/18 83/21 84/3 85/8 92/24 94/19 95/3</p> <p><b>feeling</b> [6] 6/18 35/12 75/11 85/3 90/1 93/16</p> <p><b>feelings</b> [1] 35/12</p> <p><b>feels</b> [3] 56/1 56/12 94/23</p> <p><b>feet</b> [1] 23/6</p> <p><b>felt</b> [16] 22/1 25/2 38/5 41/2 41/24 49/22 51/14 51/15 71/5 73/2 79/3 80/1 80/10 84/14 85/17 96/4</p> <p><b>few</b> [15] 5/21 9/7 18/13 20/24 22/12 23/22 25/23 28/21 32/25 52/9 72/8 73/4 81/19 83/24 90/2</p> <p><b>fibrosis</b> [1] 82/18</p> <p><b>fight</b> [5] 36/13 49/19 49/19 49/24 57/9</p> <p><b>fighting</b> [1] 49/20</p> <p><b>files</b> [1] 23/12</p> <p><b>filled</b> [1] 78/4</p> <p><b>final</b> [1] 96/25</p> <p><b>finally</b> [1] 58/24</p> <p><b>financial</b> [2] 89/19 90/24</p> <p><b>financially</b> [2] 36/8 89/20</p> <p><b>find</b> [10] 9/5 21/11 24/18 41/4 41/5 53/8 55/4 67/17 73/13 97/7</p> <p><b>finished</b> [1] 78/15</p> <p><b>first</b> [23] 5/9 9/23 11/10 15/20 22/13 32/14 40/18 40/21 41/15 43/4 47/14 54/9 54/9 58/11 66/7 70/20 74/1 74/2 74/21 75/6</p>	<p>75/23 86/6 89/21</p> <p><b>fish</b> [1] 87/3</p> <p><b>fit</b> [3] 54/23 79/1 79/4</p> <p><b>fitter</b> [1] 52/10</p> <p><b>five</b> [4] 6/17 14/14 65/10 88/10</p> <p><b>flat</b> [1] 85/4</p> <p><b>flexibility</b> [1] 89/18</p> <p><b>flicked</b> [1] 22/25</p> <p><b>floor</b> [2] 21/12 69/18</p> <p><b>flu</b> [9] 6/25 7/2 37/14 37/14 37/15 75/10 75/12 75/14 81/13</p> <p><b>flu-like</b> [3] 75/10 75/14 81/13</p> <p><b>flu-type</b> [1] 7/2</p> <p><b>focused</b> [1] 67/11</p> <p><b>fog</b> [1] 38/2</p> <p><b>follow</b> [2] 88/3 92/22</p> <p><b>followed</b> [2] 97/23 97/23</p> <p><b>following</b> [5] 14/9 34/21 35/5 51/2 98/3</p> <p><b>follows</b> [2] 2/11 13/12</p> <p><b>foot</b> [1] 31/5</p> <p><b>football</b> [1] 54/20</p> <p><b>force</b> [1] 2/22</p> <p><b>forced</b> [3] 56/13 57/5 57/6</p> <p><b>forever</b> [2] 93/6 93/20</p> <p><b>forget</b> [2] 11/12 58/15</p> <p><b>forgive</b> [1] 25/17</p> <p><b>forgot</b> [1] 60/19</p> <p><b>form</b> [3] 2/17 22/19 46/21</p> <p><b>formality</b> [1] 77/13</p> <p><b>forms</b> [1] 35/14</p> <p><b>fortunate</b> [2] 76/19 88/23</p> <p><b>forward</b> [1] 78/9</p> <p><b>forwards</b> [1] 7/16</p> <p><b>found</b> [12] 13/2 13/22 15/3 15/4 15/7 15/20 21/8 41/14 59/2 71/23 82/4 96/14</p> <p><b>foundation</b> [2] 83/12 91/18</p> <p><b>four</b> [6] 4/17 6/17 24/9 35/20 58/6 79/2</p> <p><b>fourth</b> [1] 21/10</p> <p><b>France</b> [2] 19/10 19/19</p> <p><b>frank</b> [1] 97/11</p> <p><b>FRASER</b> [2] 62/22 99/8</p> <p><b>freezing</b> [1] 80/22</p> <p><b>frequency</b> [1] 63/4</p> <p><b>friends</b> [7] 15/17 49/17 54/25 71/22 72/9 72/12 92/16</p> <p><b>frightened</b> [1] 9/15</p> <p><b>frightening</b> [1] 43/20</p>	<p><b>from</b> [78] 4/9 7/17 8/8 11/5 11/6 11/19 11/19 12/17 13/10 13/17 14/3 14/4 14/15 15/15 23/14 26/2 26/20 26/23 27/13 30/1 30/2 30/2 30/6 30/19 32/25 34/24 36/16 36/21 37/7 37/16 43/1 43/12 46/15 47/22 47/25 47/25 50/9 52/9 52/15 53/7 53/11 55/4 56/7 58/20 63/2 64/13 64/15 64/23 65/2 65/5 66/6 66/17 66/18 68/1 68/20 69/24 70/12 70/17 70/22 72/9 74/17 75/19 76/6 77/22 78/19 78/21 80/14 82/9 83/23 85/3 87/10 88/6 90/16 94/10 94/10 96/3 96/18 97/1</p> <p><b>from 1992</b> [1] 94/10</p> <p><b>front</b> [1] 87/5</p> <p><b>full</b> [7] 4/10 19/6 22/6 35/18 35/21 40/24 91/8</p> <p><b>full-time</b> [4] 35/18 35/21 40/24 91/8</p> <p><b>fully</b> [1] 57/23</p> <p><b>function</b> [1] 82/23</p> <p><b>functions</b> [2] 69/3 93/11</p> <p><b>Fund</b> [1] 90/15</p> <p><b>funding</b> [2] 75/1 75/5</p> <p><b>funeral</b> [1] 42/10</p> <p><b>funny</b> [1] 69/17</p> <p><b>furnish</b> [1] 43/4</p> <p><b>further</b> [10] 2/25 8/21 25/11 28/14 38/25 44/16 56/19 59/25 60/1 97/24</p> <p><b>future</b> [11] 56/14 61/7 69/21 71/12 71/14 83/12 83/13 91/11 91/17 91/19 91/22</p> <p><b>G</b></p> <p><b>games</b> [1] 64/2</p> <p><b>gap</b> [1] 73/14</p> <p><b>garden</b> [4] 4/19 4/21 54/21 60/16</p> <p><b>gardening</b> [1] 51/12</p> <p><b>gathered</b> [1] 26/16</p> <p><b>gave</b> [4] 11/19 11/24 78/16 89/3</p> <p><b>gay</b> [3] 8/14 11/6 27/19</p> <p><b>general</b> [5] 27/4 63/18 74/4 74/7 74/10</p> <p><b>generally</b> [1] 3/19</p>	<p><b>genetics</b> [1] 61/10</p> <p><b>gentle</b> [1] 52/23</p> <p><b>geography</b> [1] 76/20</p> <p><b>get</b> [48] 5/7 6/4 6/9 6/20 7/6 7/15 10/22 11/17 21/15 23/5 23/5 23/18 23/20 25/5 28/9 29/5 32/16 33/11 33/21 38/7 38/11 39/15 40/9 41/3 48/4 48/23 57/6 58/24 58/24 60/13 60/13 61/11 61/20 69/25 72/19 72/21 75/2 76/18 78/12 80/16 83/19 83/21 85/5 85/5 85/7 85/24 90/13 91/8</p> <p><b>getting</b> [16] 4/21 11/15 15/10 15/19 20/12 36/15 37/1 46/3 48/6 67/5 80/12 80/21 80/23 82/15 90/21 96/15</p> <p><b>girl</b> [1] 28/10</p> <p><b>girls</b> [1] 72/13</p> <p><b>give</b> [10] 3/10 9/22 21/25 23/5 23/21 29/4 37/13 49/19 49/19 88/14</p> <p><b>given</b> [23] 2/18 13/16 14/5 14/8 14/14 14/23 15/8 33/23 34/5 34/15 37/5 43/16 49/5 52/22 60/3 71/5 76/5 83/5 87/14 92/9 96/5 96/5 96/22</p> <p><b>giver</b> [2] 94/23 95/25</p> <p><b>gives</b> [1] 97/17</p> <p><b>giving</b> [8] 1/21 25/24 26/19 29/4 46/4 90/23 92/13 97/11</p> <p><b>glad</b> [1] 23/11</p> <p><b>go</b> [47] 4/16 7/3 8/25 10/8 16/3 16/14 20/6 21/4 21/11 22/2 24/24 25/2 26/17 27/14 28/5 35/18 40/1 42/12 42/20 43/12 45/24 46/7 46/9 46/11 46/14 46/25 47/17 47/19 53/5 54/22 55/16 56/25 57/20 59/1 60/16 60/20 61/11 68/10 69/5 69/11 71/19 76/15 80/21 81/17 83/22 88/21 89/18</p> <p><b>God</b> [1] 55/16</p> <p><b>goes</b> [2] 47/16 55/11</p> <p><b>going</b> [67] 1/8 3/8 4/19 7/25 8/10 8/20 9/6 10/1 10/18 12/4</p>
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<p><b>G</b></p> <p><b>going...</b> [57] 12/19 15/6 16/1 17/5 17/16 19/24 20/14 20/15 20/16 28/12 28/16 30/3 30/14 32/25 36/3 36/23 37/25 41/9 41/24 45/1 48/20 48/22 49/20 51/22 52/6 52/10 53/3 54/12 55/3 55/16 57/9 58/16 58/22 59/14 59/24 61/1 61/1 63/23 64/1 66/10 66/20 71/25 72/4 72/6 72/8 73/4 73/7 73/18 77/18 78/11 80/24 83/7 89/21 89/23 90/1 94/3 96/19</p> <p><b>gone</b> [12] 9/1 18/13 30/18 32/20 38/9 39/19 48/15 49/4 52/15 61/5 68/3 77/3 <b>good</b> [11] 5/21 9/24 39/9 45/14 54/16 58/1 58/7 79/1 79/4 81/18 85/8</p> <p><b>Google</b> [1] 24/22</p> <p><b>gosh</b> [1] 32/19</p> <p><b>got</b> [67] 4/7 5/8 6/11 6/20 6/22 7/11 8/4 8/11 8/13 8/18 8/19 8/20 9/2 9/3 9/8 9/11 10/16 10/20 10/21 10/25 11/2 11/21 11/25 15/25 19/2 19/13 20/9 20/17 21/7 21/15 21/19 22/14 23/11 23/13 24/11 24/13 25/11 31/5 31/14 37/6 39/21 40/22 42/11 42/21 50/3 52/4 53/7 54/16 60/12 60/12 68/20 72/14 72/18 72/20 72/21 73/16 75/20 78/3 79/11 80/22 84/14 85/22 88/6 90/5 91/2 92/2 96/14</p> <p><b>government</b> [4] 23/2 26/18 28/1 48/23</p> <p><b>GP</b> [3] 35/9 42/21 97/3</p> <p><b>gradually</b> [2] 4/7 40/22</p> <p><b>graduated</b> [1] 77/8</p> <p><b>Graeme</b> [8] 62/18 62/20 62/21 62/23 65/2 67/22 69/2 99/7</p> <p><b>GRAEME MALLOCH</b> [2] 62/21 99/7</p>	<p><b>Graeme's</b> [1] 68/3 <b>great</b> [4] 9/12 16/15 59/5 65/25</p> <p><b>greatly</b> [2] 16/25 27/23</p> <p><b>green</b> [1] 50/4</p> <p><b>group</b> [3] 38/23 50/9 92/20</p> <p><b>groups</b> [1] 67/16</p> <p><b>growing</b> [1] 91/6</p> <p><b>grown</b> [1] 52/25</p> <p><b>guarded</b> [1] 71/24</p> <p><b>guilty</b> [1] 25/2</p> <p><b>guinea</b> [1] 44/24</p> <p><b>guises</b> [1] 93/14</p> <p><b>guns</b> [1] 48/18</p> <p><b>guy</b> [4] 11/19 15/8 28/10 86/23</p> <p><b>H</b></p> <p><b>had</b> [174]</p> <p><b>hadn't</b> [14] 9/17 10/15 18/10 36/2 67/7 67/13 70/19 70/24 75/22 77/16 83/18 86/2 87/13 88/5</p> <p><b>haemophilia</b> [24] 30/9 31/1 43/18 58/15 62/23 63/12 63/13 63/19 64/5 64/13 65/14 66/3 71/11 77/17 78/1 82/9 84/6 84/11 84/16 84/18 84/20 86/17 94/21 95/5</p> <p><b>Haemophilia Scotland</b> [1] 58/15</p> <p><b>haemophiliac</b> [2] 31/4 60/21</p> <p><b>haemophiliacs</b> [6] 56/10 64/24 65/5 67/15 92/15 92/18</p> <p><b>half</b> [3] 8/12 47/17 59/1</p> <p><b>hall</b> [2] 19/12 19/13</p> <p><b>Hallamshire</b> [1] 36/22</p> <p><b>hallway</b> [1] 50/18</p> <p><b>hammy</b> [1] 25/14</p> <p><b>hand</b> [1] 19/15</p> <p><b>handle</b> [1] 21/25</p> <p><b>handling</b> [1] 96/2</p> <p><b>hands</b> [1] 95/16</p> <p><b>Hang</b> [1] 39/3</p> <p><b>happen</b> [6] 22/15 59/23 65/13 87/7 91/12 94/1</p> <p><b>happened</b> [24] 7/22 7/24 16/17 19/10 19/18 19/19 24/19 25/25 26/11 28/19 28/22 41/5 41/8 41/19 42/13 48/12 49/24</p>	<p>61/17 70/19 72/15 77/21 78/12 91/23 93/7</p> <p><b>happening</b> [5] 1/10 9/5 16/21 54/4 64/17</p> <p><b>happens</b> [1] 85/8</p> <p><b>happy</b> [3] 6/2 16/15 18/2</p> <p><b>hard</b> [3] 62/9 85/14 86/12</p> <p><b>hardened</b> [1] 59/19</p> <p><b>harm</b> [1] 48/14</p> <p><b>has</b> [56] 1/13 1/22 3/17 27/4 28/6 29/1 30/8 30/11 44/9 44/14 46/21 46/24 47/8 47/12 48/14 49/5 49/24 50/13 51/7 51/9 51/10 51/10 52/1 52/3 52/11 52/12 52/13 52/14 53/12 55/9 55/13 58/17 61/17 61/17 66/13 68/6 69/7 81/24 82/8 83/5 83/10 85/10 86/4 86/5 86/10 89/20 90/22 90/23 91/4 91/22 93/7 93/12 93/18 93/23 94/15 97/10</p> <p><b>hasn't</b> [1] 44/16</p> <p><b>have</b> [159]</p> <p><b>haven't</b> [3] 9/11 10/12 91/19</p> <p><b>having</b> [24] 4/16 5/2 10/2 10/5 19/10 22/19 34/9 36/13 38/9 39/1 39/5 39/19 39/20 40/16 44/5 45/10 49/16 62/7 69/20 74/7 76/11 76/15 82/14 93/9</p> <p><b>HCV</b> [1] 34/18</p> <p><b>he</b> [179]</p> <p><b>he'd</b> [5] 20/13 32/19 34/12 38/9 38/13</p> <p><b>he's</b> [21] 8/20 10/3 19/2 19/3 19/3 19/4 44/20 45/1 46/22 47/1 47/3 47/20 47/22 47/23 48/15 48/15 48/16 49/8 50/7 50/8 52/6</p> <p><b>head</b> [6] 12/22 20/11 32/5 32/20 34/10 57/1</p> <p><b>headaches</b> [1] 75/13</p> <p><b>health</b> [25] 3/25 6/11 6/13 16/24 20/3 23/16 26/25 27/5 27/8 35/5 35/15 40/4 40/25 41/1 42/4 45/9 53/13 54/21 59/12 59/15 83/4 83/12 89/10 91/16</p>	<p>91/19</p> <p><b>health-wise</b> [1] 89/10</p> <p><b>healthy</b> [3] 27/1 39/16 57/25</p> <p><b>hear</b> [7] 2/9 2/9 3/11 48/20 50/19 57/11 74/25</p> <p><b>heard</b> [6] 28/20 37/7 59/16 59/20 61/9 97/16</p> <p><b>hearing</b> [3] 39/1 75/5 89/2</p> <p><b>heart</b> [8] 8/5 13/24 14/19 15/8 17/12 20/8 59/19 92/8</p> <p><b>heavy</b> [1] 24/12</p> <p><b>held</b> [5] 75/4 79/19 79/24 79/24 79/25</p> <p><b>hell</b> [1] 44/8</p> <p><b>hello</b> [1] 33/7</p> <p><b>help</b> [8] 17/2 20/25 27/19 33/24 40/22 54/12 58/21 91/5</p> <p><b>helped</b> [5] 24/16 54/13 86/10 87/15 90/23</p> <p><b>helpful</b> [1] 90/19</p> <p><b>helping</b> [3] 21/17 34/23 34/24</p> <p><b>help</b> [11] 32/23 32/23 44/21 79/22 83/5 85/22 86/3 86/7 89/22 91/20 96/5</p> <p><b>hep C</b> [11] 32/23 32/23 44/21 79/22 83/5 85/22 86/3 86/7 89/22 91/20 96/5</p> <p><b>hepatic</b> [1] 33/19</p> <p><b>hepatitis</b> [34] 12/24 13/7 31/8 32/18 33/4 34/6 36/20 39/6 65/6 67/7 68/5 68/6 68/22 68/25 69/11 69/23 70/5 73/11 73/15 74/1 74/3 74/18 77/17 77/25 79/20 80/15 83/9 84/14 84/21 91/23 93/10 95/1 95/14 97/14</p> <p><b>hepatitis C</b> [28] 31/8 32/18 33/4 34/6 36/20 39/6 67/7 68/5 68/6 68/25 69/11 69/23 73/11 73/15 74/1 74/3 74/18 77/25 79/20 80/15 83/9 84/14 84/21 91/23 93/10 95/1 95/14 97/14</p> <p><b>hepatitis C-positive</b> [1] 68/22</p> <p><b>her</b> [66] 3/10 3/10 3/11 4/6 4/9 4/9 4/16</p>	<p>4/23 5/9 5/23 5/24 6/18 6/22 6/24 7/10 7/10 7/20 8/1 8/2 8/2 8/5 8/10 10/6 10/15 10/20 10/22 10/24 10/25 10/25 10/25 11/12 13/9 14/2 15/10 15/11 15/12 15/16 16/2 16/4 17/2 17/9 17/12 18/3 18/3 18/4 22/13 26/22 38/9 40/17 40/18 40/18 42/10 50/13 52/2 52/24 52/25 53/3 53/8 53/15 53/17 54/13 78/25 88/13 91/7 95/4 96/6</p> <p><b>here</b> [11] 2/10 3/5 25/10 25/10 25/24 29/22 45/6 55/15 56/21 57/23 61/18</p> <p><b>herself</b> [1] 15/4</p> <p><b>hid</b> [2] 41/18 84/19</p> <p><b>hide</b> [4] 41/19 48/24 52/2 84/17</p> <p><b>high</b> [2] 37/5 92/24</p> <p><b>high-level</b> [1] 92/24</p> <p><b>higher</b> [5] 66/2 72/20 94/9 94/10 94/12</p> <p><b>highlight</b> [1] 41/10</p> <p><b>highly</b> [1] 66/11</p> <p><b>hillwalking</b> [1] 46/8</p> <p><b>him</b> [25] 14/5 14/9 18/22 18/25 19/15 19/15 23/14 32/4 32/10 34/11 34/23 36/23 37/22 37/23 38/10 40/16 40/19 41/25 47/17 47/19 47/25 49/18 50/7 50/19 55/5</p> <p><b>himself</b> [2] 14/7 38/22</p> <p><b>his</b> [49] 2/6 2/8 2/13 11/20 13/16 13/19 13/24 14/9 19/2 19/9 19/12 19/15 19/17 28/8 30/8 31/15 34/10 34/21 35/15 37/23 38/13 40/15 40/25 41/1 41/7 41/11 41/24 41/25 41/25 46/10 47/5 47/10 47/22 49/6 50/8 50/13 51/10 52/12 54/19 55/1 55/2 55/3 55/4 55/13 56/7 56/12 56/15 56/17 68/4</p> <p><b>history</b> [1] 22/6</p> <p><b>HIV</b> [36] 8/11 8/11 8/12 8/13 8/14 8/18 9/3 9/4 9/9 9/19 10/2 11/4 11/17 11/21</p>	<p>11/24 12/24 13/8 13/11 13/18 13/24 14/2 14/7 14/8 14/12 14/14 15/10 15/15 15/20 21/14 23/2 26/13 27/10 27/14 44/4 64/20 70/5</p> <p><b>HIV-infected</b> [1] 14/8</p> <p><b>HIV-positive</b> [1] 14/7</p> <p><b>HIV-positivity</b> [1] 13/24</p> <p><b>HIV/AIDS</b> [1] 27/14</p> <p><b>HLA</b> [1] 13/5</p> <p><b>hmm</b> [4] 76/1 77/6 79/15 95/18</p> <p><b>hold</b> [2] 20/11 35/11</p> <p><b>holding</b> [1] 18/3</p> <p><b>holds</b> [2] 52/24 91/22</p> <p><b>holiday</b> [1] 46/9</p> <p><b>home</b> [19] 5/4 5/21 15/25 20/17 20/17 20/18 34/22 40/7 41/24 42/19 42/20 42/21 43/2 47/25 48/4 50/17 55/4 77/1 77/3</p> <p><b>honest</b> [3] 58/3 71/7 84/23</p> <p><b>hope</b> [3] 57/17 57/18 58/22</p> <p><b>hoped</b> [2] 40/21 78/11</p> <p><b>hopeful</b> [1] 82/20</p> <p><b>hopefully</b> [1] 27/14</p> <p><b>hoping</b> [2] 53/6 58/7</p> <p><b>horrendous</b> [4] 45/15 49/15 50/11 50/11</p> <p><b>horrors</b> [1] 27/10</p> <p><b>hospital</b> [26] 4/17 5/6 6/20 6/21 7/17 7/21 8/3 9/1 10/8 11/10 15/5 15/18 20/7 20/9 21/3 21/3 33/7 46/25 47/1 57/19 57/20 63/3 95/8 96/20 97/2 97/3</p> <p><b>hospitalised</b> [1] 53/14</p> <p><b>hospitals</b> [2] 12/1 20/5</p> <p><b>hotel</b> [1] 24/13</p> <p><b>hour</b> [3] 9/8 47/17 59/1</p> <p><b>hours</b> [3] 5/21 89/15 91/5</p> <p><b>house</b> [11] 10/24 20/3 31/18 36/9 38/8 38/12 38/23 41/22 51/12 83/24 91/2</p> <p><b>how</b> [31] 6/15 8/13 9/18 11/2 11/16 15/4 15/21 16/7 18/9 19/22 21/14 24/2 29/2 33/1 35/5 36/8 37/24 40/8 43/15 51/7 51/14 51/21 53/1 53/24</p>
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(31) going... - how



<b>H</b>	<b>I did [8]</b> 23/21 24/21 42/20 72/18 72/19 74/25 84/8 84/9 <b>I didn't [14]</b> 22/15 24/20 25/5 51/17 71/6 71/9 71/11 71/19 77/18 79/21 84/19 85/18 89/12 89/23 <b>I disclosed [1]</b> 77/25 <b>I do [12]</b> 17/16 26/5 28/6 36/15 36/22 38/7 39/24 75/4 83/19 85/8 90/13 91/3 <b>I don't [33]</b> 9/5 15/4 15/11 21/1 22/13 22/25 23/23 43/17 46/23 49/25 54/8 54/11 54/11 54/13 56/25 57/15 58/3 65/25 68/16 70/9 72/7 75/3 75/21 81/21 82/9 84/1 85/5 85/7 85/12 86/9 90/10 91/21 92/15 <b>I done [1]</b> 23/8 <b>I drove [2]</b> 42/13 42/16 <b>I ended [1]</b> 20/4 <b>I even [1]</b> 84/10 <b>I eventually [1]</b> 78/3 <b>I ever [1]</b> 90/24 <b>I experienced [1]</b> 37/14 <b>I fear [1]</b> 93/6 <b>I feel [4]</b> 81/18 83/21 84/3 92/24 <b>I felt [3]</b> 22/1 51/15 71/5 <b>I forget [1]</b> 11/12 <b>I forgot [1]</b> 60/19 <b>I found [1]</b> 82/4 <b>I gave [1]</b> 89/3 <b>I get [3]</b> 11/17 83/19 83/21 <b>I go [2]</b> 57/20 81/17 <b>I got [14]</b> 19/13 20/9 20/17 23/13 24/11 24/13 42/11 72/18 72/20 72/21 75/20 84/14 88/6 96/14 <b>I graduated [1]</b> 77/8 <b>I had [26]</b> 20/8 20/21 23/9 39/23 42/6 42/17 51/24 56/18 58/13 71/5 73/16 77/21 78/8 78/15 79/2 81/13 82/19 83/9 84/17 88/11 88/17 90/1 91/20 92/9 92/10 95/7 <b>I hadn't [4]</b> 75/22 77/16 83/18 86/2 <b>I have [11]</b> 3/17 26/4	26/6 33/3 37/22 60/10 66/16 68/24 82/18 86/12 91/25 <b>I hear [1]</b> 57/11 <b>I hid [1]</b> 84/19 <b>I just [17]</b> 5/21 19/2 19/14 20/1 20/11 21/25 22/2 22/24 25/4 29/4 31/4 31/20 42/18 54/10 63/17 81/20 83/22 <b>I keep [2]</b> 6/15 84/23 <b>I kept [1]</b> 72/9 <b>I kind [5]</b> 78/9 78/11 82/6 83/22 88/16 <b>I know [4]</b> 24/13 46/23 56/15 83/21 <b>I looked [1]</b> 25/6 <b>I lost [4]</b> 20/3 23/6 76/14 81/11 <b>I love [1]</b> 85/24 <b>I managed [1]</b> 42/20 <b>I married [1]</b> 22/11 <b>I may [3]</b> 2/24 81/19 93/8 <b>I mean [10]</b> 40/21 48/11 49/11 51/8 55/6 58/22 59/8 59/16 60/10 94/17 <b>I mentioned [1]</b> 94/17 <b>I met [1]</b> 49/11 <b>I might [4]</b> 33/21 57/3 73/7 90/2 <b>I moved [2]</b> 43/2 45/21 <b>I never [2]</b> 92/5 96/24 <b>I obviously [2]</b> 65/9 73/15 <b>I only [1]</b> 96/14 <b>I phoned [2]</b> 8/24 23/8 <b>I probably [4]</b> 33/23 34/1 81/16 86/23 <b>I put [1]</b> 71/14 <b>I quite [1]</b> 64/1 <b>I rang [1]</b> 42/18 <b>I realised [1]</b> 31/22 <b>I really [1]</b> 22/15 <b>I recall [1]</b> 50/15 <b>I received [1]</b> 69/15 <b>I refer [1]</b> 30/7 <b>I reflected [1]</b> 54/1 <b>I remember [12]</b> 31/17 31/19 33/16 42/11 50/17 63/23 64/3 72/6 75/10 76/15 96/15 96/20 <b>I said [4]</b> 10/17 16/1 21/5 23/6 <b>I sat [1]</b> 42/14 <b>I saw [1]</b> 42/21 <b>I say [3]</b> 86/10 89/17 91/18	<b>I see [3]</b> 45/13 45/13 45/14 <b>I seen [1]</b> 25/7 <b>I should [6]</b> 1/22 72/23 72/25 85/5 85/12 86/11 <b>I showed [2]</b> 18/1 69/16 <b>I signed [1]</b> 23/21 <b>I sort [1]</b> 25/2 <b>I started [2]</b> 45/18 95/25 <b>I stayed [1]</b> 79/6 <b>I still [1]</b> 90/6 <b>I suppose [2]</b> 42/1 45/12 <b>I take [1]</b> 74/17 <b>I talked [2]</b> 71/18 84/8 <b>I thank [1]</b> 92/12 <b>I thanked [1]</b> 19/15 <b>I then [1]</b> 84/17 <b>I think [52]</b> 14/19 21/2 25/8 27/8 27/16 28/21 35/20 37/1 39/1 41/2 42/6 54/13 55/24 60/24 63/2 64/18 65/16 67/5 67/14 67/17 67/20 68/15 68/24 69/9 69/17 69/25 72/18 72/24 74/25 77/1 77/3 77/15 77/23 78/9 78/20 79/6 81/16 81/17 81/18 83/17 85/16 85/25 85/25 87/15 88/4 90/10 90/20 90/21 94/21 95/3 96/3 96/21 19/24 23/4 23/18 59/19 96/18 <b>I totally [3]</b> 25/7 25/9 27/24 <b>I tried [1]</b> 90/10 <b>I turned [1]</b> 58/5 <b>I understand [1]</b> 63/13 <b>I used [3]</b> 45/16 57/21 85/19 <b>I walked [1]</b> 33/6 <b>I want [1]</b> 72/2 <b>I wanted [3]</b> 36/4 71/10 71/13 <b>I was [100]</b> <b>I wasn't [8]</b> 22/1 23/18 49/12 76/22 80/14 88/14 89/24 89/25 <b>I went [11]</b> 21/23 23/13 24/14 33/10 35/21 42/10 42/12 52/8 54/7 77/15 77/19 <b>I were [1]</b> 43/13 <b>I what [1]</b> 37/15	<b>I will [8]</b> 12/8 12/9 23/11 52/19 54/9 57/15 57/16 93/6 <b>I wonder [2]</b> 43/15 83/10 <b>I wore [1]</b> 84/6 <b>I worked [1]</b> 7/22 <b>I would [31]</b> 25/21 31/6 40/7 46/12 46/18 47/24 47/25 50/2 50/19 51/16 52/10 53/6 57/17 57/18 58/24 59/14 60/18 65/9 65/17 76/23 79/1 80/11 83/18 85/20 86/1 88/2 88/15 91/7 92/2 92/4 92/6 <b>I wouldn't [2]</b> 38/3 50/2 <b>I write [1]</b> 28/9 <b>I'd [22]</b> 8/3 30/18 34/22 34/23 39/16 42/9 48/3 56/7 58/6 60/12 77/3 77/23 77/25 78/8 78/14 78/14 79/3 88/1 88/23 88/24 88/25 89/1 <b>I'll [2]</b> 10/22 12/6 <b>I'm [57]</b> 9/10 10/9 12/4 17/13 17/16 18/24 19/20 20/10 21/2 21/17 22/1 23/11 24/12 25/10 28/8 28/12 28/16 30/3 30/14 32/25 37/6 37/7 47/2 48/1 52/7 57/20 58/8 59/21 59/21 59/21 59/24 61/1 61/1 70/14 71/7 71/24 71/25 72/8 73/6 82/20 83/1 83/8 83/17 83/20 84/22 85/8 85/12 86/5 86/10 86/23 89/13 89/16 91/18 92/16 92/19 94/3 94/19 <b>I've [46]</b> 8/11 8/18 15/7 25/11 25/13 37/6 37/7 37/16 44/23 44/24 45/12 45/15 47/13 49/9 51/11 51/11 51/12 51/13 56/20 56/22 56/23 56/23 56/24 59/16 59/16 59/20 60/11 64/19 65/10 66/9 68/3 70/14 72/1 81/19 81/22 82/23 83/1 86/10 87/1 90/11 90/20 91/1 92/2 92/6 94/17 94/18 <b>I've just [1]</b> 56/20 <b>idea [5]</b> 36/6 44/4	55/3 73/19 88/2 <b>identification [1]</b> 74/3 <b>identifying [1]</b> 2/14 <b>if [79]</b> 8/9 9/3 9/21 10/10 12/4 12/6 16/1 16/2 16/19 16/19 17/6 18/10 18/23 23/5 23/18 23/24 25/15 26/1 26/15 27/12 28/13 28/21 33/8 37/14 39/25 41/17 41/22 46/13 46/23 47/2 47/3 49/25 51/22 52/4 53/21 54/2 54/13 55/25 57/12 57/14 58/1 59/24 60/16 60/23 61/14 65/12 65/16 67/17 67/25 69/8 70/15 70/19 70/23 71/7 71/18 71/24 73/6 73/13 75/2 75/22 80/17 81/2 83/18 86/2 86/2 86/21 87/2 87/2 87/4 87/6 87/13 87/14 89/4 91/3 91/6 94/4 96/4 96/5 96/18 <b>if' [1]</b> 42/15 <b>ill [1]</b> 65/3 <b>ill [8]</b> 13/11 42/6 52/25 54/21 59/15 83/12 91/19 95/7 <b>image [1]</b> 2/15 <b>images [1]</b> 1/12 <b>imagine [1]</b> 48/15 <b>imagined [1]</b> 96/7 <b>immature [2]</b> 73/5 90/6 <b>immediately [1]</b> 42/25 <b>impact [13]</b> 29/23 40/25 45/9 47/12 51/5 71/21 72/16 75/9 76/11 85/10 87/22 89/20 94/15 <b>implications [1]</b> 33/21 <b>important [6]</b> 12/8 29/3 29/6 62/9 68/24 75/20 <b>inasmuch [5]</b> 5/19 6/18 15/19 20/6 20/7 <b>inception [1]</b> 27/5 <b>Including [1]</b> 14/16 <b>income [1]</b> 91/9 <b>incorrect [1]</b> 96/12 <b>increasingly [1]</b> 67/5 <b>indeed [4]</b> 15/14 30/2 54/12 62/2 <b>individual [1]</b> 59/18 <b>infect [1]</b> 26/8 <b>infected [12]</b> 9/13 9/19 14/8 27/13 27/20 28/7 31/8 34/13 55/14
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(32) how... - infected



<p><b>I</b></p> <p><b>infected...</b> [3] 56/11 67/2 82/3</p> <p><b>Infected Blood Support Scheme</b> [1] 82/3</p> <p><b>infection</b> [9] 13/15 14/2 14/4 29/24 33/18 33/24 34/21 52/13 85/10</p> <p><b>infection'</b> [1] 33/20</p> <p><b>infections</b> [5] 7/15 56/8 57/4 61/11 61/12</p> <p><b>infectious</b> [2] 85/18 85/20</p> <p><b>infer</b> [1] 76/24</p> <p><b>inflicted</b> [2] 93/23 94/25</p> <p><b>information</b> [11] 2/15 9/21 14/24 33/23 34/15 37/7 46/5 59/3 70/17 70/22 82/4</p> <p><b>informed</b> [2] 73/15 74/1</p> <p><b>inhibitor</b> [1] 66/21</p> <p><b>initial</b> [1] 37/8</p> <p><b>initially</b> [1] 36/2</p> <p><b>injection</b> [1] 95/3</p> <p><b>injuries</b> [2] 13/20 96/2</p> <p><b>injury</b> [1] 12/22</p> <p><b>ink</b> [1] 26/1</p> <p><b>innocent</b> [4] 26/8 93/3 93/3 93/4</p> <p><b>inquest</b> [4] 18/6 18/9 19/5 19/11</p> <p><b>Inquiry</b> [17] 2/18 2/19 2/23 2/25 25/3 25/4 25/4 25/6 25/21 28/7 28/20 52/22 58/6 58/23 60/6 92/8 92/22</p> <p><b>ins</b> [2] 41/21 75/3</p> <p><b>insecurity</b> [1] 53/4</p> <p><b>insight</b> [2] 97/13 97/18</p> <p><b>inspired</b> [1] 92/6</p> <p><b>instantly</b> [1] 24/23</p> <p><b>insurance</b> [7] 60/13 60/13 90/9 90/10 90/12 90/13 90/14</p> <p><b>intellectually</b> [1] 44/7</p> <p><b>intensive</b> [1] 49/16</p> <p><b>interact</b> [1] 44/8</p> <p><b>interest</b> [1] 76/21</p> <p><b>interested</b> [1] 77/9</p> <p><b>interesting</b> [1] 97/18</p> <p><b>interferon</b> [10] 36/19 37/11 37/13 37/20 81/23 82/5 82/12 82/15 93/13 96/8</p> <p><b>intern</b> [1] 21/9</p> <p><b>Internet</b> [1] 47/19</p>	<p><b>interview</b> [3] 77/10 77/11 77/17</p> <p><b>interviews</b> [1] 48/17</p> <p><b>into</b> [32] 6/17 7/12 7/21 8/4 18/6 20/9 23/20 25/7 33/5 33/6 33/10 33/14 33/25 37/23 38/11 41/8 41/8 42/16 43/2 46/25 57/18 57/20 58/22 72/5 72/24 78/23 83/22 83/23 90/5 91/8 96/20 97/13</p> <p><b>introduced</b> [1] 41/15</p> <p><b>introduction</b> [1] 3/1</p> <p><b>Inverness</b> [1] 30/20</p> <p><b>investigation</b> [1] 47/8</p> <p><b>invited</b> [4] 21/1 68/15 68/16 78/21</p> <p><b>involve</b> [1] 38/22</p> <p><b>involved</b> [7] 25/6 25/7 47/8 69/5 73/10 80/22 94/11</p> <p><b>involvement</b> [1] 22/18</p> <p><b>irrevocably</b> [1] 93/5</p> <p><b>irritable</b> [2] 83/19 83/22</p> <p><b>isn't</b> [2] 55/7 59/15</p> <p><b>isolation</b> [1] 41/12</p> <p><b>issue</b> [3] 26/13 43/19 77/19</p> <p><b>issues</b> [3] 53/13 75/5 78/11</p> <p><b>it's</b> [70] 1/5 2/3 6/22 8/18 8/18 16/3 20/7 20/19 21/6 21/6 23/25 25/13 25/20 29/6 39/3 39/14 41/15 41/16 45/5 45/5 47/13 47/15 48/25 48/25 49/3 49/22 50/4 51/14 52/3 52/5 52/5 53/4 54/10 55/6 55/24 56/15 58/19 61/12 62/9 62/9 64/23 66/6 68/20 69/17 73/21 76/4 76/4 76/20 83/1 84/1 85/15 85/22 86/8 86/12 87/4 89/9 89/10 89/14 89/15 90/13 90/23 91/11 91/23 92/5 92/20 95/10 95/10 95/11 97/15 97/16</p> <p><b>itchy</b> [1] 81/20</p> <p><b>its</b> [4] 27/15 51/7 60/7 64/12</p> <p><b>itself</b> [3] 33/15 38/16 89/7</p> <p><b>IV</b> [1] 34/23</p> <p><b>IVF</b> [1] 81/2</p> <p><b>IX</b> [1] 30/12</p>	<p><b>J</b></p> <p><b>jamb</b> [1] 33/16</p> <p><b>January</b> [6] 64/23 64/25 68/1 74/2 88/6 88/10</p> <p><b>January 1985</b> [1] 64/23</p> <p><b>January 1995</b> [1] 68/1</p> <p><b>job</b> [11] 20/3 35/11 77/5 77/10 78/3 78/4 78/7 78/15 78/21 89/6 89/15</p> <p><b>jointly</b> [1] 36/4</p> <p><b>joints</b> [1] 95/8</p> <p><b>juggling</b> [1] 51/19</p> <p><b>July</b> [3] 1/1 7/19 7/20</p> <p><b>jumped</b> [2] 5/11 89/5</p> <p><b>just</b> [135]</p> <p><b>justice</b> [2] 57/2 93/25</p> <p><b>K</b></p> <p><b>keen</b> [2] 78/7 79/11</p> <p><b>keep</b> [15] 6/15 23/20 27/1 31/15 31/16 40/5 49/19 51/15 57/6 57/9 57/25 57/25 70/3 76/16 84/23</p> <p><b>keeping</b> [1] 50/10</p> <p><b>kept</b> [4] 21/13 27/12 27/21 72/9</p> <p><b>key</b> [1] 38/10</p> <p><b>kick</b> [1] 54/20</p> <p><b>kicking</b> [1] 82/10</p> <p><b>kid</b> [2] 72/19 84/3</p> <p><b>kidney</b> [13] 4/5 4/23 5/2 5/8 5/13 7/1 12/17 12/23 13/23 14/3 14/20 15/15 26/22</p> <p><b>kidneys</b> [1] 14/20</p> <p><b>kids</b> [4] 84/11 85/13 85/24 91/5</p> <p><b>killer</b> [1] 16/16</p> <p><b>kind</b> [17] 6/13 31/12 67/21 78/9 78/11 79/19 80/1 82/6 83/22 84/1 84/5 84/15 85/4 85/9 86/2 88/16 88/24</p> <p><b>kindness</b> [3] 59/5 59/8 59/10</p> <p><b>kisses</b> [1] 85/13</p> <p><b>kitchen</b> [1] 38/15</p> <p><b>knew</b> [16] 8/14 15/16 16/20 17/5 17/6 17/17 17/18 22/5 50/15 50/20 52/1 70/15 78/10 78/18 79/2 79/2</p> <p><b>knife</b> [1] 56/13</p> <p><b>knocked</b> [3] 48/25 49/1 49/3</p> <p><b>know</b> [89] 1/7 7/4 7/5 9/14 9/18 11/2 11/22</p>	<p>12/9 15/4 15/11 16/6 16/8 21/1 21/20 21/20 22/13 22/25 23/24 24/13 25/1 25/1 31/7 31/22 37/15 41/21 42/15 43/17 43/22 44/23 46/23 46/23 47/7 47/23 48/19 48/19 49/2 49/9 49/10 50/1 50/4 50/11 51/22 54/13 55/9 56/15 57/15 61/4 61/6 61/10 66/17 69/21 70/15 70/19 71/5 71/6 71/7 72/13 72/18 73/6 75/3 78/7 79/22 83/7 83/10 83/11 83/21 83/21 84/2 84/12 84/22 85/13 85/17 85/18 85/19 85/22 85/25 85/25 86/10 87/1 88/7 88/14 89/14 89/17 90/22 91/1 91/2 91/20 92/15 92/18</p> <p><b>knowing</b> [5] 37/23 37/24 49/14 53/2 92/17</p> <p><b>knowledge</b> [3] 26/5 66/17 76/24</p> <p><b>known</b> [5] 11/5 56/7 62/17 86/5 86/8</p> <p><b>knows</b> [1] 91/20</p> <p><b>L</b></p> <p><b>lab</b> [1] 64/15</p> <p><b>labour</b> [1] 1/6</p> <p><b>labour-saving</b> [1] 1/6</p> <p><b>lack</b> [3] 45/11 60/19 92/25</p> <p><b>lady</b> [3] 5/22 7/13 22/11</p> <p><b>laid</b> [3] 83/12 83/20 91/19</p> <p><b>lame</b> [1] 48/23</p> <p><b>Langstaff</b> [1] 28/8</p> <p><b>large</b> [1] 91/1</p> <p><b>largely</b> [2] 63/14 64/11</p> <p><b>last</b> [11] 18/1 20/7 24/10 24/13 25/23 47/15 52/1 56/8 61/9 82/19 89/12</p> <p><b>late</b> [9] 1/3 3/5 26/12 33/6 35/3 36/16 37/1 42/2 66/25</p> <p><b>late 1991</b> [1] 35/3</p> <p><b>later</b> [9] 2/9 12/2 21/8 23/22 31/22 68/19 77/16 88/10 88/18</p> <p><b>latest</b> [2] 59/1 59/2</p> <p><b>laughing</b> [1] 69/18</p> <p><b>Laura</b> [1] 86/5</p>	<p><b>lax</b> [1] 26/19</p> <p><b>layman</b> [1] 28/9</p> <p><b>lead</b> [2] 6/5 93/25</p> <p><b>leak</b> [1] 27/11</p> <p><b>leaning</b> [1] 33/16</p> <p><b>learn</b> [1] 21/19</p> <p><b>learning</b> [1] 76/25</p> <p><b>learnt</b> [1] 14/6</p> <p><b>least</b> [4] 4/17 27/9 34/10 34/11</p> <p><b>leave</b> [4] 43/6 54/5 54/6 88/3</p> <p><b>leaving</b> [1] 20/10</p> <p><b>left</b> [8] 19/13 20/19 38/10 50/2 67/23 81/15 81/20 81/22</p> <p><b>leg</b> [1] 33/12</p> <p><b>legal</b> [2] 73/10 92/11</p> <p><b>legs</b> [2] 7/10 18/3</p> <p><b>length</b> [1] 80/10</p> <p><b>less</b> [5] 17/22 50/4 50/4 77/12 78/8</p> <p><b>lessened</b> [1] 41/25</p> <p><b>let</b> [6] 1/16 4/9 25/2 55/16 75/2 94/19</p> <p><b>Let's</b> [1] 55/15</p> <p><b>lethargy</b> [1] 7/8</p> <p><b>letter</b> [20] 11/25 12/9 13/9 13/12 23/14 36/18 43/8 43/21 64/23 66/6 68/1 68/20 68/23 69/16 70/14 72/4 73/16 73/18 74/2 78/2</p> <p><b>letters</b> [1] 43/9</p> <p><b>level</b> [4] 49/2 51/17 85/9 92/24</p> <p><b>levels</b> [4] 46/24 47/6 57/19 66/21</p> <p><b>libraries</b> [1] 24/24</p> <p><b>library</b> [1] 53/6</p> <p><b>licence</b> [1] 66/14</p> <p><b>lie</b> [1] 10/18</p> <p><b>lied</b> [1] 43/22</p> <p><b>lies</b> [1] 93/8</p> <p><b>life</b> [20] 4/10 6/5 6/9 14/24 16/11 24/3 26/19 28/23 47/10 57/6 60/9 60/14 61/19 71/4 83/14 85/11 87/16 90/9 90/10 90/14</p> <p><b>life-giving</b> [1] 26/19</p> <p><b>lifespan</b> [1] 27/22</p> <p><b>lifetime</b> [2] 20/22 94/20</p> <p><b>light</b> [2] 85/21 92/13</p> <p><b>like</b> [47] 4/2 6/22 11/7 17/14 18/4 18/4 18/19 18/21 21/5 22/1 23/6 25/12 25/21 37/15 38/5 39/20 44/11 46/2</p>	<p>52/7 54/23 55/13 56/12 56/19 57/18 60/14 60/15 61/19 61/19 61/24 64/3 75/10 75/11 75/13 75/14 81/13 84/2 84/3 84/15 85/8 92/1 92/2 92/4 92/8 92/12 92/23 94/1 94/6</p> <p><b>liked</b> [3] 19/1 76/23 88/15</p> <p><b>likewise</b> [1] 96/5</p> <p><b>limitation</b> [1] 93/17</p> <p><b>Lincolnshire</b> [2] 35/2 36/8</p> <p><b>line</b> [1] 85/4</p> <p><b>lines</b> [1] 32/25</p> <p><b>lining</b> [2] 22/16 22/17</p> <p><b>list</b> [1] 4/24</p> <p><b>listening</b> [1] 29/2</p> <p><b>literally</b> [1] 47/24</p> <p><b>literature</b> [1] 67/11</p> <p><b>litigation</b> [1] 22/19</p> <p><b>little</b> [9] 11/4 23/19 25/13 38/25 52/19 57/8 71/18 72/1 76/14</p> <p><b>live</b> [7] 2/7 56/13 56/13 60/14 61/23 77/3 93/6</p> <p><b>live-streaming</b> [1] 2/7</p> <p><b>lived</b> [2] 46/10 93/9</p> <p><b>liver</b> [16] 13/24 14/19 33/22 33/22 34/1 34/1 36/24 69/2 69/4 69/6 69/7 69/12 77/22 82/17 82/23 93/11</p> <p><b>lives</b> [7] 52/15 57/7 58/24 61/23 93/3 93/4 93/4</p> <p><b>living</b> [7] 4/9 19/25 36/7 41/16 53/4 59/15 83/6</p> <p><b>loan</b> [1] 51/20</p> <p><b>local</b> [3] 67/16 89/1 92/19</p> <p><b>locked</b> [1] 38/9</p> <p><b>locus</b> [1] 13/5</p> <p><b>London</b> [5] 30/17 30/18 30/18 30/20 32/20</p> <p><b>long</b> [23] 6/15 16/7 17/14 18/9 25/20 35/16 42/8 45/16 45/19 45/19 49/4 55/2 78/20 79/7 79/9 82/11 83/14 89/12 89/15 89/24 90/19 90/23 92/14</p> <p><b>long-term</b> [3] 45/16 45/19 45/19</p> <p><b>longer</b> [4] 46/8 80/1 80/8 93/22</p>
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(33) infected... - longer

<p><b>L</b></p> <p><b>look</b> [7] 4/22 13/13 18/24 20/11 54/3 73/18 91/5</p> <p><b>looked</b> [6] 5/24 6/2 10/10 25/6 68/3 92/10</p> <p><b>looking</b> [11] 19/16 25/8 40/20 47/19 47/21 61/2 77/8 78/9 78/18 79/3 91/11</p> <p><b>losing</b> [2] 44/4 49/16</p> <p><b>loss</b> [5] 7/9 7/9 7/10 32/3 81/12</p> <p><b>loss -- the</b> [1] 81/12</p> <p><b>lost</b> [6] 20/3 23/6 28/10 76/14 81/11 93/3</p> <p><b>lot</b> [11] 19/1 40/10 47/22 61/2 68/7 70/7 76/14 81/11 84/21 84/24 90/5</p> <p><b>lots</b> [2] 70/4 81/14</p> <p><b>love</b> [6] 9/13 54/8 57/17 61/15 61/15 85/24</p> <p><b>loved</b> [4] 27/23 49/13 51/16 93/21</p> <p><b>lovely</b> [1] 4/3</p> <p><b>low</b> [1] 56/17</p> <p><b>Lowe</b> [1] 1/22</p> <p><b>lower</b> [1] 51/16</p> <p><b>luckily</b> [4] 78/14 78/20 81/3 89/7</p> <p><b>lucky</b> [2] 9/11 86/5</p> <p><b>lumps</b> [1] 18/5</p> <p><b>lunch</b> [2] 31/2 60/17</p> <p><b>luncheon</b> [1] 62/15</p> <p><b>lying</b> [2] 40/19 77/20</p> <p><b>lymphoma</b> [2] 33/22 33/25</p>	<p><b>manage</b> [3] 1/8 33/24 93/1</p> <p><b>managed</b> [3] 19/22 42/20 72/21</p> <p><b>management</b> [1] 78/23</p> <p><b>manager</b> [1] 88/25</p> <p><b>Manchester</b> [6] 5/6 5/12 7/18 11/25 15/5 23/9</p> <p><b>Manor</b> [1] 38/23</p> <p><b>many</b> [18] 26/9 30/11 30/12 43/15 46/7 47/7 47/7 47/13 48/12 48/12 48/16 48/17 49/1 49/8 49/10 49/10 81/22 85/17</p> <p><b>marriage</b> [1] 86/4</p> <p><b>married</b> [7] 3/21 22/11 22/14 32/16 79/8 79/9 79/11</p> <p><b>marvellous</b> [1] 22/5</p> <p><b>masculinity</b> [1] 42/1</p> <p><b>massive</b> [4] 7/10 20/8 26/17 35/10</p> <p><b>match</b> [4] 5/13 13/3 16/15 16/15</p> <p><b>matter</b> [4] 12/12 47/16 47/19 68/9</p> <p><b>matters</b> [1] 1/23</p> <p><b>mattress</b> [1] 31/24</p> <p><b>Maureen</b> [1] 35/23</p> <p><b>maximum</b> [1] 63/4</p> <p><b>may</b> [14] 2/24 3/1 4/12 5/20 30/6 37/5 60/7 68/25 81/19 82/12 82/13 83/14 93/8 97/21</p> <p><b>maybe</b> [14] 23/19 39/24 45/4 45/17 48/21 48/21 57/16 58/1 63/3 63/5 67/15 72/11 72/13 85/7</p> <p><b>me</b> [86] 2/12 2/18 5/7 9/13 9/16 10/17 15/5 18/16 20/20 21/17 21/25 23/5 25/17 25/25 26/2 29/4 31/3 33/3 33/5 33/17 33/18 33/23 33/24 34/13 34/24 34/25 37/12 37/13 39/3 44/3 44/8 44/11 53/5 54/4 54/24 57/15 59/17 69/22 69/25 70/1 70/20 70/22 71/9 71/13 71/18 72/13 72/14 73/14 75/2 75/19 77/9 78/16 78/21 78/22 79/2 79/5 82/7 83/5 83/8 83/11 83/13 84/5 84/15 84/21 85/22</p>	<p>85/23 85/24 86/5 86/25 87/14 89/5 89/6 89/18 92/8 92/13 92/23 93/7 93/14 94/4 94/6 94/24 95/1 95/7 96/5 96/18 96/21</p> <p><b>mean</b> [18] 16/14 17/8 18/20 40/21 48/9 48/11 49/11 51/8 55/6 58/22 59/8 59/16 60/10 61/10 71/3 72/3 92/18 94/17</p> <p><b>means</b> [5] 50/9 56/11 58/19 68/5 70/16</p> <p><b>meant</b> [4] 11/4 33/20 66/18 69/21</p> <p><b>measured</b> [1] 13/4</p> <p><b>media</b> [5] 77/5 77/10 78/21 89/1 89/12</p> <p><b>medical</b> [15] 22/12 24/25 26/4 26/5 26/11 44/15 44/15 77/13 77/15 77/19 77/21 78/10 96/10 96/15 96/25</p> <p><b>medics</b> [1] 58/10</p> <p><b>meet</b> [1] 16/14</p> <p><b>meeting</b> [7] 38/25 49/13 68/13 68/16 68/18 68/21 69/20</p> <p><b>meetings</b> [1] 38/24</p> <p><b>member</b> [1] 2/13</p> <p><b>members</b> [1] 92/19</p> <p><b>memories</b> [1] 40/18</p> <p><b>men</b> [1] 50/6</p> <p><b>mental</b> [3] 42/4 53/13 83/15</p> <p><b>mentality</b> [1] 93/18</p> <p><b>Mentally</b> [1] 37/16</p> <p><b>mention</b> [3] 12/19 16/2 16/5</p> <p><b>mentioned</b> [5] 1/22 6/25 22/18 23/1 94/17</p> <p><b>mentioning</b> [1] 2/5</p> <p><b>mentions</b> [1] 16/2</p> <p><b>mess</b> [2] 7/13 88/11</p> <p><b>met</b> [10] 3/21 22/13 30/15 30/22 30/24 49/11 58/13 79/7 79/9 83/20</p> <p><b>mid</b> [1] 26/12</p> <p><b>midst</b> [1] 87/24</p> <p><b>might</b> [21] 18/9 25/14 33/21 33/25 56/7 56/14 57/3 61/2 61/3 61/11 67/2 67/22 73/7 78/10 82/7 87/7 87/7 89/4 90/2 91/12 96/23</p> <p><b>mild</b> [4] 33/18 33/20 37/14 37/14</p> <p><b>miles</b> [2] 4/18 21/6</p> <p><b>milk</b> [1] 76/15</p>	<p><b>mill</b> [1] 71/10</p> <p><b>millions</b> [1] 27/16</p> <p><b>mind</b> [8] 6/17 15/3 23/23 49/11 55/7 71/24 72/24 88/17</p> <p><b>minder</b> [1] 36/11</p> <p><b>minimal</b> [1] 82/18</p> <p><b>minister</b> [2] 57/12 57/14</p> <p><b>Ministry</b> [1] 27/8</p> <p><b>minute</b> [1] 25/18</p> <p><b>miscarriages</b> [1] 39/24</p> <p><b>mismatch</b> [1] 13/4</p> <p><b>missing</b> [1] 97/4</p> <p><b>mixture</b> [2] 34/7 74/25</p> <p><b>Mmm</b> [2] 79/15 95/18</p> <p><b>Mmm-hmm</b> [2] 79/15 95/18</p> <p><b>moment</b> [5] 1/11 2/10 39/9 68/8 73/18</p> <p><b>money</b> [8] 22/22 23/18 28/4 51/19 51/21 90/1 90/4 90/23</p> <p><b>monitored</b> [2] 66/15 66/19</p> <p><b>monitoring</b> [2] 74/13 82/21</p> <p><b>month</b> [3] 36/17 36/17 63/5</p> <p><b>month's</b> [1] 43/4</p> <p><b>monthly</b> [1] 69/3</p> <p><b>months</b> [5] 15/9 15/10 25/23 35/20 76/4</p> <p><b>mood</b> [1] 56/17</p> <p><b>more</b> [21] 3/19 10/10 18/14 35/18 39/13 41/7 41/7 41/7 44/3 46/17 52/3 57/14 72/7 76/14 77/12 78/8 79/19 84/3 84/4 86/1 90/13</p> <p><b>morning</b> [4] 1/9 5/23 47/14 72/5</p> <p><b>mortality</b> [1] 56/12</p> <p><b>mortgage</b> [3] 91/1 91/4 91/9</p> <p><b>mortified</b> [1] 31/21</p> <p><b>Morton</b> [1] 23/9</p> <p><b>most</b> [4] 49/14 68/25 83/20 89/14</p> <p><b>mother</b> [1] 63/2</p> <p><b>mouth</b> [1] 31/6</p> <p><b>moved</b> [10] 30/19 32/19 35/2 36/9 36/21 43/2 45/21 46/11 77/1 91/4</p> <p><b>moving</b> [3] 66/1 66/4 78/23</p> <p><b>MP</b> [1] 57/11</p> <p><b>Mr</b> [16] 1/16 1/21 2/3 2/5 2/12 2/21 3/1 3/3</p>	<p>3/5 23/9 23/11 28/12 59/24 94/3 94/4 99/3</p> <p><b>Mr and Mrs V</b> [1] 1/21</p> <p><b>Mr Dawson</b> [1] 94/3</p> <p><b>Mr O'Neill</b> [2] 59/24 94/4</p> <p><b>Mr Snowden</b> [1] 28/12</p> <p><b>Mr W</b> [10] 1/16 2/3 2/5 2/12 2/21 3/1 3/3 3/5 23/11 99/3</p> <p><b>Mrs</b> [1] 1/21</p> <p><b>Ms</b> [8] 1/13 1/17 3/4 29/21 62/22 99/4 99/6 99/8</p> <p><b>MS FRASER BUTLIN</b> [2] 62/22 99/8</p> <p><b>Ms Richards</b> [6] 1/13 1/17 3/4 29/21 99/4 99/6</p> <p><b>much</b> [24] 2/2 8/8 21/19 29/8 36/11 41/6 45/14 45/14 52/3 52/4 58/17 58/22 61/15 62/1 62/2 62/6 62/8 71/16 72/11 76/22 80/21 88/14 89/10 90/13</p> <p><b>multiple</b> [1] 39/23</p> <p><b>mum</b> [16] 10/25 36/5 64/3 65/7 65/10 67/1 67/5 67/16 68/2 68/10 70/11 70/24 72/10 94/22 95/20 95/24</p> <p><b>music</b> [1] 60/15</p> <p><b>must</b> [4] 2/21 26/17 37/1 93/16</p> <p><b>my</b> [143]</p> <p><b>myself</b> [17] 24/11 25/22 43/1 46/12 65/16 70/3 73/8 73/9 75/21 76/22 83/22 83/23 83/25 84/24 85/15 90/6 96/1</p>	<p><b>N</b></p> <p><b>name</b> [10] 2/11 2/12 2/13 3/8 3/11 3/11 11/13 12/18 18/22 35/24</p> <p><b>name's</b> [1] 32/19</p> <p><b>names</b> [3] 2/5 2/6 50/17</p> <p><b>naming</b> [1] 3/10</p> <p><b>narrative</b> [1] 92/22</p> <p><b>National</b> [3] 23/16 26/24 27/5</p> <p><b>natural</b> [1] 86/13</p> <p><b>naturally</b> [1] 85/14</p> <p><b>nausea</b> [2] 32/2 40/13</p> <p><b>near</b> [1] 42/13</p> <p><b>nearby</b> [1] 43/3</p>	<p><b>nearly</b> [1] 52/11</p> <p><b>necessarily</b> [2] 45/20 64/5</p> <p><b>necessitated</b> [2] 13/19 40/21</p> <p><b>need</b> [13] 8/8 12/25 23/24 44/12 45/25 48/1 62/25 68/8 72/7 77/12 81/2 83/23 87/8</p> <p><b>needed</b> [4] 22/10 51/21 78/25 88/13</p> <p><b>needle</b> [3] 33/14 37/22 96/2</p> <p><b>needs</b> [1] 45/18</p> <p><b>negative</b> [3] 13/2 13/8 44/20</p> <p><b>never</b> [20] 8/10 28/1 37/16 38/19 39/19 51/20 53/2 53/22 56/23 56/24 57/23 61/11 62/4 72/14 72/15 78/2 78/12 90/11 92/5 96/24</p> <p><b>new</b> [10] 27/3 32/23 32/23 41/16 44/18 61/5 61/6 66/1 66/24 88/4</p> <p><b>news</b> [3] 27/11 58/7 67/10</p> <p><b>newspaper</b> [2] 41/9 46/15</p> <p><b>newspapers</b> [1] 27/17</p> <p><b>next</b> [10] 23/13 29/16 42/12 53/3 53/3 57/16 61/12 62/17 68/9 80/8</p> <p><b>NHS</b> [2] 12/1 73/13</p> <p><b>nice</b> [2] 4/4 91/2</p> <p><b>night</b> [10] 15/6 24/10 24/13 31/19 35/7 40/14 40/14 48/2 48/3 60/17</p> <p><b>nightmares</b> [1] 24/5</p> <p><b>Ninewells</b> [1] 63/24</p> <p><b>no</b> [67] 2/7 4/11 4/11 4/11 7/7 8/17 8/17 8/18 9/7 9/20 10/5 10/11 10/19 12/20 14/1 20/24 24/22 25/11 25/13 26/4 27/19 28/14 29/9 31/9 33/23 34/17 34/19 35/12 36/3 36/25 38/20 38/20 39/13 43/23 46/8 46/9 47/16 47/19 54/5 54/7 55/1 55/9 61/6 63/9 63/13 63/19 63/21 63/23 64/13 65/11 65/14 65/18 65/22 67/21 70/9 74/9 74/16 74/19 80/16 82/18 83/1 86/17 86/23 93/22</p>
--	--	--	--	---	--	--

<p><b>N</b></p> <p>no... [3] 94/14 94/14 97/2</p> <p>nobody [6] 37/12 48/19 50/7 55/10 71/23 91/21</p> <p>nor [1] 55/9</p> <p>normal [6] 6/5 28/10 28/10 55/5 82/24 90/14</p> <p>normally [1] 27/18</p> <p>NORVAL [2] 29/20 99/5</p> <p>not [103]</p> <p>notable [1] 92/20</p> <p>note [2] 73/25 96/10</p> <p>notes [4] 20/13 56/20 69/16 71/25</p> <p>nothing [18] 24/22 28/14 32/8 39/21 44/3 52/5 52/5 52/7 58/20 60/1 61/6 66/3 74/15 75/12 94/1 96/17 97/1 97/7</p> <p>notice [3] 36/15 44/12 77/21</p> <p>noticeable [1] 80/15</p> <p>November [2] 20/8 74/4</p> <p>November 1992 [1] 74/4</p> <p>now [25] 2/4 12/5 17/17 20/16 31/7 34/3 35/2 36/19 39/5 42/19 45/2 51/4 53/24 57/19 59/10 60/20 62/10 64/20 68/3 70/10 82/17 84/18 89/9 89/13 97/21</p> <p>number [4] 12/7 14/11 43/8 44/14</p> <p>numerous [1] 97/5</p> <p>nurse [2] 21/10 60/25</p> <p>nursery [3] 40/17 40/23 40/24</p> <p>nurses [1] 20/18</p> <p>nursing [4] 30/20 30/21 30/22 31/15</p> <p>nutritional [1] 76/15</p>	<p>31/17 35/23 42/8</p> <p>occurrence [1] 69/11</p> <p>off [15] 9/3 21/5 29/5 42/21 43/5 45/17 61/5 75/4 79/19 79/24 79/24 79/25 88/2 88/3 96/11</p> <p>offer [4] 77/13 78/3 79/5 89/5</p> <p>offered [11] 20/22 21/22 34/18 58/18 77/5 80/2 83/1 86/15 86/20 86/21 89/5</p> <p>offhand [1] 67/21</p> <p>office [2] 50/18 78/22</p> <p>often [6] 26/6 38/5 47/2 49/22 62/25 85/3</p> <p>oh [11] 4/11 5/19 15/23 17/6 19/8 23/4 24/9 31/4 41/16 48/20 57/12</p> <p>okay [11] 7/4 19/25 22/3 23/13 30/16 45/4 70/2 72/18 85/15 86/18 94/19</p> <p>old [6] 17/11 17/20 31/5 35/20 53/9 97/13</p> <p>omission [1] 1/20</p> <p>omitted [1] 97/4</p> <p>once [9] 1/24 10/16 15/19 20/24 27/11 63/4 63/5 74/20 90/10</p> <p>once/twice [1] 63/5</p> <p>one [40] 3/15 5/4 6/24 11/24 13/4 13/15 13/18 13/23 14/15 14/20 15/2 15/5 18/21 26/18 26/21 31/17 32/20 35/22 36/15 36/17 40/18 42/8 43/14 48/5 51/4 53/10 55/9 57/14 57/21 58/8 60/18 60/19 77/9 79/19 84/5 86/6 86/25 91/9 94/25 96/20</p> <p>ones [4] 27/23 49/13 58/9 93/21</p> <p>ongoing [4] 6/6 60/19 69/4 91/10</p> <p>only [18] 2/21 13/4 14/25 20/24 26/10 28/3 45/5 49/1 58/13 59/13 64/7 65/9 66/13 71/6 92/6 92/19 96/14 97/3</p> <p>open [4] 31/2 50/20 84/18 84/23</p> <p>operation [4] 5/17 5/20 6/16 16/11</p> <p>opportunities [1] 48/13</p> <p>opportunity [5] 29/4</p>	<p>51/18 62/7 62/8 92/5</p> <p>opposite [1] 27/21</p> <p>options [1] 74/20</p> <p>or [75] 2/15 2/17 2/18 2/24 3/12 3/12 4/17 9/21 10/4 13/14 14/24 18/22 18/25 20/22 20/23 21/1 21/3 21/10 21/22 24/9 26/14 31/23 33/22 34/1 34/13 34/15 48/5 48/6 48/24 51/17 51/20 51/20 52/4 53/3 54/6 54/23 54/24 54/24 54/25 55/6 57/11 60/5 60/25 64/11 66/17 67/6 67/10 68/16 69/7 70/11 70/17 71/17 72/23 74/6 77/12 77/17 77/17 78/2 78/8 79/7 82/18 83/23 83/24 85/6 86/16 92/15 92/16 92/25 92/25 93/1 93/14 94/12 96/1 96/2 97/4</p> <p>order [10] 1/16 2/3 2/11 2/22 2/24 2/25 3/18 22/22 23/4 80/5</p> <p>ordered [1] 2/24</p> <p>ordinary [1] 1/9</p> <p>organise [1] 69/2</p> <p>organs [3] 11/20 13/22 14/11</p> <p>origin [1] 14/3</p> <p>originate [1] 26/23</p> <p>other [37] 2/13 2/14 10/9 11/12 11/21 13/21 13/23 15/2 15/14 15/15 15/22 15/24 22/17 38/25 39/2 39/2 43/14 45/2 54/19 55/8 56/10 64/4 64/5 65/5 66/4 67/15 72/12 73/21 81/21 84/2 86/17 92/15 92/17 92/19 92/23 97/12 97/16</p> <p>others [1] 65/4</p> <p>otherwise [1] 2/23</p> <p>our [18] 12/4 13/23 28/1 29/16 31/2 36/6 36/17 39/10 40/20 42/20 43/17 56/22 58/24 61/23 62/17 86/8 89/2 91/9</p> <p>ourselves [1] 13/1</p> <p>out [55] 1/6 1/17 2/10 5/19 7/11 9/5 11/8 11/9 12/6 12/8 12/9 15/4 15/4 15/7 15/13 15/20 16/12 16/16 19/12 19/13 19/21</p>	<p>20/10 21/8 21/9 23/4 23/12 23/19 24/18 27/1 27/11 28/23 31/4 32/20 40/8 41/4 41/5 43/2 43/21 44/8 44/18 45/6 47/1 50/17 54/22 55/17 60/16 67/11 67/17 71/23 72/14 76/25 77/14 84/5 95/7 96/14</p> <p>outcome [1] 38/16</p> <p>outcomes [1] 92/11</p> <p>outgoing [4] 4/3 83/17 84/3 84/7</p> <p>outpouring [1] 87/8</p> <p>outs [2] 41/22 75/3</p> <p>outside [2] 19/14 24/14</p> <p>outwardly [1] 71/8</p> <p>over [21] 24/24 25/23 25/25 28/6 30/11 31/18 35/5 44/19 44/19 49/9 51/5 66/11 66/13 66/15 66/24 67/14 81/14 88/3 94/9 94/18 95/10</p> <p>oversight [1] 64/13</p> <p>overstuffed [1] 57/14</p> <p>own [13] 6/18 9/24 10/6 10/19 10/25 21/23 27/15 42/3 46/1 50/8 56/12 66/17 76/24</p>	<p><b>P</b></p> <p>pad [1] 76/25</p> <p>paediatric [5] 63/17 63/18 63/19 63/23 67/20</p> <p>page [1] 69/8</p> <p>paid [1] 93/22</p> <p>pain [3] 42/15 43/1 50/1</p> <p>paint [1] 57/16</p> <p>pan [2] 38/13 38/14</p> <p>panic [1] 27/16</p> <p>papers [1] 17/8</p> <p>par [1] 81/19</p> <p>paragraph [2] 66/7 68/23</p> <p>paragraphs [1] 12/10</p> <p>parent [4] 36/4 40/7 51/13 65/16</p> <p>parents [19] 64/4 65/18 66/16 66/18 69/9 69/14 69/16 69/24 71/9 71/16 73/25 74/6 77/4 94/11 94/16 94/20 95/6 97/14 97/15</p> <p>parents' [1] 10/24</p> <p>parks [1] 54/22</p>	<p>Parliament [3] 48/16 48/21 57/16</p> <p>part [13] 32/23 45/8 51/17 55/25 67/24 74/4 74/9 78/17 84/13 84/15 86/8 91/5 92/21</p> <p>part-time [3] 51/17 78/17 91/5</p> <p>particular [7] 14/23 15/2 17/25 18/21 60/4 62/3 94/22</p> <p>particularly [1] 73/3</p> <p>partly [1] 85/16</p> <p>pass [1] 87/3</p> <p>passages [1] 30/6</p> <p>passed [7] 9/16 23/3 26/22 56/11 78/2 95/19 95/24</p> <p>passing [2] 79/23 95/14</p> <p>passions [1] 51/4</p> <p>past [1] 75/2</p> <p>paternity [1] 88/2</p> <p>patient [4] 19/2 22/4 42/9 42/12</p> <p>patients [5] 13/23 15/24 21/14 27/19 93/19</p> <p>pats [1] 57/1</p> <p>Paul [3] 12/7 64/22 67/25</p> <p>Pauline [1] 97/23</p> <p>Pauline Reid [1] 97/23</p> <p>Pause [7] 4/3 8/7 8/9 17/15 56/20 72/2 94/5</p> <p>pay [5] 30/22 31/16 36/10 43/4 51/15</p> <p>paying [1] 36/17</p> <p>payment [1] 90/15</p> <p>payments [2] 90/16 90/21</p> <p>PCR [1] 44/20</p> <p>peaks [1] 81/17</p> <p>Penrose [4] 25/4 58/6 58/23 92/10</p> <p>Penrose Inquiry [3] 25/4 58/6 58/23</p> <p>people [49] 11/14 14/14 14/18 23/2 23/16 24/25 26/8 27/13 38/25 41/17 41/21 41/23 43/15 43/16 43/20 43/25 44/11 44/11 45/3 45/6 45/17 45/19 47/20 49/8 49/11 49/17 50/10 50/15 50/16 53/1 55/19 57/7 57/23 58/19 59/5 59/8 59/11 61/2 68/25 69/11 72/11 84/19 84/23</p>	<p>85/18 86/6 89/14 89/17 92/7 92/23</p> <p>people's [1] 50/1</p> <p>perfect [2] 13/4 58/19</p> <p>perhaps [3] 1/5 27/14 75/2</p> <p>period [3] 9/14 36/7 42/2</p> <p>permanent [1] 78/16</p> <p>permission [1] 2/17</p> <p>person [11] 4/2 4/4 15/12 15/22 26/2 50/20 55/9 58/12 83/17 83/20 95/2</p> <p>personal [2] 26/11 93/16</p> <p>personality [1] 44/5</p> <p>petrified [1] 79/23</p> <p>Philip [1] 63/15</p> <p>Philip Cachia [1] 63/15</p> <p>phone [16] 5/5 5/9 8/19 8/22 16/2 16/4 16/4 23/10 24/24 48/3 48/4 48/17 50/20 88/6 89/3 89/6</p> <p>phoned [4] 8/24 15/5 23/8 78/4</p> <p>phoning [1] 47/18</p> <p>photograph [2] 17/25 18/1</p> <p>photographs [2] 3/14 3/20</p> <p>phrase [2] 44/25 55/21</p> <p>physical [3] 41/1 46/7 86/13</p> <p>physically [4] 37/16 51/8 51/9 86/11</p> <p>physio [1] 42/9</p> <p>physiotherapist [1] 45/8</p> <p>physiotherapy [1] 30/19</p> <p>pick [1] 28/17</p> <p>picked [1] 11/6</p> <p>picking [2] 46/4 72/14</p> <p>piece [1] 59/2</p> <p>pieces [1] 48/18</p> <p>pig [1] 44/24</p> <p>pint [1] 26/22</p> <p>pipeline [1] 70/1</p> <p>pizza [1] 31/3</p> <p>placate [1] 43/23</p> <p>place [10] 13/3 16/19 16/20 16/22 21/11 26/15 27/2 49/23 55/12 70/20</p> <p>plague [2] 8/15 11/6</p> <p>plan [1] 36/2</p> <p>planned [2] 35/19 40/2</p>
--	--	--	---	---	---	--

<b>p</b>	39/5 80/12 80/24 81/3 81/5 <b>prejudice</b> [1] 70/7 <b>prelim</b> [1] 72/5 <b>prescribed</b> [1] 35/9 <b>preserve</b> [1] 2/4 <b>press</b> [4] 24/23 43/13 68/7 70/6 <b>pretences</b> [1] 19/25 <b>pretty</b> [4] 75/10 76/17 81/11 82/14 <b>prevent</b> [1] 93/1 <b>previous</b> [2] 23/9 25/4 <b>previously</b> [2] 64/18 92/9 <b>primarily</b> [1] 82/8 <b>prior</b> [4] 12/23 36/23 63/16 92/10 <b>private</b> [1] 92/10 <b>privileged</b> [1] 62/5 <b>probably</b> [26] 16/6 33/9 33/23 34/1 67/17 67/20 67/23 70/21 72/22 76/6 76/13 76/23 81/16 83/9 83/17 83/20 86/7 86/10 86/13 86/23 86/23 87/10 90/22 94/20 95/11 96/12 <b>problem</b> [5] 1/11 43/23 65/1 67/13 93/18 <b>problems</b> [7] 1/4 4/5 12/6 15/18 23/12 33/12 45/20 <b>proceeded</b> [1] 5/17 <b>process</b> [3] 4/20 88/8 92/21 <b>procurement</b> [1] 64/14 <b>product</b> [2] 66/1 74/9 <b>products</b> [7] 30/12 64/8 65/23 67/3 67/9 74/5 94/12 <b>profession</b> [3] 22/12 44/15 45/10 <b>profit</b> [1] 26/17 <b>profoundly</b> [1] 44/14 <b>programme</b> [1] 22/25 <b>progress</b> [1] 13/9 <b>progression</b> [1] 72/17 <b>promise</b> [1] 24/21 <b>promised</b> [1] 24/18 <b>promotions</b> [1] 88/24 <b>proper</b> [3] 26/15 78/18 79/3 <b>properly</b> [2] 28/1 55/19 <b>property</b> [2] 23/19 43/2 <b>proposing</b> [1] 1/24 <b>protect</b> [2] 97/14	97/15 <b>proud</b> [1] 84/12 <b>proudly</b> [1] 84/7 <b>proved</b> [1] 44/1 <b>provision</b> [1] 1/12 <b>provisional</b> [1] 66/14 <b>psychiatric</b> [2] 53/14 53/15 <b>psychiatrist</b> [2] 53/18 53/25 <b>psychological</b> [3] 20/23 20/25 86/16 <b>psychologists</b> [1] 21/24 <b>public</b> [1] 27/4 <b>publication</b> [1] 58/5 <b>published</b> [3] 1/25 2/17 3/12 <b>purified</b> [1] 66/11 <b>purity</b> [4] 66/2 94/9 94/10 94/12 <b>purpose</b> [2] 49/6 68/21 <b>purposes</b> [1] 13/1 <b>pushed</b> [1] 86/25 <b>put</b> [22] 4/19 4/24 5/9 26/15 28/24 30/23 37/11 38/13 48/22 48/24 49/25 54/9 54/9 58/16 59/6 71/14 88/11 88/16 92/7 93/17 93/18 96/21 <b>putting</b> [3] 4/21 34/23 47/21	<b>Q</b> <b>question</b> [6] 36/25 41/15 41/20 45/22 48/20 60/5 <b>questioned</b> [7] 3/4 29/21 62/22 95/6 99/4 99/6 99/8 <b>questioning</b> [1] 16/18 <b>questions</b> [5] 25/11 28/16 45/11 56/18 91/25 <b>quickly</b> [2] 35/18 89/8 <b>quiet</b> [3] 27/13 60/14 61/19 <b>quite</b> [24] 1/7 11/13 22/1 28/21 37/1 37/2 63/14 63/23 64/1 64/12 67/21 69/9 75/13 75/20 81/13 81/18 84/2 84/21 89/1 89/8 89/15 89/15 90/22 95/11	<b>R</b> <b>race</b> [1] 27/1 <b>Radio</b> [1] 22/25 <b>Radio 4</b> [1] 22/25	<b>radios</b> [1] 17/9 <b>radiotherapy</b> [1] 52/9 <b>raging</b> [1] 53/23 <b>rain</b> [1] 42/11 <b>raise</b> [2] 1/16 49/2 <b>raised</b> [1] 1/23 <b>ran</b> [1] 53/10 <b>rang</b> [2] 5/5 42/18 <b>ranks</b> [1] 24/25 <b>rare</b> [1] 69/10 <b>rash</b> [1] 81/13 <b>rather</b> [1] 46/1 <b>rational</b> [1] 55/6 <b>read</b> [6] 12/6 12/8 12/9 20/13 32/25 92/2 <b>ready</b> [2] 22/1 22/4 <b>real</b> [1] 44/11 <b>realised</b> [2] 31/22 39/3 <b>reality</b> [1] 85/3 <b>really</b> [36] 17/24 17/24 22/15 34/12 34/12 36/11 38/2 38/21 40/6 40/9 41/21 42/5 45/12 52/5 62/7 62/9 66/4 67/8 69/21 71/7 72/15 72/24 75/3 78/7 78/9 78/12 80/1 82/10 85/8 85/14 86/7 87/13 88/14 88/16 89/25 94/17 <b>reason</b> [5] 7/22 27/25 34/8 34/11 55/9 <b>reassure</b> [1] 70/1 <b>reassured</b> [2] 93/11 93/12 <b>reassuring</b> [2] 1/7 45/7 <b>rebuild</b> [1] 57/22 <b>rebuilt</b> [1] 24/3 <b>recall</b> [6] 9/21 14/23 37/19 43/11 50/15 70/9 <b>recalled</b> [1] 35/22 <b>recalls</b> [1] 33/1 <b>receive</b> [3] 22/22 63/6 63/8 <b>received</b> [10] 1/25 5/1 12/16 12/17 43/8 64/7 69/15 70/14 73/24 90/15 <b>receiving</b> [1] 67/3 <b>recently</b> [2] 53/5 64/19 <b>recipient</b> [3] 13/22 15/2 15/15 <b>recipients</b> [5] 13/21 13/24 14/11 14/21 15/2 <b>recognised</b> [4] 20/7 22/13 22/14 52/12 <b>recollection</b> [5] 65/11	65/14 65/18 65/20 65/25 <b>record</b> [1] 17/11 <b>records</b> [6] 96/10 96/15 97/1 97/2 97/3 97/7 <b>recover</b> [1] 54/14 <b>recovered</b> [1] 37/16 <b>recovery</b> [1] 13/10 <b>redacted</b> [50] 3/6 3/8 3/15 3/15 3/16 3/23 5/9 5/13 6/13 7/20 8/10 8/25 9/12 10/22 10/23 11/3 11/15 11/24 12/11 13/7 14/2 14/21 14/24 15/3 15/7 15/9 15/14 15/20 15/25 16/7 16/22 16/24 17/19 17/19 18/6 18/9 19/1 19/9 19/16 19/17 19/19 19/23 20/15 20/22 21/15 21/21 22/3 24/18 53/25 54/17 <b>reduce</b> [1] 48/14 <b>reduced</b> [1] 37/9 <b>redundancy</b> [3] 88/9 88/16 89/3 <b>redundant</b> [1] 87/18 <b>refer</b> [4] 17/7 30/7 32/10 71/25 <b>referred</b> [1] 2/21 <b>reflected</b> [2] 54/1 87/9 <b>reflective</b> [1] 97/16 <b>refused</b> [1] 45/1 <b>regard</b> [2] 20/5 95/17 <b>regarding</b> [2] 27/11 28/2 <b>regardless</b> [2] 27/1 71/15 <b>regards</b> [1] 23/17 <b>regular</b> [5] 4/12 6/5 75/14 96/16 96/21 <b>regularly</b> [1] 24/7 <b>Reid</b> [1] 97/23 <b>rejected</b> [1] 90/11 <b>rejection</b> [2] 6/8 78/21 <b>relate</b> [2] 39/12 97/8 <b>relation</b> [4] 1/12 44/2 73/11 96/25 <b>relationship</b> [3] 55/1 86/9 86/13 <b>relatives</b> [2] 26/9 92/16 <b>released</b> [1] 27/3 <b>relevant</b> [1] 12/9 <b>reliant</b> [1] 57/24 <b>relief</b> [1] 9/12 <b>relieved</b> [4] 9/16 69/9 69/15 69/19 <b>relying</b> [1] 46/1 <b>remains</b> [1] 2/22	<b>remarkably</b> [1] 60/3 <b>remarried</b> [1] 22/7 <b>remember</b> [25] 26/4 27/6 31/17 31/19 33/16 34/6 36/15 36/23 38/8 39/24 42/11 50/17 63/23 64/3 65/9 65/18 72/6 75/4 75/10 75/13 76/15 82/10 96/15 96/20 97/6 <b>remembers</b> [1] 40/16 <b>remind</b> [1] 85/15 <b>reminder</b> [2] 17/9 61/16 <b>reminders</b> [1] 17/6 <b>reminding</b> [1] 27/21 <b>removal</b> [1] 12/23 <b>removed</b> [1] 65/2 <b>renal</b> [2] 12/13 12/13 <b>rent</b> [2] 36/17 43/4 <b>rental</b> [1] 43/2 <b>repeat</b> [1] 7/15 <b>repeating</b> [2] 19/20 28/6 <b>replace</b> [1] 78/25 <b>reply</b> [1] 73/23 <b>report</b> [1] 1/18 <b>reported</b> [1] 3/12 <b>represents</b> [1] 28/13 <b>requested</b> [1] 96/24 <b>require</b> [3] 4/12 66/12 66/14 <b>requiring</b> [1] 6/5 <b>research</b> [2] 45/25 47/9 <b>researching</b> [1] 41/8 <b>reserved</b> [1] 84/3 <b>resolved</b> [1] 89/7 <b>respect</b> [1] 3/13 <b>respectively</b> [1] 13/25 <b>respects</b> [1] 48/8 <b>respond</b> [2] 1/23 1/24 <b>response</b> [3] 1/18 1/25 30/25 <b>responses</b> [1] 59/12 <b>responsibility</b> [3] 56/2 94/24 95/4 <b>rest</b> [2] 11/1 58/18 <b>restored</b> [1] 1/9 <b>restriction</b> [1] 2/3 <b>result</b> [5] 12/21 33/8 65/20 66/23 78/1 <b>results</b> [4] 68/4 70/18 70/20 72/20 <b>resuscitate</b> [1] 14/9 <b>resuscitation</b> [2] 13/17 14/5 <b>retire</b> [1] 78/24 <b>retirement</b> [1] 51/2 <b>retrospect</b> [1] 37/4 <b>reviewed</b> [1] 13/21
----------	--	--	---	--	--	---	--

<p><b>R</b></p> <p><b>reviews</b> [1] 96/21</p> <p><b>revoke</b> [1] 2/24</p> <p><b>rhyme</b> [1] 55/9</p> <p><b>Richards</b> [6] 1/13 1/17 3/4 29/21 99/4 99/6</p> <p><b>riding</b> [1] 51/5</p> <p><b>right</b> [18] 3/24 10/3 12/17 17/14 30/5 33/12 44/1 46/23 48/22 54/2 54/11 54/11 57/14 58/16 61/1 62/19 87/5 87/24</p> <p><b>rights</b> [1] 93/19</p> <p><b>ring</b> [1] 47/25</p> <p><b>risk</b> [4] 43/9 44/11 79/21 96/2</p> <p><b>risks</b> [4] 34/15 34/20 94/11 94/14</p> <p><b>river</b> [3] 42/13 42/14 42/16</p> <p><b>road</b> [4] 10/1 12/21 13/20 14/9</p> <p><b>Robbie</b> [1] 39/5</p> <p><b>Robison</b> [1] 58/14</p> <p><b>rolling</b> [1] 69/18</p> <p><b>room</b> [11] 3/11 20/16 33/4 33/5 33/10 33/14 33/15 47/7 64/2 64/4 83/23</p> <p><b>roulette</b> [1] 55/8</p> <p><b>round</b> [17] 1/13 4/18 10/23 10/24 21/6 53/18 60/23 74/21 75/6 75/23 75/25 76/14 80/2 80/9 81/6 81/10 87/16</p> <p><b>routine</b> [2] 67/24 74/12</p> <p><b>ruined</b> [1] 93/4</p> <p><b>rumours</b> [1] 67/6</p> <p><b>run</b> [1] 47/24</p> <p><b>running</b> [2] 33/6 89/16</p> <p><b>rush</b> [2] 33/9 80/16</p> <p><b>rushed</b> [1] 37/2</p> <p><b>Russian</b> [1] 55/7</p>	<p>21/5 21/16 21/19 22/3 23/6 23/10 23/10 24/4 24/17 28/6 32/7 33/1 33/7 33/8 33/21 34/14 39/13 41/22 42/19 43/14 44/22 46/2 46/20 47/13 52/1 53/19 54/3 54/8 55/2 55/8 55/13 55/22 58/15 61/10 61/13 62/3 71/20 73/1 73/16 83/3 87/20 89/9 96/9</p> <p><b>same</b> [14] 15/17 15/18 15/18 19/18 30/23 30/23 39/4 40/10 41/2 45/14 65/5 68/12 87/4 97/17</p> <p><b>sample</b> [2] 65/2 65/4</p> <p><b>sat</b> [2] 10/24 42/14</p> <p><b>save</b> [1] 51/21</p> <p><b>saving</b> [3] 1/6 16/11 28/23</p> <p><b>saw</b> [4] 5/23 42/21 67/12 69/16</p> <p><b>say</b> [37] 5/6 11/12 13/13 22/9 23/15 25/12 25/14 25/15 38/3 38/5 41/17 41/23 48/1 49/18 49/18 49/20 51/21 52/10 53/24 54/18 56/3 56/6 56/19 57/12 57/22 59/14 60/23 61/1 72/2 84/1 86/10 86/24 87/24 88/6 89/17 91/18 92/1</p> <p><b>saying</b> [10] 10/21 18/24 18/24 21/13 23/14 23/23 28/18 36/24 43/23 68/2</p> <p><b>says</b> [19] 8/18 9/2 13/6 37/4 39/9 44/2 47/4 50/5 52/12 52/24 54/18 57/15 64/23 66/8 68/23 69/8 73/24 83/19 96/10</p> <p><b>scan</b> [1] 69/2</p> <p><b>scandal</b> [1] 92/17</p> <p><b>scans</b> [1] 82/19</p> <p><b>scared</b> [3] 69/20 71/8 71/12</p> <p><b>scaremongering</b> [1] 43/19</p> <p><b>scars</b> [2] 77/21 77/24</p> <p><b>scary</b> [1] 44/4</p> <p><b>scene</b> [1] 27/19</p> <p><b>scheme</b> [4] 58/17 82/3 90/16 90/18</p> <p><b>school</b> [12] 40/17 53/6 53/10 53/11 55/4 71/22 71/23 72/3 72/5 72/6 72/23 75/3</p>	<p><b>schooling</b> [1] 72/16</p> <p><b>Scotland</b> [3] 46/11 58/15 58/16</p> <p><b>Scottish</b> [5] 58/17 64/7 66/10 82/2 90/16</p> <p><b>screaming</b> [1] 24/7</p> <p><b>screen</b> [4] 12/5 74/4 74/8 74/11</p> <p><b>scrupulous</b> [1] 95/16</p> <p><b>second</b> [9] 20/9 39/9 39/16 39/17 49/23 68/23 75/25 76/14 96/8</p> <p><b>secret</b> [2] 71/24 72/9</p> <p><b>Secretary</b> [1] 2/18</p> <p><b>secretive</b> [1] 84/4</p> <p><b>secrets</b> [1] 56/22</p> <p><b>security</b> [4] 23/21 53/2 61/22 90/24</p> <p><b>see</b> [24] 6/18 6/21 9/3 12/4 13/14 16/2 21/14 21/23 23/12 24/25 36/23 45/13 45/13 45/14 50/19 53/16 53/18 55/19 55/19 68/1 68/21 69/3 71/9 71/13</p> <p><b>seeking</b> [2] 97/14 97/15</p> <p><b>seem</b> [6] 7/17 34/8 48/18 59/13 81/21 97/4</p> <p><b>seemed</b> [6] 11/5 36/12 37/2 51/20 67/11 92/12</p> <p><b>seemingly</b> [1] 5/17</p> <p><b>seems</b> [1] 92/22</p> <p><b>seen</b> [10] 3/17 3/17 25/7 39/8 43/8 49/8 50/12 60/22 67/10 97/3</p> <p><b>send</b> [1] 77/12</p> <p><b>sense</b> [10] 16/22 18/16 18/21 19/2 41/11 56/1 83/6 93/6 94/23 95/3</p> <p><b>sent</b> [1] 65/4</p> <p><b>sentence</b> [3] 16/12 28/24 71/6</p> <p><b>separate</b> [3] 42/24 43/1 97/22</p> <p><b>September</b> [6] 5/1 12/2 12/12 12/22 13/3 66/12</p> <p><b>September 1984</b> [2] 5/1 12/12</p> <p><b>September 1992</b> [1] 12/2</p> <p><b>serious</b> [1] 20/6</p> <p><b>servant</b> [1] 3/23</p> <p><b>service</b> [9] 1/9 6/12 26/25 27/5 45/9 59/12</p>	<p>63/13 64/13 91/4</p> <p><b>services</b> [2] 53/12 59/13</p> <p><b>session</b> [1] 61/9</p> <p><b>set</b> [3] 27/16 38/24 96/6</p> <p><b>sets</b> [2] 15/13 82/19</p> <p><b>settee</b> [1] 40/19</p> <p><b>seven</b> [1] 7/23</p> <p><b>seven-day</b> [1] 7/23</p> <p><b>several</b> [1] 35/8</p> <p><b>severe</b> [4] 33/12 53/13 62/23 81/13</p> <p><b>shake</b> [2] 75/12 81/21</p> <p><b>shakes</b> [1] 76/16</p> <p><b>shall</b> [1] 1/14</p> <p><b>shared</b> [1] 56/22</p> <p><b>sharing</b> [1] 3/19</p> <p><b>she</b> [141]</p> <p><b>she'd</b> [5] 4/24 9/13 9/15 11/12 12/16</p> <p><b>she's</b> [10] 6/22 10/21 18/2 52/25 53/2 53/11 53/14 54/16 83/20 86/7</p> <p><b>sheet</b> [2] 31/23 31/24</p> <p><b>sheets</b> [1] 40/15</p> <p><b>Sheffield</b> [1] 36/22</p> <p><b>shield</b> [1] 51/25</p> <p><b>shift</b> [3] 7/23 8/24 31/3</p> <p><b>shifts</b> [1] 31/16</p> <p><b>shoe</b> [2] 78/15 88/24</p> <p><b>Shona</b> [1] 58/14</p> <p><b>Shona Robison</b> [1] 58/14</p> <p><b>shook</b> [1] 19/15</p> <p><b>shop</b> [1] 87/3</p> <p><b>shopping</b> [1] 48/2</p> <p><b>short</b> [6] 27/22 29/14 38/4 90/19 90/23 92/2</p> <p><b>shortly</b> [1] 31/14</p> <p><b>should</b> [23] 1/22 10/4 10/4 10/18 15/25 29/7 36/14 43/20 44/22 58/10 58/20 59/22 66/15 72/23 72/25 83/14 85/5 85/7 85/12 86/11 86/14 90/20 90/24</p> <p><b>shoulder</b> [1] 50/5</p> <p><b>shoulders</b> [1] 50/6</p> <p><b>shouldn't</b> [4] 10/17 24/12 70/18 86/24</p> <p><b>shout</b> [1] 58/12</p> <p><b>shouting</b> [1] 58/9</p> <p><b>showed</b> [2] 18/1 69/16</p> <p><b>showing</b> [1] 3/18</p> <p><b>shown</b> [4] 3/14 13/17 25/22 59/5</p> <p><b>shut</b> [1] 43/20</p>	<p><b>sick</b> [3] 40/17 43/5 43/6</p> <p><b>side</b> [9] 20/16 37/10 37/12 37/19 76/6 81/10 87/20 96/11 96/22</p> <p><b>sign</b> [2] 22/19 23/15</p> <p><b>signed</b> [2] 23/21 42/21</p> <p><b>significant</b> [1] 56/16</p> <p><b>silly</b> [1] 90/6</p> <p><b>silver</b> [2] 22/16 22/17</p> <p><b>similar</b> [3] 73/22 76/13 89/24</p> <p><b>simply</b> [1] 50/3</p> <p><b>since</b> [10] 4/6 6/15 21/21 26/6 27/5 53/13 81/15 82/21 82/25 86/5</p> <p><b>single</b> [2] 48/2 49/3</p> <p><b>sir</b> [9] 1/20 28/8 28/15 29/11 29/18 60/2 62/6 62/12 97/9</p> <p><b>Sir Brian</b> [1] 28/15</p> <p><b>Sir Brian Langstaff</b> [1] 28/8</p> <p><b>sister</b> [1] 54/24</p> <p><b>sit</b> [1] 44/12</p> <p><b>sitting</b> [5] 5/4 10/9 21/12 25/24 64/3</p> <p><b>situation</b> [7] 57/5 59/9 69/10 82/17 87/22 89/7 89/14</p> <p><b>six</b> [6] 10/14 14/17 14/18 39/10 76/3 93/9</p> <p><b>sixth</b> [1] 18/21</p> <p><b>skin</b> [1] 81/20</p> <p><b>Skipton</b> [1] 90/15</p> <p><b>sleep</b> [4] 42/7 42/8 46/19 60/17</p> <p><b>sleep-deprived</b> [1] 42/8</p> <p><b>sleeping</b> [1] 5/20</p> <p><b>slept</b> [1] 31/18</p> <p><b>slightest</b> [1] 69/19</p> <p><b>slightly</b> [1] 93/10</p> <p><b>slow</b> [1] 28/2</p> <p><b>small</b> [3] 50/9 60/24 77/21</p> <p><b>smoke</b> [1] 38/15</p> <p><b>smoker</b> [2] 24/12 24/12</p> <p><b>smoking</b> [1] 48/18</p> <p><b>SNBTS</b> [2] 64/15 67/9</p> <p><b>Snowden</b> [1] 28/12</p> <p><b>so</b> [131]</p> <p><b>so-called</b> [1] 27/17</p> <p><b>soaked</b> [2] 31/23 31/23</p> <p><b>social</b> [2] 41/12 59/13</p> <p><b>socialise</b> [1] 41/13</p> <p><b>society</b> [2] 43/18</p>	<p>92/20</p> <p><b>sold</b> [1] 26/16</p> <p><b>sole</b> [1] 51/13</p> <p><b>Solicitor</b> [1] 2/19</p> <p><b>solicitors</b> [3] 23/8 73/12 73/19</p> <p><b>some</b> [37] 2/5 4/5 12/1 12/5 12/15 22/18 23/18 26/5 27/25 28/20 34/11 36/5 36/5 48/8 48/23 49/11 58/19 58/20 59/18 60/6 61/4 61/5 65/6 68/6 68/17 71/25 72/20 73/10 79/16 81/16 82/3 86/21 88/24 90/15 93/11 97/4 97/16</p> <p><b>somebody</b> [15] 21/4 41/16 46/1 47/4 47/18 48/5 48/6 55/8 70/16 70/17 78/5 78/25 85/21 87/5 91/22</p> <p><b>someone</b> [1] 56/9</p> <p><b>something</b> [23] 1/16 1/18 10/19 14/25 15/3 16/3 18/23 18/25 19/10 19/10 45/24 48/11 57/13 71/17 76/20 84/6 84/12 84/17 84/19 85/8 86/12 91/12 92/5</p> <p><b>sometimes</b> [2] 48/1 83/19</p> <p><b>somewhere</b> [1] 46/15</p> <p><b>son</b> [4] 39/22 40/20 42/7 54/18</p> <p><b>soon</b> [2] 28/9 73/7</p> <p><b>sore</b> [1] 18/5</p> <p><b>sorry</b> [14] 1/3 1/20 2/19 8/7 17/13 19/4 20/19 25/4 25/25 57/12 57/13 58/8 58/10 74/10</p> <p><b>sort</b> [42] 1/6 8/12 17/11 18/22 18/23 18/25 22/2 24/15 25/2 35/11 39/13 40/6 40/7 41/10 41/23 44/22 45/6 46/16 48/2 63/3 63/25 64/3 66/23 67/6 70/6 71/12 75/1 79/22 79/24 79/25 80/6 80/8 82/10 86/1 86/19 86/25 87/1 89/12 89/21 90/1 90/24 95/10</p> <p><b>sorted</b> [3] 55/17 57/7 69/25</p> <p><b>sorts</b> [1] 25/13</p> <p><b>soul</b> [1] 52/23</p> <p><b>source</b> [1] 13/14</p>
--	--	---	--	--	---

<b>S</b>	52/24 55/2 55/13 55/23 56/3 73/1 83/3 84/25 87/9 92/2 92/9 92/21 <b>statements</b> [3] 1/24 30/4 52/22 <b>status</b> [1] 79/20 <b>stayed</b> [2] 79/6 83/8 <b>staying</b> [1] 41/24 <b>stick</b> [3] 37/22 49/11 96/2 <b>sticks</b> [2] 15/2 84/5 <b>stigma</b> [2] 9/25 70/4 <b>stigmatised</b> [3] 10/2 10/4 10/5 <b>still</b> [27] 9/10 9/18 10/13 11/1 11/23 24/4 40/10 43/5 44/21 48/4 52/10 59/9 69/10 71/13 76/8 78/11 81/1 82/20 83/3 83/8 84/22 88/5 88/19 90/6 92/14 93/20 96/22 <b>stock</b> [1] 78/23 <b>stockroom</b> [1] 21/12 <b>stomach</b> [2] 37/23 77/22 <b>stones</b> [2] 83/12 91/18 <b>stood</b> [1] 33/15 <b>stop</b> [8] 4/9 40/16 43/24 55/14 75/19 76/7 96/23 96/24 <b>stopped</b> [3] 34/24 38/19 96/18 <b>stories</b> [8] 39/1 45/15 50/1 50/11 59/7 59/16 59/20 62/8 <b>story</b> [12] 28/22 41/18 43/13 46/3 56/22 57/7 58/2 58/4 59/18 92/5 97/11 97/13 <b>stove</b> [1] 38/13 <b>straight</b> [2] 9/3 19/11 <b>straightaway</b> [7] 4/25 5/7 5/8 5/10 8/19 23/10 45/24 <b>strangely</b> [1] 84/12 <b>streaming</b> [1] 2/7 <b>stress</b> [5] 20/5 20/20 46/21 89/16 94/21 <b>strong</b> [1] 92/7 <b>struggled</b> [4] 35/11 54/18 76/13 90/12 <b>struggling</b> [3] 31/14 31/15 42/3 <b>stuck</b> [1] 23/20 <b>student</b> [1] 30/19 <b>studies</b> [5] 31/15 68/4 73/9 75/18 89/25 <b>stuff</b> [1] 67/10 <b>subsequently</b> [9]	13/17 14/6 14/25 37/9 64/16 70/23 73/16 90/8 95/22 <b>success</b> [1] 6/11 <b>successful</b> [2] 5/18 81/8 <b>such</b> [9] 2/15 7/2 16/15 20/19 40/4 43/9 46/25 57/20 65/7 <b>sudden</b> [1] 87/3 <b>suddenly</b> [1] 39/2 <b>suffer</b> [1] 17/24 <b>suffered</b> [1] 17/25 <b>sufferer</b> [1] 28/22 <b>suffering</b> [5] 39/4 42/4 76/6 96/17 96/23 <b>Suffice</b> [1] 13/13 <b>suggested</b> [1] 82/5 <b>suicide</b> [1] 56/25 <b>summer</b> [1] 78/14 <b>supplies</b> [1] 64/14 <b>supplying</b> [1] 28/3 <b>support</b> [13] 20/23 21/22 22/10 50/7 51/24 57/10 58/17 59/10 77/2 82/3 86/16 88/13 91/9 <b>supporting</b> [1] 48/6 <b>suppose</b> [3] 38/4 42/1 45/12 <b>sure</b> [5] 10/9 21/2 28/8 37/6 37/7 <b>survive</b> [2] 39/25 93/20 <b>survived</b> [1] 18/10 <b>suspect</b> [1] 37/4 <b>suspicious</b> [1] 67/6 <b>sustain</b> [1] 35/15 <b>sweat</b> [1] 85/19 <b>sweating</b> [1] 24/8 <b>sweats</b> [2] 35/7 40/14 <b>swellings</b> [1] 96/3 <b>switches</b> [1] 85/21 <b>swollen</b> [1] 95/8 <b>sworn</b> [2] 62/21 99/7 <b>sympathy</b> [1] 57/2 <b>symptoms</b> [14] 6/14 31/12 37/14 37/19 38/1 38/19 39/19 40/11 75/10 75/14 81/12 81/13 81/15 81/22 <b>syringes</b> [3] 60/21 60/21 60/22 <b>system</b> [2] 7/23 36/12 <b>systemic</b> [1] 92/25 <b>systems</b> [1] 12/4	<b>T</b> <b>table</b> [1] 77/20 <b>tainted</b> [2] 27/12 28/3 <b>take</b> [25] 1/7 6/8 6/22	8/2 8/8 8/8 9/2 9/7 9/7 17/14 20/15 21/5 25/18 27/11 29/10 43/3 44/12 45/16 46/12 46/19 55/25 60/21 62/10 74/17 83/23 <b>taken</b> [13] 7/20 20/8 26/2 27/12 28/19 36/25 37/1 48/13 51/2 51/7 86/22 88/1 91/1 <b>taking</b> [3] 9/10 10/3 60/23 <b>tales</b> [1] 28/20 <b>talk</b> [11] 3/5 5/9 13/9 21/4 29/22 48/16 68/8 68/10 71/16 86/19 87/8 <b>talked</b> [3] 53/17 71/18 84/8 <b>talking</b> [5] 8/12 48/11 51/6 64/4 66/18 <b>talks</b> [1] 84/9 <b>tape</b> [1] 17/11 <b>task</b> [1] 55/21 <b>tasks</b> [1] 46/7 <b>Tayside</b> [2] 64/11 73/13 <b>tea</b> [2] 24/11 24/15 <b>team</b> [1] 28/8 <b>tearful</b> [1] 61/9 <b>tears</b> [2] 26/1 37/23 <b>technological</b> [2] 1/4 1/11 <b>technology</b> [1] 1/5 <b>teen</b> [1] 4/6 <b>teenager</b> [2] 71/13 73/5 <b>teeth</b> [1] 59/21 <b>television</b> [3] 5/5 17/9 27/17 <b>tell</b> [21] 5/3 8/6 9/24 10/13 18/23 29/1 41/17 55/10 56/22 62/8 70/3 70/16 71/2 71/20 77/7 79/18 89/19 91/21 92/5 94/15 97/21 <b>telling</b> [5] 18/17 19/3 32/4 62/3 70/10 <b>tempered</b> [1] 38/4 <b>ten</b> [1] 50/3 <b>term</b> [4] 45/16 45/19 45/19 46/23 <b>terms</b> [10] 13/10 19/7 30/8 54/5 64/12 64/14 70/5 78/13 87/16 89/19 <b>terrible</b> [1] 26/7 <b>terribly</b> [1] 53/7 <b>terrifies</b> [2] 44/3 44/8 <b>test</b> [8] 9/3 9/9 32/24	34/18 61/1 65/21 68/5 70/12 <b>tested</b> [9] 12/24 13/7 64/20 65/17 67/16 73/17 74/18 95/22 95/23 <b>testimony</b> [3] 1/17 30/14 97/16 <b>testing</b> [3] 13/11 70/20 73/14 <b>tests</b> [8] 16/18 16/20 16/21 27/25 32/23 69/3 82/23 93/11 <b>than</b> [15] 17/22 35/19 40/1 44/3 46/1 46/17 52/3 52/11 58/18 66/4 79/20 81/21 84/2 86/17 90/14 <b>thank</b> [27] 2/2 3/19 6/11 25/11 25/17 25/21 28/11 29/3 29/4 29/8 29/9 29/11 32/22 59/24 61/25 62/1 62/5 62/6 62/6 62/7 62/12 92/12 97/10 97/18 97/19 97/19 97/25 <b>thanked</b> [1] 19/15 <b>thankfully</b> [3] 60/12 72/14 75/19 <b>thank</b> [1] 92/4 <b>that</b> [485] <b>that's</b> [55] 1/13 2/12 3/24 6/7 7/3 8/15 8/15 9/25 10/19 11/15 11/22 15/1 17/13 17/14 21/20 21/20 22/3 24/9 24/15 25/10 27/6 29/25 39/13 39/14 40/8 40/17 45/3 46/23 47/10 48/7 51/13 53/1 55/7 62/19 62/24 64/9 64/16 64/17 70/12 72/24 77/13 77/24 79/5 79/24 80/17 81/25 82/6 82/20 83/8 85/16 86/24 95/1 95/9 96/12 96/12 <b>their</b> [14] 1/21 1/23 2/16 26/17 27/9 30/3 31/18 39/1 49/13 50/17 52/15 52/15 55/7 57/6 <b>them</b> [23] 6/21 20/10 24/22 27/21 30/6 49/12 49/18 51/25 57/24 59/18 60/11 61/3 66/9 71/10 71/11 71/13 71/18 71/19 79/4 89/3 94/18 94/19 95/12 <b>theme</b> [1] 54/22	<b>then</b> [54] 1/22 4/18 4/23 5/1 7/19 10/25 11/8 11/8 11/15 11/16 11/18 12/15 12/25 13/6 13/10 13/11 13/13 13/21 14/20 16/18 23/13 25/15 26/1 26/6 31/5 35/18 36/19 38/7 40/23 42/21 46/11 49/2 49/13 51/9 53/13 54/15 56/1 56/6 60/9 63/17 65/6 67/25 69/5 73/7 75/25 76/8 79/6 81/15 81/18 82/25 84/17 88/9 89/6 90/8 <b>theories</b> [1] 44/1 <b>therapy</b> [1] 75/6 <b>there</b> [83] 2/6 2/10 7/19 8/1 8/20 9/2 10/9 14/1 16/18 16/19 16/20 18/6 20/24 21/5 21/7 23/1 23/3 23/14 23/22 24/21 24/22 24/23 25/12 30/6 30/21 32/7 34/7 34/8 34/11 38/6 42/14 44/23 47/2 47/3 48/12 49/4 49/12 50/7 50/8 50/17 51/20 53/3 55/8 56/19 57/17 57/22 58/22 60/18 63/12 63/12 63/19 63/25 64/1 64/2 64/13 66/23 67/23 68/7 69/4 70/1 70/4 70/7 73/14 74/10 74/25 78/10 80/16 80/16 81/19 86/18 86/21 87/5 89/6 89/14 89/22 91/25 92/14 95/23 96/17 96/19 97/2 97/5 97/7 <b>there's</b> [27] 5/8 12/15 12/18 28/13 36/25 39/10 43/23 44/3 48/20 49/10 50/7 50/9 51/8 58/19 59/25 61/5 61/6 61/6 65/6 67/21 81/17 86/19 89/18 91/21 94/4 96/10 97/1 <b>thereafter</b> [1] 2/23 <b>therefore</b> [1] 92/20 <b>these</b> [9] 26/10 43/15 43/15 45/5 45/11 49/17 59/8 59/10 85/15 <b>they</b> [91] 4/18 4/19 4/20 5/7 6/12 6/21 6/24 6/25 7/1 8/25 10/20 11/8 11/10 15/16 15/17 15/19 15/23 16/19 21/24
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<b>T</b>	75/21 77/1 77/3 77/15 77/18 77/23 78/9 78/20 79/6 81/16 81/17 81/18 81/22 83/17 83/19 85/12 85/16 85/19 85/25 85/25 86/9 86/21 87/9 87/15 88/4 89/23 90/10 90/20 90/21 91/21 94/21 95/3 96/3 96/21 <b>thinking [14]</b> 6/15 7/2 7/4 8/17 9/4 9/4 10/14 10/16 11/16 11/21 39/24 42/14 56/25 72/6 <b>third [5]</b> 21/10 80/2 81/5 81/10 87/16 <b>this [124]</b> <b>Thomas's [3]</b> 32/21 32/22 33/7 <b>those [16]</b> 3/11 3/19 17/7 26/3 35/15 51/6 56/18 66/14 77/24 90/21 91/25 92/11 93/19 93/21 93/22 97/8 <b>though [2]</b> 83/4 91/14 <b>thought [21]</b> 6/4 6/25 7/25 9/13 19/24 19/24 23/4 23/18 26/7 27/14 31/20 36/3 44/20 54/1 55/2 59/19 67/8 79/1 87/1 92/6 96/18 <b>thoughts [1]</b> 44/1 <b>thousands [2]</b> 26/8 26/9 <b>threatened [1]</b> 39/23 <b>three [11]</b> 4/17 7/23 13/2 17/22 17/25 19/18 19/19 24/9 69/3 77/21 93/13 <b>three-shift [1]</b> 7/23 <b>throes [1]</b> 11/9 <b>through [33]</b> 10/5 10/18 22/24 23/23 30/24 31/23 31/24 36/16 38/14 40/22 42/2 45/3 52/4 52/6 52/8 52/11 53/12 59/14 67/2 68/3 71/10 72/19 72/21 73/16 75/1 75/20 76/18 78/22 81/18 82/2 86/9 96/15 97/5 <b>throughout [3]</b> 38/15 64/6 86/15 <b>throwing [1]</b> 57/16 <b>ticking [1]</b> 83/6 <b>tight [1]</b> 51/19 <b>time [83]</b> 1/7 7/16 7/17 8/8 9/14 16/6	17/3 18/18 19/13 21/5 21/17 21/25 22/24 26/6 27/25 31/7 31/13 33/20 35/18 35/21 36/5 36/5 36/22 38/1 38/7 38/13 39/11 40/24 41/1 41/2 41/12 42/6 42/8 42/10 43/5 43/25 43/25 43/25 45/14 46/6 47/22 48/15 48/17 48/21 48/22 48/22 49/3 50/5 51/17 53/23 55/3 56/9 56/17 57/11 57/17 58/25 65/5 65/10 66/13 67/20 69/14 70/4 70/7 73/22 75/16 76/14 78/17 78/25 79/16 80/7 80/10 80/11 80/17 81/8 81/16 83/6 83/25 84/8 85/9 86/15 88/25 91/5 91/8 <b>times [9]</b> 2/23 4/17 24/9 35/8 38/6 47/13 49/1 55/11 83/21 <b>timing [1]</b> 82/14 <b>tired [1]</b> 75/13 <b>tiredness [1]</b> 75/15 <b>to [628]</b> <b>today [5]</b> 18/1 24/10 56/13 69/10 97/21 <b>together [7]</b> 18/2 31/14 46/8 46/9 47/21 50/3 55/18 <b>tokens [1]</b> 46/15 <b>told [78]</b> 5/7 5/20 6/7 8/15 8/16 9/23 9/23 10/10 10/11 10/12 10/15 10/25 10/25 11/11 11/12 11/18 11/23 15/9 15/9 15/11 15/11 15/12 16/6 16/7 19/9 20/10 20/25 26/21 29/7 30/25 31/3 32/7 32/18 33/1 33/3 33/5 33/17 33/17 33/25 34/3 34/15 37/13 39/6 39/15 43/19 45/23 56/23 56/24 58/2 58/4 58/10 62/4 64/16 64/19 65/20 65/24 66/4 68/14 69/14 69/23 69/24 70/3 70/24 70/25 71/1 71/2 71/20 72/10 73/12 74/6 74/6 74/10 74/11 76/4 78/4 78/8 89/22 94/11 <b>toll [1]</b> 51/7 <b>tombstone [3]</b> 11/6 17/7 27/17	<b>tomorrow [5]</b> 51/22 51/23 97/21 97/22 97/25 <b>too [5]</b> 24/10 37/5 58/11 81/22 89/24 <b>took [8]</b> 6/24 8/2 9/6 13/3 32/23 40/6 41/25 43/3 <b>top [1]</b> 33/11 <b>torment [2]</b> 59/14 59/15 <b>total [1]</b> 92/25 <b>totally [6]</b> 15/11 25/7 25/8 25/9 25/9 27/24 <b>touch [5]</b> 6/20 6/20 23/11 80/21 85/18 <b>touched [1]</b> 85/21 <b>touching [1]</b> 85/20 <b>tough [2]</b> 36/10 76/17 80/11 80/17 81/8 66/7 76/9 92/14 <b>toxic [2]</b> 48/9 55/25 <b>traffic [3]</b> 12/22 13/20 14/9 <b>trained [1]</b> 4/22 <b>training [2]</b> 26/4 45/13 <b>transcript [1]</b> 2/7 <b>transfusion [5]</b> 13/19 14/4 14/15 26/14 66/10 <b>transmission [2]</b> 34/16 79/21 <b>transmitted [1]</b> 14/2 <b>transpired [1]</b> 13/15 <b>transplant [8]</b> 4/24 12/13 13/3 13/10 14/3 17/23 18/11 26/23 <b>transplants [1]</b> 26/14 <b>trauma [1]</b> 93/7 <b>traumatic [3]</b> 20/4 20/20 46/21 <b>travel [3]</b> 90/12 90/13 90/14 <b>treat [3]</b> 7/1 20/16 21/14 <b>treated [3]</b> 15/19 30/11 63/10 <b>treating [2]</b> 94/24 95/7 <b>treatment [53]</b> 12/16 17/2 21/24 27/3 28/23 33/10 34/22 37/13 38/16 38/17 39/11 44/22 45/2 45/3 52/10 63/1 63/6 66/22 66/24 74/20 74/22 75/22 75/23 76/3 76/11 77/2 80/2 80/9 80/11 80/13 80/19 80/25 81/2 81/4 81/6 81/8 81/23 82/12 82/20 82/22 84/4 84/10 87/17 87/25 93/13 93/17 94/23	95/25 96/8 96/13 96/16 96/18 96/22 <b>treatment-giver [2]</b> 94/23 95/25 <b>treatments [4]</b> 44/16 44/17 44/18 70/1 <b>trepidation [1]</b> 93/8 <b>trial [3]</b> 36/20 37/3 37/21 <b>trailing [1]</b> 32/22 <b>trials [1]</b> 37/8 <b>tried [6]</b> 43/23 69/25 71/15 90/10 90/11 94/18 <b>trip [3]</b> 4/18 21/6 21/6 <b>troughs [1]</b> 81/17 <b>trust [6]</b> 12/1 44/25 45/11 57/22 57/24 60/20 <b>truth [5]</b> 19/3 25/9 28/9 41/5 57/2 <b>try [10]</b> 1/6 24/18 24/21 24/21 41/10 44/16 47/25 58/16 72/7 76/16 <b>trying [13]</b> 27/1 33/11 37/25 38/11 40/5 42/22 43/1 51/24 52/2 57/6 71/8 80/19 90/5 90/25 91/3 91/6 <b>Tuesday [1]</b> 1/1 <b>tunnel [1]</b> 92/14 <b>turn [2]</b> 60/23 94/3 <b>turned [7]</b> 7/12 16/16 19/16 43/14 53/18 58/5 58/13 <b>TV [5]</b> 11/6 17/10 41/9 48/17 59/7 <b>twice [2]</b> 53/14 63/5 <b>two [15]</b> 3/14 10/1 14/19 18/2 28/4 40/23 42/6 42/17 47/21 47/21 60/8 81/12 82/11 88/1 97/22 <b>type [2]</b> 6/25 7/2 <b>typical [1]</b> 86/23	16/17 29/2 33/24 36/20 45/18 45/25 49/24 56/4 63/13 64/20 71/2 <b>understanding [3]</b> 15/13 15/14 64/6 <b>understood [5]</b> 5/15 5/16 20/14 22/3 66/20 <b>unfair [1]</b> 95/4 <b>unit [5]</b> 4/19 4/21 13/18 33/6 33/19 <b>units [2]</b> 13/15 13/19 <b>university [11]</b> 54/15 72/21 72/22 72/23 75/16 76/8 76/9 76/18 77/5 78/14 78/16 <b>unless [3]</b> 2/17 2/23 60/5 <b>unlikely [1]</b> 76/5 <b>unsuccessful [1]</b> 75/23 <b>until [15]</b> 1/9 16/21 29/10 45/2 55/16 60/12 62/10 63/15 67/7 67/14 70/12 75/4 82/10 95/25 98/3 <b>unwell [12]</b> 31/10 34/8 34/11 41/6 51/9 76/13 80/14 83/8 88/12 90/25 91/3 91/6 <b>up [58]</b> 4/22 7/25 11/6 16/4 17/10 18/3 19/15 20/4 20/9 20/11 20/18 20/18 21/12 21/15 23/8 24/7 24/11 24/13 25/3 25/6 28/17 31/15 31/16 33/13 35/9 36/9 38/11 38/24 40/14 42/13 43/20 44/6 44/12 46/10 47/18 49/2 49/19 49/19 49/25 52/25 56/20 58/5 58/13 58/13 65/14 67/7 67/13 67/24 71/14 72/1 72/6 75/11 76/16 78/3 78/4 86/22 91/6 95/25 <b>upon [1]</b> 93/23 <b>ups [1]</b> 96/16 <b>upset [9]</b> 11/13 52/3 56/9 57/3 59/22 71/9 78/12 85/5 85/6 <b>upsetting [1]</b> 85/6 <b>upstairs [2]</b> 8/5 38/12 <b>urgency [1]</b> 12/12 <b>urine [1]</b> 31/22 <b>us [45]</b> 3/14 3/20 5/3 10/23 11/20 18/2 19/3 23/20 23/21 27/1 29/2 30/9 35/13 36/12 40/21 41/19 43/23 45/4 45/7 54/12 55/10
----------	---	--	--	--	---

<p><b>U</b></p> <p>us... [24] 57/25 57/25 59/5 60/3 61/4 61/18 62/3 70/16 70/17 73/13 77/7 79/18 80/17 80/19 89/19 92/13 93/20 93/22 93/24 93/25 94/15 97/12 97/17 97/21 use [4] 4/22 35/12 50/18 57/8 used [7] 16/19 28/1 28/17 45/16 46/7 57/21 85/19 useful [1] 97/17 useless [1] 35/12 usual [1] 86/17 utter [1] 21/16</p> <p><b>V</b></p> <p>varied [1] 63/2 various [2] 35/14 97/6 vary [1] 2/24 vCJD [3] 43/9 43/13 44/2 very [72] 2/2 2/4 4/4 4/4 7/11 7/11 15/16 15/16 15/17 15/17 20/6 20/6 24/2 26/18 27/9 27/12 27/22 28/9 28/20 29/8 31/2 34/20 35/9 35/10 35/16 36/11 38/4 39/23 41/14 48/6 52/23 54/3 56/16 56/17 57/7 57/8 57/12 57/13 60/24 62/1 62/2 62/2 62/6 68/12 70/14 71/8 71/18 72/13 76/4 77/11 79/11 83/3 83/22 84/7 84/7 84/12 84/18 84/22 86/5 87/4 87/23 88/10 88/12 89/7 90/3 92/18 92/20 95/4 95/13 95/16 97/10 97/17 via [3] 14/2 26/13 26/22 vial [1] 61/5 victims [1] 57/5 Victoria [1] 21/3 views [1] 90/18 VIII [7] 63/7 66/10 66/11 74/5 94/9 94/10 94/25 viral [1] 68/4 virological [3] 74/4 74/7 74/11 virology [1] 66/23 virtually [1] 35/8 virus [10] 6/25 7/3</p>	<p>12/25 15/10 38/17 39/15 65/3 67/2 91/14 93/9 viruses [1] 74/15 visions [1] 37/22 visit [3] 11/10 31/17 46/10 visited [1] 5/24 volunteered [1] 8/2 vomited [1] 35/7</p> <p><b>W</b></p> <p>W2781 [2] 2/12 2/21 wages [1] 51/18 wait [6] 16/21 60/11 74/21 80/1 80/7 80/12 waited [1] 79/16 waiting [7] 9/2 9/8 19/14 37/22 64/4 75/1 78/3 waiver [3] 22/20 23/15 23/22 wake [2] 24/7 38/10 waking [1] 75/11 walk [2] 57/18 92/13 walked [5] 19/20 21/8 33/6 46/25 50/2 walking [1] 33/13 walls [1] 64/1 wannabe [1] 32/11 want [28] 9/25 10/1 10/4 24/20 25/5 25/15 41/17 41/21 44/20 44/24 55/18 55/19 55/20 56/25 57/1 57/2 57/2 60/6 60/16 61/4 71/9 71/11 72/2 79/21 84/19 85/18 86/18 87/6 wanted [9] 36/4 36/5 39/16 44/16 71/10 71/13 80/25 81/1 87/13 wanting [2] 21/24 41/3 wants [1] 48/19 ward [4] 15/18 30/23 53/15 53/16 wards [1] 47/1 warehouse [2] 78/15 78/17 was [440] washing [1] 95/16 wasn't [28] 6/23 11/8 16/18 16/20 16/22 22/1 23/18 31/22 32/7 34/10 36/11 40/5 40/19 45/20 49/12 54/19 54/23 63/15 70/17 72/24 76/3 76/22 78/20 80/14 88/14 89/24 89/25</p>	<p>96/9 waste [1] 21/16 watch [1] 17/10 watched [1] 17/11 watching [2] 5/5 43/13 way [27] 5/11 11/22 22/23 37/11 38/5 40/20 43/7 46/1 48/1 50/13 52/15 54/2 54/11 67/21 68/17 69/18 70/18 76/21 76/23 85/5 86/5 86/9 90/7 90/19 90/23 93/3 97/4 ways [1] 49/15 we [198] we'd [11] 10/10 11/14 28/5 36/3 36/9 39/10 39/12 39/13 40/6 61/24 64/18 We'll [4] 6/22 21/13 22/4 62/10 we're [16] 1/8 3/8 15/23 20/15 20/15 20/16 22/3 39/3 46/18 48/11 55/16 57/24 59/9 59/14 66/4 73/18 we've [23] 1/3 5/8 8/19 9/1 9/2 9/8 11/25 12/5 21/19 28/19 43/8 46/25 49/22 50/12 51/6 59/6 59/6 59/7 62/4 68/20 91/2 97/3 97/16 website [1] 89/2 wedding [1] 3/15 week [7] 4/17 24/9 52/1 59/16 61/9 63/4 78/2 weekend [1] 46/14 weeks [11] 6/16 6/17 10/7 10/14 11/23 20/24 23/22 68/18 81/18 81/19 88/1 weight [8] 7/9 7/10 32/3 40/15 76/15 76/16 81/11 81/12 welcome [1] 62/8 welfare [3] 59/12 59/13 93/19 well [49] 4/16 6/2 6/18 6/23 9/4 9/6 14/19 15/1 15/16 15/23 19/11 19/24 21/19 22/11 23/18 26/9 31/2 31/14 41/12 43/12 45/4 45/20 49/12 50/7 53/22 54/6 57/25 60/10 60/10 64/11 66/20 72/13 72/22 72/22 73/7 75/14</p>	<p>75/21 77/11 77/11 83/15 85/16 85/25 88/13 88/14 90/2 92/18 93/24 95/22 97/20 well-being [1] 83/15 went [32] 5/21 6/18 6/21 9/7 10/23 13/13 19/15 21/4 21/23 23/13 24/14 24/15 28/23 30/20 31/2 31/17 33/10 35/21 36/19 42/2 42/10 42/12 52/8 53/16 54/2 54/7 54/14 54/15 63/17 77/11 77/15 77/19 were [124] weren't [9] 11/8 16/19 34/14 34/18 72/11 73/4 74/10 74/17 80/23 wet [3] 31/19 31/20 31/21 what [119] what's [12] 9/5 9/5 10/22 45/9 51/5 54/3 55/7 61/12 72/6 73/8 82/17 83/15 whatever [3] 54/25 60/7 83/24 whatsoever [7] 7/14 16/23 20/2 21/17 26/5 65/15 65/19 when [70] 1/6 1/21 5/19 5/22 6/24 7/20 8/3 8/17 11/11 11/15 15/24 18/25 21/4 22/4 22/13 25/3 25/6 27/15 28/19 30/15 30/21 30/25 32/13 35/20 36/7 38/6 38/23 41/15 42/3 43/21 44/18 45/15 45/23 46/9 46/11 46/18 46/24 48/19 50/16 51/22 52/2 53/16 55/11 57/20 60/20 62/25 66/25 68/9 69/15 70/24 70/25 71/1 73/3 74/5 77/19 77/23 77/24 78/15 80/7 82/4 83/7 84/14 85/7 88/21 89/21 94/9 95/5 95/13 95/25 96/14 whenever [1] 54/24 where [15] 7/23 37/6 47/4 47/4 47/19 53/10 61/13 79/5 81/18 81/19 83/21 84/17 89/9 89/24 96/10 whether [10] 13/14</p>	<p>14/23 18/22 20/25 69/4 69/6 69/7 82/7 94/12 95/6 which [27] 3/16 3/17 3/17 9/11 10/20 12/18 20/5 20/20 27/19 28/18 35/23 35/24 41/22 42/12 64/23 66/1 68/5 73/16 73/24 77/22 82/11 82/24 85/6 89/13 92/2 95/4 97/6 while [7] 35/25 42/24 54/14 73/8 90/3 90/6 91/5 whilst [5] 78/14 81/2 88/23 96/16 97/15 whitewash [1] 58/12 who [42] 2/13 12/21 15/11 15/12 19/6 26/2 26/10 26/16 26/18 26/25 27/13 27/20 28/10 28/12 28/23 45/3 45/17 52/23 56/1 56/10 57/5 57/8 58/19 59/13 64/5 66/14 67/19 73/22 77/20 79/19 84/13 89/2 91/20 91/21 91/22 92/16 93/20 93/21 93/22 94/22 94/25 95/2 whole [5] 26/13 41/18 46/3 83/5 97/12 whom [1] 26/18 whose [1] 57/7 why [23] 10/4 10/4 10/18 16/17 16/18 16/19 16/21 25/10 26/7 28/1 49/24 55/9 64/10 70/15 70/20 73/19 74/24 75/4 76/2 79/18 79/24 82/1 82/6 wife [22] 2/13 3/5 5/7 10/2 24/3 26/12 26/12 27/24 28/19 28/22 41/24 79/7 79/11 79/20 79/22 80/7 81/1 81/5 83/19 85/13 88/12 91/4 wife's [2] 23/17 26/21 Wilkie [3] 67/19 68/10 68/12 will [44] 1/25 2/4 2/7 2/7 2/9 3/11 6/19 7/4 9/7 9/7 12/4 12/8 12/9 23/5 23/11 23/20 28/8 29/2 29/10 39/15 47/7 47/14 47/15 52/19 53/21 54/9 57/15 57/16 57/23 60/6 60/9 61/10 65/4 66/5 66/12</p>	<p>66/14 69/2 69/5 77/13 91/17 93/6 93/20 93/21 93/25 wise [1] 89/10 wish [1] 94/4 wished [1] 80/18 wishes [1] 62/17 wishing [1] 93/24 with [109] withheld [2] 70/17 70/21 within [2] 47/16 49/23 Withington [1] 21/2 without [9] 1/8 3/10 6/5 46/4 47/17 47/18 47/18 59/1 60/17 witness [8] 2/12 2/21 16/9 29/16 30/1 35/22 62/17 97/24 witness's [2] 2/14 2/15 witnesses [1] 97/23 won't [6] 1/10 2/10 3/18 23/16 54/6 61/13 wonder [4] 43/15 75/2 82/6 83/10 wondered [1] 83/7 wonderful [1] 26/2 word [4] 10/16 28/17 44/21 84/16 worded [1] 69/19 words [3] 8/10 19/17 92/7 wore [1] 84/6 work [33] 1/13 8/24 21/5 26/25 30/24 35/14 35/18 35/21 36/1 38/1 40/1 40/7 41/24 42/21 45/14 47/25 48/1 51/12 53/7 57/21 59/4 76/5 78/13 85/14 86/12 87/22 88/2 88/3 88/6 88/18 88/21 91/7 96/19 worked [6] 7/22 22/12 40/8 51/16 51/17 89/1 working [18] 7/24 33/19 37/8 39/2 40/5 45/8 45/15 49/13 51/16 76/3 76/4 78/15 78/17 87/16 88/23 89/9 96/9 96/22 world [2] 2/10 89/12 worried [15] 10/10 34/12 34/25 53/8 61/3 72/10 72/11 72/12 80/23 85/20 89/25 89/25 91/16 91/18 95/19 worry [8] 32/8 33/18 69/24 88/18 88/21 91/7 91/10 94/21</p>
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<b>W</b> <b>worrying [1]</b> 60/17 <b>worse [4]</b> 4/7 4/7 81/24 82/15 <b>worst [2]</b> 57/5 96/6 <b>worthless [1]</b> 41/2 <b>would [104]</b> <b>wouldn't [8]</b> 25/1 25/1 33/23 34/2 38/3 38/6 50/2 86/24 <b>write [3]</b> 26/1 28/9 60/15 <b>written [5]</b> 11/25 45/17 59/7 72/1 92/9 <b>wrong [5]</b> 10/17 10/22 47/4 54/2 85/24 <b>wrote [2]</b> 25/13 43/17	<b>yes [92]</b> 1/20 3/7 3/22 3/24 4/1 4/6 4/8 4/14 14/10 14/13 14/22 18/15 18/15 21/23 22/8 23/14 28/25 29/25 30/10 30/13 31/5 31/6 31/11 31/24 32/3 32/3 32/6 32/9 32/12 32/17 32/19 34/4 34/22 34/24 34/24 35/4 35/17 35/20 35/25 37/18 38/23 39/7 39/10 40/3 40/12 40/14 40/15 41/13 42/5 43/10 44/10 44/18 45/22 46/18 47/11 47/11 48/11 49/7 49/9 49/9 49/9 50/22 50/22 50/24 51/1 51/3 52/18 52/18 52/21 53/2 54/22 54/22 55/6 55/6 55/15 56/5 56/5 56/15 56/17 63/11 74/9 74/14 79/13 80/4 80/6 81/9 81/25 82/16 90/17 91/18 95/15 96/12 <b>yesterday [1]</b> 1/21 <b>yesterday's [1]</b> 1/17 <b>yet [4]</b> 43/21 57/24 66/13 91/24 <b>you [370]</b> <b>you'd [7]</b> 11/5 35/19 39/5 40/1 67/3 77/1 96/9 <b>you'll [6]</b> 23/15 24/7 25/17 36/25 39/16 87/3 <b>you're [29]</b> 3/5 7/2 7/4 8/10 8/17 9/4 9/11 15/6 21/17 22/4 25/8 29/22 39/15 41/15 45/23 46/3 49/2 51/22 55/11 57/12 60/22 65/7 81/23 83/3 87/2 87/2 89/9 89/23 96/23 <b>you've [40]</b> 3/14 5/23 6/11 8/13 8/19 9/3 10/20 11/3 16/9 17/1 18/8 18/16 22/18 23/11 24/2 24/3 24/4 24/17 34/14 35/22 46/20 48/8 48/25 49/5 51/2 52/4 52/22 55/22 60/3 62/4 64/16 70/23 71/20 83/3 87/9 89/9 90/8 90/12 90/15 91/14 <b>young [9]</b> 21/8 21/9 21/10 42/7 42/17 43/15 62/25 63/3	94/23 <b>your [129]</b> <b>yourself [3]</b> 44/4 45/8 73/3 <b>yous [1]</b> 25/10			
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(41) worrying - vous