

1 **Tuesday, 22 June 2021**  
 2 **(10.00 am)**  
 3 **SIR BRIAN LANGSTAFF:** Now Nick, you'd like to be called  
 4 Nick, I gather?  
 5 **THE WITNESS:** Yes, that's correct.  
 6 **SIR BRIAN LANGSTAFF:** You can see me, can you?  
 7 **THE WITNESS:** Yes, I can.  
 8 **SIR BRIAN LANGSTAFF:** Obviously you can hear me, we can  
 9 hear you.  
 10 **THE WITNESS:** Yes.  
 11 **SIR BRIAN LANGSTAFF:** You're at home, are you?  
 12 **THE WITNESS:** I am, in my computer room. I'm sorry  
 13 I can't be with you all.  
 14 **SIR BRIAN LANGSTAFF:** Well, so are we, but these things  
 15 happen. You're talking to a full room here, if you  
 16 can picture it, as full as we are able to be under  
 17 current restrictions. Yesterday there were something  
 18 like 400 people during the day watching beyond this  
 19 room, so that's who you're talking to. Ms Richards  
 20 will ask you the questions once Mary has given you the  
 21 oath.  
 22 So Mary, would you please swear Nick in.  
 23 **NICHOLAS SAINSBURY (affirmed)**  
 24 **Questions by MS RICHARDS**  
 25 **MS RICHARDS:** Good morning, Nick, can you see and hear me?

1

1 **Q.** Now, you then joined Treloar's in 1974 at the age of  
 2 11.  
 3 **A.** Yes, that's right. And the reason that that happened  
 4 was I was attending the junior school at home, which  
 5 coincidentally was right opposite our home. The  
 6 problem was, I was never there because of bleeds into  
 7 my left knee. By about -- no, before I went to  
 8 Treloar's, I think I spent -- missed a total of about  
 9 a year and a half of school with my knee. I was in  
 10 Oxford on traction for eight weeks, I was in Hull  
 11 Royal in traction and plaster for six weeks, and then  
 12 I had my second hare lip and cleft pallet operation,  
 13 which bled profusely for several weeks.  
 14 So I missed most probably most of the last year  
 15 to 18 months, and we happened to mention this when we  
 16 were down at Oxford to Dr Charles Rizza and it was him  
 17 that told us about Treloar, so we got an appointment,  
 18 went down to see it and, although I didn't  
 19 particularly fancy being so far away from home and my  
 20 parents didn't like it either, it was Hobson's choice,  
 21 because it was the only way that I saw that I would  
 22 get an education and have the medical support that I  
 23 needed on the site. That's how I got there.  
 24 **Q.** You remained there until 1980. We'll look at your  
 25 records in relation to your treatment at Treloar's in

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1 **A.** I certainly can. Thank you very much.  
 2 **Q.** Nick, you had severe haemophilia A diagnosed when you  
 3 were a baby?  
 4 **A.** That's correct, yes.  
 5 **Q.** In terms of the treatment that you received in  
 6 childhood before you went to Treloar's, was that  
 7 largely in Kingston upon Hull?  
 8 **A.** Yes, and also the Oxford Haemophilia Centre. I went  
 9 down there for several reasons. When I was very  
 10 young, we didn't even have cryoprecipitate.  
 11 I remember even now having plasma at the age of five  
 12 and getting reactions to that. And then I think I was  
 13 about six when I had -- six or seven -- when I had my  
 14 first dose of cryoprecipitate and, of course, at the  
 15 time that was a wonder drug.  
 16 **Q.** Before you went to Treloar's in 1974, do you know  
 17 whether you were treated with factor concentrates or  
 18 was your treatment solely plasma and then  
 19 cryoprecipitate?  
 20 **A.** I think it was almost entirely plasma, and then  
 21 cryoprecipitate. The only exception I can remember  
 22 offhand, up to 1974, was when we went on holidays to  
 23 France, and I think my parents were given two doses,  
 24 two or four doses of concentrate just in case of  
 25 an emergency, which thankfully we didn't need.

2

1 a few minutes but, more generally, what were your  
 2 recollections of receiving treatment at Treloar's?  
 3 How often -- what kind of treatment, and where would  
 4 you go to be treated?  
 5 **A.** Well, when I joined, of course, it was purely, um,  
 6 purely a boys school, so we weren't mixed. So we had  
 7 our own sick bay. We would go up to the sick bay and  
 8 we would either have a transfusion of cryoprecipitate,  
 9 where they would put it on a drip and let it go, or if  
 10 it was during the day, they tended to take us to the  
 11 local Lord Mayor Treloar Hospital, which was about  
 12 3 miles away and we'd be tret (sic) there. I've got  
 13 memories of being kept in there in a few days as well  
 14 as being in the sick bay at Treloar's. But those were  
 15 the -- probably the first couple of years, and then  
 16 I think we gradually started to get the Factor VIII  
 17 concentrate.  
 18 At first it seemed okay. I did read the warning  
 19 label on the bottle. It said, "Warning this product  
 20 cannot be guaranteed to be free from viral infection".  
 21 And I said to one of the haemophilia nurses I said,  
 22 "What does this mean, really?" She said, "Take no  
 23 notice, it's just there for legal purposes. It's  
 24 because it's from America". So I thought nothing more  
 25 of it.

4

1 And we had an outbreak of hepatitis B, I think, in  
2 the autumn of 1975. And it happened to be the day of  
3 the school medical, I went up to my friend [redacted]  
4 and I looked at him, he was yellow, bright yellow. We  
5 didn't know what had happened, we joked about it a bit  
6 but it transpired that him and about 15 other boys had  
7 contracted hepatitis B. And we all thought "What's  
8 going on?" But the only explanation we were ever given  
9 was when the headmaster stood up at meal time and said,  
10 "I understand that some of you are worried about this  
11 hepatitis that's been going round". He said, "We've  
12 been told to ask you not to worry, there are two types  
13 of hepatitis, the fatal kind, serious, and the  
14 non-fatal, mild type, and you've got the mild type so  
15 there's nothing to worry about."

16 And that's all the information we were given. But  
17 it was disturbing to see that the boys were affected for  
18 a long time afterwards. They had to hand their plates  
19 in to the canteen staff, and all their cutlery,  
20 crockery, it all had, I think, a red spot in the middle  
21 and they had to hand that over in front of everybody.  
22 And I just thought that was awful.

23 **Q.** Your recollection in your statement was that this  
24 hepatitis B outbreak was around 1975, 1976?

25 **A.** I think it was the autumn term of 1975. It was -- I'd

5

1 had merged and it had become a co-educational  
2 establishment, that the Haemophilia Centre moved to be  
3 within the school itself?

4 **A.** Yes, well, I would say --

5 **Q.** Can you recall that?

6 **A.** Yeah, well, we -- you know, it was much better then,  
7 you just had to walk up the corridor through the  
8 doors, and you were there. Yes, it was better. It  
9 was on the site. You'd go in, you'd report -- clinic  
10 after breakfast or the evening clinic -- or, you know,  
11 if something had cropped up during the day we'd just  
12 have to go up and tell them and they'd make  
13 arrangements for you to be tret. But yeah, it was  
14 better.

15 **Q.** And did there come a point where you were treating  
16 yourself?

17 **A.** Yes. That started for me in 1979. I mean, the  
18 self-infusion programme was pretty new at that time.  
19 And they were teaching us in batches of four. And we  
20 had a little chat with -- was it Dr Wassef, you know.  
21 When, you know -- cleanliness, when to have a bleed,  
22 how much to have, and all this. But there was no real  
23 concern over the safety of the blood mentioned at all.  
24 None at all, as I recall.

25 And then I proceeded with the home infusion

7

1 been there about a year, I think, when it happened.

2 **Q.** Other than your own choice in reading the product  
3 leaflet and the response that you then got from the  
4 haemophilia nurse, and the information you've just  
5 reported being relayed by the headmaster, "There are  
6 two types of hepatitis, the fatal and non-fatal, this  
7 is the mild form", was any other information ever  
8 given to you at Treloar's about any risks of being  
9 treated with concentrates?

10 **A.** No. When we did move over on to concentrate, I do  
11 remember asking, "Will we get reactions to it like we  
12 had with cryoprecipitate?" Which -- I said, "That's  
13 horrible". And the nurse or whoever it was said, "No,  
14 you won't, because this product, this stuff, it's  
15 a lot purer" --

16 **Q.** And I think?

17 **A.** -- "and clean."

18 **Q.** And I think you've got recollections of being treated  
19 by a range of doctors at Treloar's. You've identified  
20 Dr Kirk, Dr McHardy, Dr Aronstam and Dr Wassef in your  
21 statement?

22 **A.** Yeah, Dr Kirk, Dr McHardy, yeah, that sounds about  
23 right, yeah. Dr Wassef and Dr Aronstam.

24 **Q.** Then after you'd been there three or four years, we  
25 understand in the late 1970s, after the two schools

6

1 training. I found it very difficult. One of the  
2 reasons was I had a severe brain haemorrhage at a very  
3 young age and one of the main things it did was affect  
4 my fine hand co-ordination, and that's been a problem  
5 throughout my life. So to get hold of a small needle,  
6 hold it and then twist it around and get it into  
7 a vein and do all the other -- it was a nightmare.  
8 And it took me a long time. And if it hadn't been for  
9 one particular person, I don't think I would ever have  
10 achieved it, and that was a lovely nurse called Annie.  
11 She would sit with me time after time and she would  
12 put the tourniquet on, and did a needle into her own  
13 arm, and I did one in my own arm at the same time, so  
14 we did it together. You know, that's how dedicated  
15 she was.

16 But I did feel a bit under pressure because I'd  
17 booked to go on a school trip to Canada in June of 1979,  
18 and I was a bit annoyed to be told that you had to be  
19 able to treat yourself in order to go because there was  
20 nobody going with us that could administer Factor VIII.  
21 I thought that was a bit strange. Obviously they just  
22 don't want to pay for a nurse to go with us. But, you  
23 know, I managed it. But, yeah, I found it very  
24 difficult. But I got through it and it was really  
25 thanks to that nurse.

8

- 1 Q. And when you did self-treat, if you felt the need for  
2 treatment, can you talk us through what you would do  
3 in terms of getting the product? You'd go to the  
4 Centre in the school?
- 5 A. Yes. What I'd do is give -- if I felt a bleed coming  
6 on and it wasn't clinic, I would go up to the Centre,  
7 just check-in with the nurse on duty, say, "I've got  
8 an elbow bleed", and then I would go into the room,  
9 there would be a set of scales on the floor, weighed  
10 myself, and then I would look up the chart that we had  
11 on the wall, so many kilograms, you know, against  
12 this, 20% raised, and we were told to use a product --  
13 the combination of bottles -- not all one product, but  
14 to use a combination that would get us as close as  
15 possible to, I don't know, 550 units. So it did vary  
16 a little bit as to which I would use. And then  
17 I would fill in a treatment slip saying what I'd done,  
18 give it to the nurse, and I would be told to see the  
19 doctor at the next clinic appointment, which was  
20 either in the evening or the next morning.
- 21 Q. And in terms of which concentrate you would be  
22 self-treating yourself with, was there a -- I mean,  
23 we've heard other witnesses describe a fridge and  
24 going to the fridge and taking their concentrate. Was  
25 that your recollection or did it happen differently in

9

- 1 I'm sorry, it's my own handwriting, I can't read.  
2 TREL0000074\_022.
- 3 So we can see, Nick, this is a letter,  
4 December 1975.
- 5 A. Yes.
- 6 Q. It's from Dr Kirk. And this is from your -- although  
7 we don't have a name and the "Dear" -- or your name in  
8 it, it's from your Treloar's records.
- 9 A. Yeah, I was actually surprised to see it, because as  
10 I think -- as it's been mentioned already, there was  
11 no parental involvement in our treatment at all.  
12 None. But even that, it doesn't really tell you  
13 a lot, I don't think.
- 14 Q. No. Let me just read it out so others can follow.  
15 So it is dated December '75. It says "Dear" and  
16 then it's a blank:  
17 "In view of the problems of hepatitis in  
18 haemophilia, I have been asked by Dr Rosemary Biggs,  
19 of the Oxford Haemophilia Centre, to conduct a survey  
20 on this subject.  
21 "Your son has been selected to receive only  
22 Kryobulin when he requires transfusing. By limiting him  
23 to this type of factor VIII containing material it will  
24 be easier to trace the source should he contract  
25 hepatitis.

11

- 1 your time?
- 2 A. No, I mean, as far as I remember, once you'd been  
3 trained up on it, you know, you would -- once you'd  
4 seen the doctor at clinic or, as I say, reporting, you  
5 were just left to get on with it. I mean, if you had  
6 problems somebody would come and help you, but the  
7 whole idea was, obviously, that they were trying to  
8 prepare us for life after school and wanted us to just  
9 get on and be able to do it ourselves.
- 10 But I mean, I have to say, you know, there  
11 was -- four of us trained at a time and we did help  
12 each other out. I mean, I can remember one occasion,  
13 by coincidence all four of us turned up with a very  
14 bad elbow bleed, and I was absolutely doubled up, and  
15 one of the boys, [redacted], he was the same, but he  
16 went around and helped all three of us before doing  
17 his own. I've never forgotten that. I thought, you  
18 know, that's such a self-less act from someone who was  
19 in so much pain himself, you know.
- 20 So, I mean, we did help each other.
- 21 Q. And I am going to ask you to look with me at a few of  
22 the records from Treloar's, Nick.
- 23 A. Yeah, sure.
- 24 Q. So Soumik, could we have, first of all,  
25 TREL0000071\_022. I've given you the wrong reference.

10

- 1 "If you have any queries concerning this survey  
2 I would be happy to discuss the matter with you."  
3 Do you know whether your parents ever received  
4 this letter?
- 5 A. I don't think so, unless maybe I was sent home  
6 with it. I've got no recollection of the letter.  
7 I do remember -- having thought about it the last day  
8 or two, I do seem to remember them saying we just use  
9 Kryobulin. But I thought nothing of it. So I don't  
10 quite know. I mean, I might have been sent home with  
11 that letter, I don't know, but I do remember speaking  
12 to my mother some years ago, when the campaign started  
13 I think, and I said to her, "Were you and Dad ever  
14 sent any letter from the doctors at Treloar talking  
15 about my treatment?" She said, "No."
- 16 **SIR BRIAN LANGSTAFF:** I'm curious about this. Can we just  
17 have look at the whole letter. There's nothing at the  
18 bottom which says, "Do you consent?"
- 19 A. No.
- 20 **SIR BRIAN LANGSTAFF:** There's nothing which asks for  
21 consent.
- 22 A. No, no, and we weren't asked for consent. But the  
23 point is, we were at school, you see. I mean, the  
24 thing about a boarding school is that you're at  
25 school, you're away at school all the time. You just

12

1 do as you're told. Mostly. [Laughs]. But, yeah,  
 2 I mean for the most part, you know, they looked after  
 3 us pretty well, but as regards stuff like this, no,  
 4 there was nothing consensual. It always bothered me  
 5 a bit that if you were very poorly in bed with a very  
 6 bad bleed, they never just rang up your parents and  
 7 said, "Just to let you know, he's in bed and we're  
 8 going to keep an eye on him over the next few days".  
 9 It just wasn't.

10 And it went further than that. I was quite  
 11 surprised actually to see a discipline letter that had  
 12 been sent to somebody in 1978. I've never seen that  
 13 type of letter. I would have expected one around  
 14 1978/79 when we went out and got drunk and were  
 15 grounded, but I've never seen that sort of letter.

16 And also there was a lot of bullying going on  
 17 between 1974 and 1977, with some quite serious results.  
 18 I mean, I had my ear split open by a boy. He got a 50p  
 19 fine. They didn't inform -- the school didn't inform my  
 20 parents. And I didn't -- by the time you get home, you  
 21 just want to forget things. And then they found out the  
 22 following term and I got into more trouble from the  
 23 house master for not telling them than he did. He got  
 24 a 50p fine and I saw him the next day with a smirk on  
 25 his face.

13

1 about?  
 2 **A.** Yes. Yes, yes. I mean, there was hepatitis B but,  
 3 I mean, we were never told the difference between  
 4 hepatitis A and B. We didn't know anything about  
 5 non-A, non-B hepatitis. We knew nothing about that at  
 6 all. I don't even know -- I'm not even quite sure  
 7 when that became recognised, non-A, non-B hepatitis.  
 8 But I do remember at that time we had a meeting with  
 9 our MP, and I explained what had happened. I said  
 10 we'd been promised self-sufficiency and we hadn't  
 11 received it. And all he said was that, "Oh was it  
 12 a ministerial promise?" He said, "Well, they're not  
 13 really worth anything." So, okay. So that was the  
 14 attitude of the local MP.

15 It was just, if you like, complete apathy about it  
 16 all. So we weren't really aware that, you know, this is  
 17 serious and we didn't know for example, that one bottle  
 18 of Factor VIII was from many, many donors. We didn't  
 19 know that.

20 **Q.** If we look at the next document we can see a follow-on  
 21 in relation to the use of Kryobulin. It's  
 22 TREL0000074\_021.

23 **A.** That's it. Yes.

24 **Q.** This is another letter from Dr Kirk, 27 February 1976.  
 25 But this doesn't purport to be to your parents; it's

15

1 **SIR BRIAN LANGSTAFF:** Can I just bring you back to this  
 2 letter?

3 **A.** Yeah, sure.

4 **SIR BRIAN LANGSTAFF:** Would your parents have understood  
 5 anything about Kryobulin as opposed to anything else?

6 **A.** No. I mean up until, it had always been -- I used to  
 7 go to Hull Royal Infirmary up to the age of 10 -- up  
 8 to 11, I think it was, and I would be tret on the  
 9 paediatric ward there, and the fact that the  
 10 cryoprecipitate was sent over from another hospital,  
 11 so waiting half a day. But I think the first time  
 12 they would have become personally aware of the new  
 13 concentrate was when my brother started home treatment  
 14 I mean, he's four years younger than me and he started  
 15 at 16, same as me. It was the first time it had been  
 16 done in Hull. So I think that would have been the  
 17 first time that they actually saw concentrate. But,  
 18 of course, what little I had, I would have had at  
 19 school.

20 **MS RICHARDS:** Nick, if you're right with your recollection  
 21 that the hepatitis outbreak was in the autumn term  
 22 of 1975, in terms of any reference to hepatitis in  
 23 this letter, you -- is this right, you'd understood  
 24 that if there was any hepatitis risk, it would be of  
 25 something that was mild and nothing to be worried

14

1 to Dr Raper the consultant haematologist at Kingston  
 2 General Hospital.

3 **A.** Yes.

4 **Q.** It says:

5 "Dear Dr Raper,

6 "You were kind enough to co-operate in the  
 7 Hepatitis Study by making available Kryobulin for the  
 8 routine treatment of this boy. Unfortunately, over the  
 9 past few weeks we have had several severe reactions to  
 10 this product and Nicholas, who has not had an  
 11 anaphylactic type reaction for three years, was  
 12 affected.

13 "Because of the seriousness of one of the episodes  
 14 I do not think it is advisable to give this product to  
 15 those boys who reacted to it. I am gradually  
 16 transferring boys on to Hemofil and wonder whether it  
 17 would be possible for Nicholas to receive this instead  
 18 of Kryobulin. Failing that, perhaps he could be  
 19 restricted to Cryoprecipitate."

20 It looks as though Dr Kirk is writing to Dr Raper  
 21 so that when you go home on holidays --

22 **A.** Yeah, the two centres were very good at writing to  
 23 each other. They just forgot about the patient and  
 24 the parents.

25 **Q.** Do you recall anything about having an aphylectic

16

1 reaction to Kryobulin?

2 **A.** No, I don't. I've been trying to rack my brain the  
3 last few days, and I don't. I'm sure it probably did  
4 happen. I don't know how severe it was. It said some  
5 were severe. But it doesn't ring a bell with me.  
6 Doesn't ring a bell at all.

7 **Q.** Were you aware that you were apparently participating  
8 in something called the Hepatitis Study?

9 **A.** No, I was just asked if I -- I was just asked or --  
10 well, asked/told to trial Kryobulin for the holidays.  
11 And I think they actually gave me -- I thought that  
12 was the holiday that they gave me a supply of  
13 Kryobulin to take home. I'm not -- obviously that  
14 must have been another time, if Dr Raper made it  
15 available. But there was another time I seem to  
16 remember where I was sent home with some Kryobulin.  
17 And also, I think it was through a -- I can't  
18 remember, it was maybe for prophylaxis but I do  
19 remember being sent home, and I'm sure it was with  
20 Kryobulin.

21 Because my brother was trained up he took on --  
22 very kindly took on the job of doing my injections  
23 during the holidays. And I do remember, he was doing  
24 this, and there was a request for a blood sample to be  
25 taken and sent back to the college. And my brother,

17

1 on the same day. We just went down to the Oxford  
2 Haemophilia Centre. But, yeah, I've got many memories  
3 of having the Factor VIII in the caravan and my  
4 brother doing it for me. I remember doing the boring  
5 part, sat there twizzling it to dissolve it all. We  
6 both hated doing that. But yeah, I remember that.

7 **Q.** If we move to 1977 with TREL0000074\_020. This is  
8 another letter from Dr Kirk to Dr Raper in Hull.  
9 11 March 1977. We can see in the first paragraph it  
10 refers to you having trouble with elbow joints and  
11 being severely infected, and then the recommendation  
12 is that you have a limited period of prophylaxis.

13 **A.** Yeah.

14 **Q.** If we look at the second paragraph -- sorry, the end  
15 of the first paragraph, it says:

16 "Since the middle of February therefore we have  
17 treated him prophylactically with 440 units of Hemofil  
18 on alternate days which has been fairly successful in  
19 that he has any had two elbow bleeds in that time."

20 Then Dr Kirk asks if it is possible for you to  
21 continue with prophylaxis throughout the holidays.

22 Do you recall whether there was any discussion,  
23 either with you or with your parents, about the  
24 potential implications of receiving treatment  
25 prophylactically rather than on demand?

19

1 quite rightly, was a bit wary of doing that. And he  
2 rang up and I think he spoke to Dr Raper and Dr Raper  
3 said, "Oh yeah, give it a go and see how you get on".  
4 I think my brother, bless him, he took a blood sample  
5 from me, parcelled it all up and sent it off. But  
6 I do remember at the time thinking that's a bit much.

7 **Q.** I think the episode you're referring to, we've got  
8 a document that might refer to that. It's  
9 TREL0000074\_023.

10 **A.** It's difficult, isn't it when you're trying to think  
11 back.

12 **Q.** This is Dr Raper to Dr Kirk, October 1975:

13 "During the summer holidays Nicholas had two forms  
14 of treatment. First of all Cryoprecipitate [and you're  
15 given that on a number of occasions]. However he also  
16 had some concentrate given to him by his brother ...  
17 while he was on holiday and the Sainsbury family have  
18 a book in which they keep all their home family  
19 records."

20 **A.** Yeah, we used to go away on holiday in a caravan and  
21 we would take some with us in a little fridge that we  
22 had in the caravan. But we also, I remember on  
23 a couple of occasions, we also used to go down to  
24 Wallingford on Thames, I think it was, and I do  
25 remember on a couple of occasions we were both poorly

18

1 **A.** I mean, our only concern at that time, you know, was  
2 reducing bleeds. You've got the use mentioned of  
3 splints, which we used all the time to rest it, rest  
4 joints. But, yeah, they used that and they would use  
5 prophylaxis as well. But, yeah, it was purely about,  
6 you know, stopping or minimising bleeds. To be  
7 honest, at the time, and even now, I think it was  
8 necessary. Yeah, I went for a very prolonged periods  
9 of just one bleed after another, alternate elbows, it  
10 like left marks almost sometimes.

11 **Q.** Did your treatment continue on a prophylactic basis?  
12 I think there are references in the documents that  
13 suggest that you certainly did have prophylactic  
14 treatment after this. Can you recall for how long?

15 **A.** I had periods of prophylaxis whilst I was at Treloar,  
16 and I think during the holidays. And I remember also  
17 having it when we went on a school trip to Germany, we  
18 fixed things up so I could go along to the hospital in  
19 Cologne, the Haemophilia Centre, and have it there,  
20 alternate days. That was very well organised. But  
21 no, they never sort of said, you know, if you have  
22 this there's a heightened risk of hepatitis. I mean,  
23 I think everyone was just thinking about, you know,  
24 really, the job at the time was to try to keep our  
25 joints going.

20

1 Q. Then we can see another document which gives us an  
 2 indication of the range of products you received.  
 3 TREL0000221\_006, please. We can see that that is  
 4 a record in relation to you.  
 5 A. Yeah.  
 6 Q. There's a reference there "Frequency: alt day", which  
 7 I imagine is alternative day --  
 8 A. Alternative days, yes.  
 9 Q. -- and then:  
 10 "Indication: Prophylaxis for frequent bleeds  
 11 into both elbows."  
 12 A. Yes.  
 13 Q. I think we can see it's 1980. If we look then at the  
 14 table and just run down the material. We've got here  
 15 dates that run from April to May 1980, so this is just  
 16 a sample from your records, Nick, and we can see  
 17 you're getting Lister, Lister, Factorate, Factorate,  
 18 Lister -- and, sorry, can we have the whole list,  
 19 Soumik, otherwise I'll lose track -- Factorate,  
 20 Factorate, Lister, Lister, Factorate, Factorate,  
 21 Lister, Lister, Kryobulin.  
 22 A. Yeah.  
 23 Q. There are other records to similar effect --  
 24 A. The Kryobulin, you see, after saying I shouldn't have  
 25 it, they still gave me it.

21

1 A. No, I mean, as I remember, at the beginning of each  
 2 term, we always did blood tests and I think a large  
 3 part of it was to make sure we hadn't developed  
 4 inhibitors. And I do remember them doing pre- and  
 5 post-level, so they would take a blood sample before  
 6 you had Factor VIII and then a blood sample 20 minutes  
 7 after you've had it, just to check that they're  
 8 getting the raise that they want. And I think they  
 9 were doing that once a term. That's my recollection.  
 10 Q. Do you recall ever being told what the results or  
 11 significance of the results of any of these tests  
 12 were?  
 13 A. No, no, they never said there was a problem. So you  
 14 just assumed that there wasn't a problem. But no,  
 15 I mean, hepatitis -- I mean, after that outbreak that  
 16 I mentioned, it just all seemed to go quiet, never  
 17 mentioned, really.  
 18 Q. Then just in terms of a final entry from your  
 19 Treloar's records, if we look at TREL0000074\_003, this  
 20 is a letter 12 December 1979 from Dr Wassef, again to  
 21 Dr Raper in Kingston. If we look at the third  
 22 paragraph we can see Dr Wassef telling Dr Raper that:  
 23 "Biochemically, his SGOT has been intimately  
 24 raised for the past ten months and his total proteins  
 25 occasionally raised."

23

1 Q. There are other records for other periods of time that  
 2 you were at Treloar's, which again indicate that you  
 3 received multiple different types of product; is that  
 4 your recollection as well?  
 5 A. Yeah, I think I've said in my statement, I received  
 6 every type of product there was. And I suspect that  
 7 the reason that was, they were trying to get as close,  
 8 unit-wise, to what was needed to give the raise  
 9 that I needed. I think that's why. But, you know,  
 10 look, it's incredible, or it feels incredible, that  
 11 they didn't try to limit it more to one product. But  
 12 then, on the other hand, you see, there was over 50 of  
 13 us from all over the country. So, you know, they  
 14 would have needed a large supply on hand all the time.  
 15 They probably that no choice but to get it from  
 16 different places. That's what I would think.  
 17 Q. Then if we look at TREL0000221\_018, again, this is  
 18 just a sample from your Treloar's records, Nick. On  
 19 the left-hand side we've got the heading "Serum  
 20 hepatitis" and we can see reference to antibody and  
 21 antigen testing, 1978 recorded as negative, and then  
 22 January 1979 and April 1979, it's recorded as antibody  
 23 positive, antigen negative, and then it's only the  
 24 antigen column then filled in. Do you recall anything  
 25 about testing for any form of hepatitis?

22

1 Again, was that information ever shared with you  
 2 or your parents, to your knowledge?  
 3 A. I don't know what it means even now, SGOT, never been  
 4 told, never mentioned.  
 5 Q. So the picture you're describing, Nick, is very much  
 6 one of dialogue between the Treloar's Centre and your  
 7 home Centre --  
 8 A. Yes.  
 9 Q. -- but no equivalent or even similar dialogue with you  
 10 as patient or with your parents as your parents.  
 11 A. No, and I think that was a picture that was painted  
 12 yesterday as well, and I think anybody to who gives  
 13 evidence from Treloars will say the same.  
 14 Q. There's a couple of documents which I'm not sure  
 15 whether we've got available for display. I'm going to  
 16 call out the name. If we haven't got them it doesn't  
 17 matter, Soumik. But TREL0000221\_067. We do?  
 18 Excellent.  
 19 We can see if we look at the top of the page, it's  
 20 an entry in relation to you, again this has come from  
 21 your Treloar's records. There's a date given,  
 22 5 June 1978. But the reason for showing this is we've  
 23 got there the stamp "HEPATITIS RISK"?  
 24 A. Yeah.  
 25 Q. Is that something you knew about appearing on any of

24

1 your records, until you saw this?

2 **A.** No, it doesn't ring a bell at all. Obviously,

3 when they took blood samples, they just took them

4 straight into the -- but I don't recall seeing that at

5 all. It doesn't even ring a bell.

6 **Q.** Then I'm going to try one further document, Soumik.

7 TREL000074\_028. So this just takes us back to 1975.

8 Again, it's a letter from Dr Kirk to Dr Raper, and

9 then if we just look at the text of it, and it might

10 help in relation to the issue about hepatitis B. It

11 says:

12 "Within the last few days it has come to my

13 attention that twelve patients treated at this Centre

14 have been given a material which has proved to be

15 [hepatitis B antigen] positive by radio-immunoassay

16 testing. The above patient [that's you] received the

17 material (Kryobulin factor VIII concentrate

18 [number] 06M6575) on the following date -- 27 June 1975.

19 "Your patient fortunately has antibody to

20 hepatitis B and hopefully this will protect him from

21 becoming jaundice. Should he develop symptoms and signs

22 I would be most grateful if you could arrange for two

23 10ml samples of clotted blood to be sent to me for

24 antibody and antigen tests."

25 Again, it's not an insignificant piece of

25

1 **A.** That's right.

2 **Q.** And you were then again under the care of the

3 Kingston Hospital in Hull.

4 **A.** Yeah.

5 **Q.** And do you know what products you were treated with in

6 the years after you left Treloar's?

7 **A.** Well, I remember Hemofil and Factorate. So it was

8 those two up until everything kicked off sort of

9 mid-eighties. And then they brought in -- gradually

10 they brought in heat-treated Factor VIII. I can't

11 remember what brand it was. And then eventually it

12 was a recombinant. I forget the name of it now. And

13 now the very latest, longer lasting stuff.

14 **Q.** Did Dr Raper or any of the other staff at the

15 Kingston General Hospital in Hull tell you at all

16 in -- whether in the first part of the eighties or,

17 indeed, at any time before that, of the any risks

18 associated with the use of concentrates?

19 **A.** No. Obviously we were always aware of the label on

20 the bottle but they never said anything -- to me, no.

21 They never said, "There's a bit of a problem with

22 concentrate, would you like to go on to

23 cryoprecipitate and sort it out?" But you see, there

24 again that brought up many, many other difficulties.

25 I mean, I've had so many discussions with my brother

27

1 information about events going on at the school. Do you

2 know whether that information was ever communicated by

3 Treloar's to your parents.

4 **A.** I don't think so, no. No. No, as I say, I did ask my

5 mum, you know, when we're campaigning, I said, "Apart

6 from my end of term report, did you ever get anything

7 medical from the school?" And the answer was no. No,

8 we never had anything. I found one copy, blank copy

9 of a letter that may or may not have been sent, but it

10 says, "Dear parent/guardian, your son has been placed

11 on a trial of [whatever it was]. If you have any

12 questions, please contact me". But I've no

13 recollection of my parents mentioning that letter or

14 speaking to me about it.

15 Without further -- you know, without further

16 explanation I don't think they would. I think they

17 would just think he's getting his treatment, he's

18 doing okay. We were just ordinary working class, if

19 you like, family. We didn't really know all this.

20 I'm a little bit surprised because I always

21 thought that Dr Aronstam was very open with us. He

22 never sat down and had this sort of discussion about

23 this stuff with us. Not me, anyway.

24 **Q.** We can take that down, thank you, Soumik.

25 You then left Treloar's in the summer of 1980.

26

1 with this. He wouldn't have been able to go away to

2 college and do his degree. I would probably have

3 found it very hard to get a job, of any sort, and work

4 full time. So what do you do?

5 **Q.** Now you were infected with HIV, as a result of --

6 **A.** Yes.

7 **Q.** -- your treatment, not at Treloar's probably, given

8 the time, but your subsequent treatment, and infected

9 with hepatitis C quite possibly as a result of your

10 treatment at Treloar's. I am going to ask you about

11 how you found out about each of those diagnoses, but

12 if we look first of all at a letter you've exhibited

13 to your witness statement it gives us some dates.

14 Soumik, it's WITN18000002.

15 **A.** Yes, I asked my current doctor, haematologist, to

16 prepare this for me. I found my notes so confusing

17 when I did look through them.

18 **Q.** WITN --

19 **A.** I'd need(?) it.

20 **Q.** Sorry, WITN18000002. I'm seeing zeros where there are

21 none.

22 **A.** Yeah, a letter dated 14 June 2018. That one?

23 **Q.** That's the one.

24 If we go to the next page, you're absolutely

25 right, it's a letter dated 14 June 2018, from

28

1 Dr Allsup, your consultant haematologist, and it says,  
2 if we go down:

3 "Following on from your last formal in the  
4 Haematology Clinic you asked for information about the  
5 dates of which you found to be infected with  
6 Hepatitis B, C and HIV and the date on which you were  
7 told of these infections.

8 "I accessed all your old medical records and  
9 reviewed the information in them. For Hepatitis B, the  
10 first positive test result is date 27th July 1990.

11 I can find no documentation in case notes stating  
12 whether or not you were informed of this result.

13 "For Hepatitis C, the date of the first positive  
14 test is 13 July 1990 and in the medical notes this is  
15 first commented on the 21 September 1993. Again there  
16 is nothing to determine whether or not you were informed  
17 of this test result around or earlier.

18 "For HIV the date of the first positive test  
19 result is 17 August 1989. There is an earlier test for  
20 HTLV-3 which is an historic name for HIV. There was a  
21 positive test result for HTLV-3 on the 2 July 1986.  
22 There was a comment in the records about this test being  
23 positive on 30 December 1985. Similar to the above two  
24 tests, there is no clear documentation as to what dates  
25 you were formally informed of these test results."

29

1 was, my dad said, "He's living at home with us, he's  
2 getting good food, he's living a good lifestyle, he's  
3 going to work, can we at least give him a period of  
4 time where he doesn't have to know?" And the doctor  
5 went along with that. And I think the reason he then  
6 had to tell me a couple of years later because, of  
7 course, we were getting money from the Macfarlane  
8 Trust, so I think he would have been in trouble over  
9 that if he hadn't told me. But also, I had to go to  
10 another centre for orthopedic treatment.

11 And whilst I didn't really blame my dad for  
12 trying to help me, and trying to protect me -- I mean,  
13 that's what parents do -- I was cross because I'd been  
14 in a lot of pain for six months, and I said to them,  
15 "Look, well, that's fine, but [they] should have told  
16 me when I told you that I needed to go to another  
17 centre, not just left me to struggle to work."

18 And I thought -- because my father was there,  
19 I didn't really say what I thought. Had I been on my  
20 own I'd have said to the doctor, "And that's your  
21 fault". But he was the particularly apathetic man.  
22 Ex-army. Because he dealt with things like leukaemia  
23 and that, I think he tended to think that, well,  
24 haemophiliacs don't have it so bad, they're all right  
25 most of the time. I (unclear). We got very low doses

31

1 Now I want to take these in turn, Nick.

2 **A.** Sure, yeah.

3 **Q.** And we'll start with the first in time, the HIV,  
4 HTLV-III results. And we see there reference to there  
5 being an HTLV-III test result in July '86 and  
6 a comment about positivity in December '85. And then  
7 an HIV test in August '89.

8 What's your recollection of how and when you  
9 learnt that you had been infected with HIV through  
10 your treatment?

11 **A.** Well, what actually happened was I went down for the  
12 test at the clinic. I think it would have been  
13 about 1985. And a week or so later I came home from  
14 work and my dad said that the hospital had rung, and  
15 that my test was negative. I thought, great.  
16 Two years later I needed to go to another hospital for  
17 treatment with my -- you know, because more problems  
18 with my knee. And I asked the doctor at the time,  
19 a Dr Montgomery, if he would write to them and raise  
20 this. And I got quite annoyed because he kept not  
21 doing it. So -- and then, I suddenly had a letter  
22 from him asking me to go down and see him the next  
23 day, and my dad said, "I'll take you", and went in --  
24 a bit -- I guess there had been a bit of a conspiracy.  
25 I had tested positive on the test, but what happened

30

1 of Factor VIII, nothing like the strength of doses that  
2 we would get -- I'd had at Treloar's, you know, and  
3 I tended to bleed longer. So it didn't really do me any  
4 good by limiting the Factor VIII. I was positive anyway  
5 for HIV, and my joints were worse. So I lost out both  
6 ways.

7 So -- yeah, I can understand why my dad wanted to  
8 protect me, and my mum. I mean, she was very, very  
9 upset by it all. We were hearing about it in the press  
10 and then we saw that the former pupil from Treloar had  
11 died, that we had both known some years earlier, and  
12 there was a particularly graphic picture on telly of him  
13 with sores all over his face. I think it was with all  
14 that in mind that my dad said, "Well, let's try and at  
15 least give him a bit of an extended holiday from it."

16 **Q.** You said in your statement you weren't sure when you  
17 were first informed of your HIV status but you thought  
18 it was after that second test result in 1989. Is that  
19 right or do you think it was earlier than that?

20 **A.** Let me think, yeah. Yeah, because I remember when  
21 I went down to see the doctor with my dad, the other  
22 thing was upsetting was, earlier that year, I'd got  
23 a promotion within the Civil Service and had started  
24 to work at the Land Registry, which had opened up in  
25 Hull. So I had all this suddenly crash on me just as

32



1 I was trying to learn a new job as well and was  
2 starting up on learning to drive. So I had all that  
3 drop on me. And I still had to go to another Centre  
4 to get orthopaedic treatment for my legs. So it was  
5 a no winner all round.

6 **Q.** In terms of your hepatitis C test result, if we go  
7 back to the first page of this letter, we see there,  
8 in the third paragraph, reference to a positive test  
9 on 13 July 1990 and then a comment on it in the  
10 medical notes in September 1993.

11 **A.** Yes.

12 **Q.** What's your recollection of how you learnt about  
13 hepatitis C?

14 **A.** Well, firstly, like every other haemophiliac who was  
15 already HIV positive, I was not informed of my  
16 hepatitis C statement until after what became known as  
17 the 1991 settlement where the Government settled out  
18 of court with us on an ex gratia payment, on ex gratia  
19 payment, in return for dropping the legal action at  
20 court. But they also concluded the waiver which said  
21 that "I agree not to take legal action in the future  
22 for any action regarding hepatitis viruses."

23 I remember at the time we were all absolutely  
24 furious, because we didn't know what was going to happen  
25 in the future. We were told we more or less had to sign

33

1 **A.** Yeah. I saw the claim form that they were putting in  
2 and I rang up to query it. I said, "You know,  
3 I didn't know about" -- and they said, "Well, it does  
4 say in your notes that you are hepatitis B positive".  
5 I said, "Oh, fair enough, then, just include it", but  
6 I don't know that within the group settlement we got  
7 anything for it. I mean, the settlements -- I have to  
8 have a think. I think -- I think the settlement --  
9 also, I'm thinking about the settlement with the drug  
10 companies a few years later. I don't know that there  
11 was an amount included for hepatitis B. If there was  
12 it would have been very little, because they gave us  
13 very little for the hepatitis C infection. I think  
14 the total award turned out at something like 21,000,  
15 22,000. And that was after more than ten years of  
16 fighting. And we were told it would be £200,000 and  
17 it would take a couple of years. It took 10 years and  
18 we got 20,000.

19 But as to how that was broken down, we were never  
20 told.

21 **Q.** I want to ask you -- sorry, we can take that down,  
22 Soumik -- about how your physical health then  
23 developed over the following years. You've said in  
24 your statement that for the first few --

25 **SIR BRIAN LANGSTAFF:** Were you going to deal with

35

1 it. If one person didn't sign it, nobody would get  
2 anything. So we signed it. And then it's obvious that  
3 they knew in 1990 I was positive, and the settlement was  
4 in 1991, and it shows there it was casually mentioned to  
5 me on that day, "And you know about this liver thing  
6 that you've got, the hepatitis C", and I think I said,  
7 "No". Yeah. And so we signed away our rights, our  
8 rights legally. And we were left with another  
9 potentially serious infection that we knew nothing  
10 about.

11 I mean, it might have been, for example, what they  
12 said to me out of clinic is, "We recommend that you  
13 don't drink any alcohol". Surely that could have been  
14 just as relevant then as it is now. So, you know -- and  
15 we were also told that there was a 5 per cent chance of  
16 sexual transmission. I mean, this is -- all comes down,  
17 again, to the non-intentional infection of partners. So  
18 what the hell were they playing at? They were playing  
19 roulette with our lives -- not just our lives but any  
20 sexual partners.

21 **Q.** And in relation to hepatitis B you've said in your  
22 statement that the first you learnt of a hepatitis B  
23 positive result was when you were involved in a class  
24 litigation against an American pharmaceutical company  
25 in 2003 and you saw your medical records?

34

1 hepatitis B?

2 **MS RICHARDS:** Hepatitis B? Yes, I just did, sir.

3 **SIR BRIAN LANGSTAFF:** I thought that was hepatitis C.  
4 That was hepatitis B, sorry.

5 **MS RICHARDS:** No, it was the hepatitis B. Oh -- the  
6 question was in relation to hepatitis B.

7 **SIR BRIAN LANGSTAFF:** Thank you.

8 **MS RICHARDS:** And in relation to hepatitis B, as you said,  
9 Nick, you were just told casually, "You've got this  
10 liver thing"?

11 **A.** Yeah, yeah.

12 **SIR BRIAN LANGSTAFF:** And the record suggests that the  
13 first mention in the medical notes was in July 1990,  
14 which -- there's no mention at any stage of the  
15 significance of the antibody positive tests taken at  
16 Treloar's.

17 **MS RICHARDS:** No. Not as far as --

18 **A.** No, and they were positive back then, so I don't quite  
19 know what's happened there. But I can only assume  
20 that he didn't have access to my Treloar notes.  
21 I think that's probably why, in fairness to him.  
22 Because obviously my Treloar notes were separate. And  
23 when I needed to pop in my Treloar notes for the  
24 American litigation, I rang up the school and they  
25 still had them and they sent me a copy. But when

36

1 I needed them now for the Inquiry, I rang up, and  
 2 I was told a bit officiously, "Oh, we wouldn't keep  
 3 that sort of thing here. That's part of the NHS".  
 4 And the Centre was very different -- not connected to  
 5 the school and all this. And said -- and I said,  
 6 "Well, I've rung you before, all right, some years  
 7 ago, and you had them all on site then", and she said,  
 8 "I've spoken to the supervisor about this, who said we  
 9 definitely don't have them". So I just said, "Thank  
 10 you very much", and ended the call.  
 11 But then I've been sent them anyway so it was just  
 12 a matter, really, of not knowing where they had been  
 13 sent to.

14 **SIR BRIAN LANGSTAFF:** Thank you.

15 **MS RICHARDS:** So you'd talked in terms of your physical  
 16 health, of everything -- and this is from your  
 17 statement -- being fine for the first few years and  
 18 you began to hope that that would remain the case.

19 **A.** Yeah, yeah.

20 **Q.** But then you began to experience night sweats and then  
 21 infections in mouth, tongue, and throat.

22 **A.** Yeah, yeah. And I knew when I got the -- started  
 23 getting the night sweats because they'd been asking me  
 24 regularly at the clinic, "Have you had any night  
 25 sweats?" I was saying, "No, no, no, no".

37

1 **Q.** You've explained in your statement that by 1996 your  
 2 overall health was severely compromised, leading to --

3 **A.** Yes.

4 **Q.** -- you having to give up what you describe as your  
 5 dream job in 1997.

6 **A.** Yeah. Both my knees had declined very badly by this  
 7 point. My left knee, which had been bad since the age  
 8 of ten, that was fixed and painful and my right leg,  
 9 which had always been very strong, I think it was in  
 10 terrible shape. In fact, I had them both replaced and  
 11 the right one I had done first because it was more  
 12 painful, and they said it was three-quarters gone.  
 13 And it was the most excruciating thing that I've ever  
 14 been through, and that's saying a lot.

15 And then I developed a huge lump on the side of my  
 16 knee, which I had for two years. I think what happened  
 17 was the drain got blocked -- they put a drain in --  
 18 I suspect that the drain got blocked and all the blood  
 19 just builds up. I don't know why otherwise it would  
 20 just go like that. So I had that for two years. Then  
 21 I had my -- the infection cellulitis, and I think I said  
 22 to the doctor "Well, I'm not going to lose my leg,  
 23 am I?" and he said, "Well, I don't know yet". That  
 24 shook we a bit.

25 Then I had the left knee done a few months later

39

1 I thought: what are you talking about? And then they  
 2 started happening. And it was two or three times  
 3 a night. And I was scared. I didn't tell my mum and  
 4 dad. I didn't want them to be changing sheets every  
 5 night and my mum worrying, so I just put up with it.

6 And then I think my first -- actually an infection  
 7 was candida thrush in the mouth. I thought: I mean  
 8 I sweat a lot, have I got rabies? You know, sort of  
 9 thing.

10 So I went along to the Haemophilia Centre, they  
 11 said it was thrush, and they just gave me some drops to  
 12 put in my mouth. But that was very, you know, quite  
 13 a long process of no tablet given, and got it -- you  
 14 know, it was quite unpleasant.

15 **Q.** And you developed sores over your face at one point?

16 **A.** Herpes, facial herpes, yeah. Yeah, I had that. But  
 17 we think that that might have been down to one of the  
 18 drugs I was given, because I was taken off of them  
 19 when that happened, because I also -- they also tested  
 20 my haemoglobin and my haemoglobin was very low.  
 21 I remember I was -- my chest was hurting and I found  
 22 it very hard to move around, I told them -- so I had  
 23 red cells for that, I think. And I had treatment  
 24 there, which -- I was in for two weeks. They tret one  
 25 and then the other.

38

1 and they said it was quite a difficult operation. There  
 2 was very little room to get it in and it took me a very  
 3 long time to get mobile. I did all the physio and that,  
 4 and that was excruciating. But, by that time, my HIV  
 5 symptoms were getting worse. I just felt poorly in  
 6 myself, I didn't really know why. I went back to work  
 7 and, after about a month, the welfare officer came up to  
 8 me and said "Look", she said, "you're going downhill by  
 9 the day, what's wrong? We can all see the weight is  
 10 almost dropping off you on a weekly basis". And I just  
 11 said "Well, just give me a bit of time", I said, "I'm  
 12 sure everything will be all right".

13 Then about a week later, a union official came up  
 14 to me in the corridor and said, "Nick, I'd better tell  
 15 you this", he said, "they're looking to start taking  
 16 disciplinary action against you because of your sick  
 17 leave record". I said, "Thanks very much for telling  
 18 me". So I just went home and sat and typed out a letter  
 19 and applied for early retirement on medical grounds and  
 20 took it -- and I took it -- took the letter in, and  
 21 I didn't go back to work.

22 **Q.** You said in your statement that, up until this point  
 23 in time, I think your HIV care had been delivered  
 24 through your Haemophilia Centre. But your family  
 25 became so concerned about your physical condition that

40

1 your brother called the hospital and demanded that you  
2 see an AIDS specialist --

3 **A.** Yes.

4 **Q.** -- and it was only then that you were given  
5 anti-retroviral treatment for the first time?

6 **A.** Yes, and I found out it had been available for  
7 two years. I mean, previously all they'd given me at  
8 the Haemophilia Centre was this tablet that supposedly  
9 would give me some protection against pneumocystis,  
10 which is an infection of the lungs, which was a very  
11 common infection for HIV, probably one of the first  
12 major ones, and people were dying of it. So I was  
13 taking a great big chalk-like tablet each day. But  
14 then, when, as I say, I deteriorated suddenly, and my  
15 brother said to me, he said, "We thought you'd had  
16 a stroke", I was acting very strangely. I was very,  
17 very weak. I could hardly move.

18 We got to the AIDS clinic, and the doctor said,  
19 "Oh you've come just in time", he said, "Your CD4 count  
20 is 17 and your viral load was god knows how many  
21 thousands".

22 But I'd already spoken to the haematology doctor  
23 and he said, "Well, we only send you there if you have  
24 an infection we can't handle". So I made a formal  
25 complaint against him. I mean, it could have cost me my

41

1 been taking it for a while I felt tired all the time and  
2 then I got really, really depressed. I were just sat  
3 there in floods of tears, and I went along for my next  
4 appointment and I saw Dr Shields who had just started,  
5 taking over from Dr Montgomery, and he said, "You've got  
6 chronic clinical depression, and it's the interferon  
7 that's causing it".

8 So he started me on anti-depressants and  
9 I improved, but I didn't clear the virus. And a couple  
10 of years later, he said, "We'd like to try again", and  
11 put me on anti-depressants again and went thorough a  
12 separate course of treatments. I was lucky it cleared.  
13 I was a bit surprised but, yeah, it cleared. So  
14 obviously nobody knows what long term damage had been  
15 done from infection.

16 **Q.** Do you continue to have your liver monitored?

17 **A.** Yes, I do. In fact, I haven't been well lately, and  
18 I spent a few days in hospital with this lymphedema  
19 that I got, and cellulitis, and they did a load of  
20 tests then, and one doctor said to me, "Oh, it's  
21 because of your hepatitis C, it's damaged -- you've  
22 got liver damage and that affects the proteins that  
23 were produced, that, you know, your lymphatic system  
24 needs".

25 And I thought, well, I was a bit surprised because

43

1 life, and the reply that the hospital gave me was that  
2 they interviewed Dr Raper and they claim that I said  
3 that because I had a rough time during the course of  
4 hepatitis C treatment, that I didn't want anything for  
5 HIV. Well, that was plainly ridiculous. And, even if  
6 I had said that at the time, why didn't you say, "Well,  
7 look, I think you really ought to consider it?" He told  
8 me that I was at the point where I could be getting  
9 serious infections but he didn't suggest again that  
10 I ought to consider treatment or see the specialist.

11 And, you know, his reply was that I'd turned it  
12 down because I had a bad time with hepatitis C  
13 treatment. I could have been on treatment for  
14 two years. I was absolutely furious. He just got away  
15 with it.

16 **Q.** In terms of the treatment for hepatitis C, you  
17 underwent treatment with interferon and ribavirin.

18 **A.** Twice, yes.

19 **Q.** What were you told by the consultant in advance were  
20 the likely side effects of that treatment?

21 **A.** Well, that was Dr Montgomery, "Now don't be silly, it  
22 only lasts for a few days". Sorry, that's how he  
23 spoke. We always mimic it.

24 No, he just said, you know, basically you might  
25 feel rough for a few days, but that's it. But after I'd

42

1 my latest scan which was only a few months earlier, they  
2 said everything was fine and, in fact, my scores for  
3 fibrosis had actually gone down a bit and all my blood  
4 tests were fine. So I thought that's a little bit  
5 strange. And then when I spoke to another doctor, he  
6 said, "Well, you've shielded a year, and then there's  
7 everything else you've been through that year", he said,  
8 "probably stress, and the fact that you were sheltering,  
9 so you've just had astronomical bad luck".

10 And I'm waiting for more tests to be done at the  
11 moment and I'm waiting for an urgent cancer biopsy that  
12 was supposed to have been done within a fortnight, and  
13 that's a month ago now. So, yeah, I've -- it seems, if  
14 they're right, that the hepatitis C has now led to  
15 severe lymphedema. So I can't walk -- go outside the  
16 house. I can't wear shoes and socks. It's very  
17 painful. So I've swapped the pain of a bleed, once  
18 a week, for this. Yeah.

19 **Q.** Nick, were you ever offered counselling or  
20 psychological support over the decades?

21 **A.** No. A friend did come forward recently, because he'd  
22 heard about things that happened to me from March last  
23 year, and he said, "Well, I'm working for the Terrence  
24 Higgins Trust", he said "They're very good". Well, he  
25 just talked, and I had a chat with a trauma

44

1 counsellor, a very nice lady. And I just said, you  
2 know, I said, "I've heard of people having counselling  
3 for, you know, I don't know, a terrorist attack or  
4 a car crash or something, but one serious event", but  
5 I said "really how are you meant to cope when it's one  
6 serious event after another".

7 And she said to me, after having gone through  
8 everything that has happened, she said, "You cannot go  
9 through a life like that without being very severely  
10 traumatised".

11 Yeah, she has helped a little bit, the problem is,  
12 with all these things, it's time. Last year was  
13 particularly hard. I went on holiday to Cape Verde with  
14 my friend [redacted], who was also my support worker.  
15 He had what we thought was a bit of a cold. We flew out  
16 there and, after a few days, he started to go downhill.  
17 And, of course, the pandemic was, if you like, crashing  
18 down all over the world. We took him to get medical  
19 attention two days before we came home. He was taken  
20 into hospital and I was isolating in my bedroom, hotel  
21 room, for four days. I tested positive for Covid,  
22 he did, but when I was reunited with [redacted], he was  
23 just laid on a bed, hooked up to oxygen, couldn't walk.  
24 And I think I was there two days and I think he just --  
25 they said he was stable and should get better, and then

45

1 position that we're in.

2 **Q.** Nick, I'm just going to ask you next a little about  
3 your experience of the financial support or financial  
4 assistance trust and schemes. You've explained in  
5 your statement you received grants from the Macfarlane  
6 Trust from time to time --

7 **A.** Yeah.

8 **Q.** -- and then you've talked in your statement more  
9 generally about the Trust and schemes not always being  
10 helpful or approachable. What was your general  
11 experience of interaction with them?

12 **A.** Well, when the Macfarlane Trust was set up and we'd  
13 had the initial £20,000, all the haemophiliacs had  
14 £20,000, and they'd set up this nice charity, made us  
15 charity cases, and I think the payments were something  
16 like £80 a month in the day, when it all started but  
17 you could apply for grants. I mean, the first thing  
18 I applied for was a really nice armchair for my joints  
19 and everything, and it was turned down because  
20 I didn't have any AIDS symptoms.

21 So I didn't apply for any more for quite a long  
22 time, but then, as time went on, I heard of other  
23 people getting grants and thought, "This is wrong",  
24 and I started to apply for things, driving lessons,  
25 Motability car deposit. It wasn't too bad. It was

47

1 one night he just suddenly died. And it was during  
2 a power blackout. And then I said, "Are you  
3 repatriating him?" He -- they buried -- they buried  
4 him. Straightaway.

5 So I was there another five days, I had the  
6 Haemophilia Centre help. I had contacted my local MP,  
7 who contacted the local officials at the Foreign Office,  
8 and I was given priority on the air ambulance. So it  
9 started on the Monday, with them and the help of my  
10 lovely brother, Philip, and his wife Jackie, I was back  
11 home on Friday, the 29th. [Redacted] died on the  
12 [redacted], which was when lock-up started here. The  
13 last thing he said to me was, "Don't worry, we'll get  
14 through this together, Nick, we'll rebuild our lives".  
15 And I thought "Oh, he'll be fine in a few days". He was  
16 so positive. And then he just went. So it was pretty  
17 horrendous.

18 And then, of course, it was straight into  
19 shielding. And I think that's partly what has led me to  
20 this point. So it's been pretty tough.

21 I mean, we're known to be self-reliant and tough,  
22 and resilient, but we shouldn't have to be. You  
23 shouldn't have to survive in life. You should be able  
24 to thrive in life. That's what we've lost. But, of  
25 course, too many have lost their lives. But that's the

46

1 a bit of a faff filling out the forms and having to  
2 get the receipts, I thought fair enough.

3 But it was always a bit vague what they would  
4 and wouldn't pay for. And I had a bit of -- it paid  
5 one year for me to have a course of complementary  
6 therapy, £200. And I asked the following year for the  
7 same, "What is this complementary therapy? We know  
8 nothing about it". And all this. And I tried to  
9 explain. I also mentioned that, you know, I was due  
10 my next Motability car and would I still be able to  
11 get £1,000 towards a deposit. And the lady I was  
12 speaking to, she didn't speak very good English, I'm  
13 afraid to say I got a bit ratty. I said, "I just  
14 can't cope with this, it's ridiculous", I said "Forget  
15 it", put the phone down, went out. When I came back,  
16 my mum said, "Oh, a lady has just rung me up and said,  
17 "Your son has been very rude to one of our staff".  
18 I said, "What?" They had actually rung my mother up  
19 and spoken to her as if I was at school, which  
20 I thought was ridiculous.

21 Anyway, I'd explained then, put the application  
22 in, and I'd got the money, got the grant. But, you  
23 know, what a battle it was at times. You know,  
24 I applied for some new double glazing and also the cost  
25 of redecorating a room that hadn't been done in many

48

1 years. And they sent the money for the double glazing  
2 and I wrote back and said, "Could you please tell me  
3 what you are including for decorating?" And I got  
4 rather a short reply saying "We paid you your middle  
5 quote on the -- on your new windows, that should be  
6 enough".

7 And, you know, it was always like that. It just  
8 wasn't really a pleasant experience. Some of it was  
9 routine, but it wasn't particularly pleasant, sometimes.

10 **Q.** You've made this general observation in your  
11 statement, Nick. You say this:

12 "I feel that we've been made to fight for every  
13 penny for a period of 30 years ..."

14 **A.** Yes.

15 **Q.** "... whilst at the same time we've watched people die  
16 without receiving any support at all."

17 **A.** Exactly right.

18 **Q.** You've talked in your statement about the involvement  
19 in campaigning. I think in contrast with -- in the  
20 early years after you were infected, when you decided  
21 to sort of carry on and keep things within the family,  
22 and so on and --

23 **A.** -- hard shell --

24 **Q.** -- and not get involved in --

25 **A.** -- shuttered down, yeah.

49

1 society as if we were evil.

2 **Q.** Then in more recent years, you have become involved in  
3 campaigning. You told us in your statement that you  
4 had meetings with governments, with trusts, with MPs,  
5 and you've also tried to put questions and obtain  
6 answers from Government. Is that a fair summary?

7 **A.** Yeah, yeah. As I say, I started getting involved,  
8 I think, about 15 years ago. It was when Tainted  
9 Blood, I think, first started up, and also I went to a  
10 meeting in the Lake District to discuss the American  
11 litigation, and that's when that started. So, yeah,  
12 it's all come from that. I mean, I can't remember the  
13 number of times I've gone down to London or Manchester  
14 or Leeds and everyone is so sorry that all this  
15 happened, "We want to do the right thing and we're  
16 searching for a solution", Anne Milton said, you know.  
17 And then when she retired and Anna Soubry took over  
18 Anne Milton, "Why have these schemes not been reformed  
19 yet? Outrageous". Well, she didn't. It's just been  
20 like that. It's all been pass the parcel, it's been  
21 30 years of pass the parcel.

22 And we only got the Inquiry because, of course,  
23 Theresa May messed up her election campaign and ended up  
24 with a minority government, because she'd refused us one  
25 before, as had every other Prime Minister. So it was

51

1 **Q.** I'm sorry, I talked across you.

2 **A.** Yes. Yeah. It made us think, shell down, nobody  
3 outside the family knew. But we heard horrific  
4 stories over the years of people who had started  
5 campaigning. They had their cars vandalised with  
6 "AIDS" written on it, they had it daubed on their  
7 house doors, their windows, they were jeered at in the  
8 street. One woman came back from burying her husband  
9 to find "AIDS lives here" scrawled all over the front  
10 of the house and things like that.

11 I've heard stories of one man having to be rescued  
12 from his own home by his GP and the police because  
13 people had formed a barrier outside and wanted him out.  
14 And then you've already heard about what happened to the  
15 boys that were actually at Treloar at the time, that  
16 there were journalists hanging round. You couldn't even  
17 just go down to the village shop and get some sweets  
18 without a journalist following them and asking for  
19 an interview. Outrageous. And it wasn't out of  
20 concern, it was sensationalism in the press. They were  
21 calling us things like "ticking time bombs". Just  
22 awful.

23 We were just people who had been given  
24 a treatment, that was supposed to enhance our lives, it  
25 was killing us and we were being tret by the media and

50

1 a political error on her behalf, that got us here.

2 I also think the fact that it was -- Grenfell Tower  
3 happened almost at exactly the same time that we were  
4 asking, she felt she couldn't do one without the other.

5 Again, it's been a very long and hard campaign.  
6 I mean, I can remember going down to London once a few  
7 years ago and we hired a hearse with a coffin in it.  
8 And we had a message for the Treloar boys on the side,  
9 and on the back we had a picture of a young boy, Colin,  
10 who died, I think, aged seven or something, he was our  
11 poster boy. And we had this going all round London, and  
12 it stopped, and we did press interviews, walked behind  
13 it for a few hundred yards, I remember all that, went  
14 down to Witney, where David Cameron was Prime Minister  
15 and protested outside his office.

16 We walked through Central London with banners. It  
17 has been endless. We met with a Government facilitator,  
18 I think, six years ago, and he was going to report what  
19 we wanted, and then we never really -- I don't think we  
20 heard another thing about it. So it's been a really  
21 tough fight. And every increase that we've got, I think  
22 we've had to scratch it out of the Government, scratch  
23 it out of their eyes almost.

24 **Q.** Nick, the last thing I was just going to ask you about  
25 is this, I've already asked you if you want to tell us

52

1 about something. There was a photo, I think, in The  
 2 Sunday Times recently which I think was a photo --  
 3 **A.** Oh, yes.  
 4 **Q.** -- of yours?  
 5 **A.** Yes, my photo.  
 6 **Q.** I'm hoping we've got it, to put up on screen.  
 7 RLIT0000664, Soumik. It may have been sent in  
 8 the course of Nick's evidence.  
 9 And if we go to the next page, it should be the  
 10 next one. There we are.  
 11 **A.** Yes, that's it.  
 12 **Q.** If we zoom in on the photo.  
 13 **A.** Yes, it's a very, very powerful photo. It was  
 14 taken -- we went on a school trip to Canada, as  
 15 I think I mentioned. And for the weekend, a local  
 16 family who had two sons with haemophilia invited the  
 17 five of us who had haemophilia to join them on their  
 18 annual holiday. They had a cabin by Lake Ontario in  
 19 the forest, and it was nice, and we spent the weekend  
 20 with them. That photo was actually taken on my 16th  
 21 birthday. So it's very powerful and, as you can see,  
 22 I'm the only one left. And the fact that what we were  
 23 looking at yesterday is particularly poignant.  
 24 The boy in the middle, [redacted], he was one of  
 25 my best friends down there and his birthday was

53

1 **A.** It speaks for itself. I mean, a picture paints  
 2 a thousand words, doesn't it? But that is probably  
 3 one of the most poignant photos that I'll ever see,  
 4 I think. I didn't look particularly -- I just found  
 5 it one day and I suddenly realised, God, I'm the only  
 6 one left. It shocked me. And that's when I first  
 7 started to use it for, you know, to put faces to  
 8 people who were no longer here.  
 9 **Q.** Thank you for sharing it with us, Nick. We'll take it  
 10 down. I want to check the transcript is up and  
 11 running again, I think it probably is.  
 12 Nick, if you just wait there for a moment, I'm  
 13 going to turn to Mr Snowden who represents you and see  
 14 if there is anything further --  
 15 **SIR BRIAN LANGSTAFF:** It is active.  
 16 **MS RICHARDS:** -- it is -- that he would wish me to ask  
 17 you. No.  
 18 Sir Brian, do you have any questions for Nick  
 19 before I ask him if he has anything he would like to --  
 20 Questions from SIR BRIAN LANGSTAFF  
 21 **SIR BRIAN LANGSTAFF:** No, I don't.  
 22 I have one question for you, actually. Nick may  
 23 be able to comment, I don't know.  
 24 Can we go back to TREL0000221\_018.  
 25 This really arises out of two things in Nick's

55

1 [redacted]. He was exactly a week older than me.  
 2 We went right the way through school together. He  
 3 was, I think, one of the first people I spoke to. I saw  
 4 him upset, he had his arm in a sling, "I don't know  
 5 where we were supposed to go and get treatment here".  
 6 So I went with him to find out and chatted. And he was  
 7 from Lewisham. And his mum was widowed. He, like me,  
 8 had a brother who was four years older. So we had quite  
 9 a lot in common. And I found out, I think it was from  
 10 Caroline Windsor, I asked if she could find out for me,  
 11 he died at the age of 32.  
 12 [Redacted].  
 13 **Q.** Sorry, I'm just going to --  
 14 **A.** -- and he was -- (overspeaking) --  
 15 **MS RICHARDS:** -- sorry --  
 16 **SIR BRIAN LANGSTAFF:** Nick, can you just pause for a  
 17 moment.  
 18 **MS RICHARDS:** -- can I just stop you for a moment? Can we  
 19 just stop the transcript.  
 20 Nick, I'm just conscious that you're potentially  
 21 sharing information about people --  
 22 **A.** I'm not naming anybody.  
 23 **Q.** No, I know, but we have the photo so --  
 24 **A.** Oh, fair enough, yeah.  
 25 **Q.** -- if you don't mind.

54

1 evidence. One is his recollection of the nurse  
 2 saying -- or the headmaster saying, "Don't worry about  
 3 all the hepatitis you've got because there are two  
 4 types, one is fatal and serious, the other is not fatal  
 5 and mild, and you've got the mild one."  
 6 **A.** Yeah.  
 7 **SIR BRIAN LANGSTAFF:** There is only room in this form for  
 8 one form of hepatitis, because it has -- we had an  
 9 antibody and antigen test at the time, and there was  
 10 no antigen and antibody test for non-A, non-B at any  
 11 time during the 1970s.  
 12 **A.** Never heard of it.  
 13 **SIR BRIAN LANGSTAFF:** So this has to relate to  
 14 hepatitis B?  
 15 **A.** Yes.  
 16 **SIR BRIAN LANGSTAFF:** Is there any other form which might  
 17 value recorded any symptoms similar to this of which  
 18 the Inquiry is aware which relate to non-A, non-B?  
 19 **MS RICHARDS:** Sir, the only documents that we've seen in  
 20 the records that would be relating to that potentially  
 21 are the ongoing liver function tests in their various  
 22 manifestations. There is nothing that expressly  
 23 refers in any of Nick's records from Treloar's to  
 24 non-A, non-B hepatitis.  
 25 **SIR BRIAN LANGSTAFF:** So as far as we know there was no

56

1 systematic record of whether pupils might be suffering  
 2 in the same way as there was for hepatitis B?  
 3 **MS RICHARDS:** Nothing that we've seen. There are other,  
 4 similar documents, slightly different format, but  
 5 talking about serum hepatitis, but again, they're  
 6 divided into the antibody and antigen testing and are  
 7 clearly related to hepatitis B.  
 8 **SIR BRIAN LANGSTAFF:** Yes, thank you very much.  
 9 That's all that I wanted to ask, Nick. And  
 10 you'll understand, I think, why I ask it. Because of  
 11 your very clear recollection.  
 12 **MS RICHARDS:** Nick, is there anything that you would like  
 13 to say?  
 14 **A.** Yeah, I'd just like to say a few words about Treloar.  
 15 There were many positive things about it. I mean, we  
 16 got the education that we wouldn't have got. We got  
 17 the treatment we wouldn't have got. We got the  
 18 opportunities to do things which I'd never have been  
 19 able to do at home. But when I joined, in 1974, it  
 20 was, you know, a very harsh, if you like, regime. It  
 21 wasn't very personal. You know, away from home  
 22 66 per cent of the year. It was a bit draconian,  
 23 surnames used only. All of us hated that. It was  
 24 cold, institutional, no warmth. Our house masters  
 25 tended to be ex-military and only a few years away

57

1 next term and decided to have a chat with the  
 2 housemaster but the housemaster was very embarrassed  
 3 that he didn't know about it. And he moaned at me for  
 4 the rest of term and told everybody else. And  
 5 I thought: well, why didn't you pick up the phone and  
 6 say, "I'm sorry that your son who is in my care has had  
 7 a serious injury and that I will sufficiently punish the  
 8 boy"? I mean, nothing was said. He was given a 50p  
 9 fine and went off and I saw him laughing the next day.  
 10 I mean, that's taught him nothing. It's cost a massive  
 11 amount of Factor VIII. And I would think that bullying  
 12 and fighting must have consumed an awful lot of  
 13 Factor VIII. I mean, the headmaster said we banned  
 14 football in 1978. I remember that happening. And I had  
 15 a conversation with my housemaster, where I was trying  
 16 to say to him, you know, "It's like using  
 17 a sledge-hammer to crack a walnut". They were doing  
 18 things -- they would want to do things like send us to  
 19 bed after supper if we had a bleed. If we had a slight  
 20 elbow bleed we had to go to bed at half past seven as if  
 21 we were punished. I had a big row with him about that,  
 22 I said, "You're just not tackling the right things."  
 23 As regards what I'd like to actually say, I mean,  
 24 the -- yeah, the story of Treloar's and the grim deaths  
 25 of 70 plus former students who were killed by

59

1 from retirement and I just don't think they could  
 2 really cope or knew how to tackle issues like  
 3 bullying.  
 4 And this is relevant because the serious  
 5 incident of bullying that I both endured and witnessed  
 6 were serious, and would have used a massive amount of  
 7 Factor VIII. I won't name -- I mean, one boy,  
 8 labelled gay, he ran away and never came back. And  
 9 the housemaster was like, "Oh, he ran away and went  
 10 home all on his own", and I said, "Good for him, sir",  
 11 and walked on. But there was nothing ever said that,  
 12 "We're so sorry that the pupil has gone through this."  
 13 Another example, I was attacked from behind once.  
 14 My glasses were punched right through my ear. So you  
 15 can imagine the amount of Factor VIII needed for that.  
 16 The boy concerned got a 50p fine. But I've always  
 17 thought, shouldn't me parents have been notified? And  
 18 the boy's parents? Things like that.  
 19 I mean, I can give more examples. I mean, they  
 20 talked about consent. They talked about communicating.  
 21 There was just nothing. I mean, I was particularly  
 22 embarrassed -- I didn't tell my mum and dad because by  
 23 the time you get home from boarding school, it's another  
 24 world. You want to put it behind you.  
 25 And unfortunately my dad accompanied me back the

58

1 contaminated Factor VIII, which was intended to enhance  
 2 their lives, it's a tragedy within the tragedy that  
 3 contaminated blood scandal in this country.  
 4 The lives of those who died is commemorated in  
 5 a beautifully designed stained glass window within  
 6 a chapel at the school. And those of us who have  
 7 survived continue our campaigns for truth and justice.  
 8 Our story has featured in the Sunday Express, The Mail  
 9 on Sunday, the BBC, Sky, and our efforts continue on  
 10 this story, along with all the other many aspects of the  
 11 disaster.  
 12 I do wish to make clear that none of us apportion  
 13 any blame to the medical staff at the school, who were  
 14 always supportive and made every effort to look after us  
 15 all. We believe that Treloar was singled out for  
 16 non-consensual trials for previously untested  
 17 Factor VIII concentrate, without parental consent, and  
 18 really without our consent, and we look to you, the  
 19 Inquiry team, to uncover the truth of what happened. We  
 20 hope that we get not only answers to those questions but  
 21 the answers to all of the many, many issues that have  
 22 been raised by the contaminated blood scandal. We have  
 23 already waited 30 years and far too many have died,  
 24 their time has run out. Justice delayed is justice  
 25 denied.

60

1 When talking about the effects of the contaminated  
2 blood tragedy, it's only natural to focus on our  
3 families and friends, countless others who had their  
4 lives blighted. I must pay tribute to all of them.

5 One was a haemophilia nurse at the Lord Mayor  
6 Treloar College at Alton in Hampshire who helped look  
7 after approximately 19 haemophilia boys including  
8 myself. She had compassion and care in her work,  
9 infusing and caring for us when we had a bleed, in her  
10 patients when training us when we self-infused  
11 Factor VIII and looked after ourselves more  
12 independently. Won a special place in all our hearts.  
13 I was therefore saddened to hear, some years ago, that,  
14 following her much deserved retirement, she was  
15 reluctant to accept visits from her former boys because  
16 she felt a terrible weight of guilt for injecting us  
17 with contaminated Factor VIII.

18 None of us blamed her or any of the other medical  
19 team at Treloar's. We all loved her. And I was  
20 relieved to hear from another Treloar boy who had  
21 managed to visit her a few times before her death and  
22 put her mind at rest.

23 I have never been offered any counselling or  
24 psychological support. I believe I would have found it  
25 useful to have somebody independent to talk to in the

61

1 all the doctors and nurses who looked after me, the  
2 physiotherapist at Treloar who got me walking again, the  
3 speech therapist who helped me to learn to talk after my  
4 cleft palate operation. I had no upper teeth.

5 And finally I'd like to thank you, Sir Brian, you  
6 and your Inquiry team, your dedication, hard work, and  
7 compassion, which is far more infinite than the  
8 compassion that has been shown to many of the people who  
9 have been supposed to have looked after us over the  
10 years. Thank you very much.

11 **SIR BRIAN LANGSTAFF:** Well, thank you, Nick.

12 [Applause]

13 Did you hear that? A round of applause for you.

14 **A.** Oh I didn't actually, sorry. [Laughs]

15 **SIR BRIAN LANGSTAFF:** I wondered if you'd heard it.

16 **A.** No. Never mind.

17 **SIR BRIAN LANGSTAFF:** It follows from your description,  
18 which none of us, I think, will forget, and many of us  
19 would have thought, perhaps, of the Treloar's story as  
20 a tragedy within a tragedy, and you've given it  
21 colour. But particularly, can I just thank you for  
22 giving us your evidence when you have told us, reading  
23 between the lines of what you've said, that you are  
24 unwell, when today by chance is the day when Andy  
25 would have had his birthday, and he's obviously

63

1 early days, when I feared for my life.

2 I sought my own support in many ways. I joined  
3 the local Body Positive group. I am now at a point in  
4 my life where I've lived with this for so long, I've  
5 lived through so much, that I feel I have enough support  
6 in my brother and the people I talk to online and on  
7 social media. Although I did lose my best friend Andy  
8 last year and the loss of his support has been  
9 devastating.

10 If I can -- just have a thank you to do. I'd like  
11 to dedicate my evidence to my late parents, Mollie and  
12 Brian, who have travelled so much of this terrible  
13 journey with me with nothing other than unconditional  
14 love and support. I would also like to dedicate to the  
15 boys at the Lord Mayor Treloar College who were infected  
16 as young men and who, by the time they left school, had  
17 unknowingly lived half their natural lifespan due to  
18 this dreadful catastrophe.

19 Out of 89 haemophilia boys who attended the  
20 school, I am one of only 16 left. This story is as much  
21 theirs as it is mine.

22 I would just like to end by thanking my brother,  
23 Philip, and Jackie, for their support, since our mum  
24 died, particularly the last year, in getting me home  
25 from Cape Verde and looking after me. I'd like to thank

62

1 a very, very sad loss. And these things make it  
2 particularly difficult, I have no doubt, to give  
3 evidence. So thank you very much indeed for that.

4 **A.** Thank you.

5 **MS RICHARDS:** Sir, if we take a break now, and then, if we  
6 might trespass on people's lunchtime with the next  
7 witness, if possible, I would like to finish his  
8 evidence in one go, which might mean a late lunch, and  
9 then we can have the afternoon for our third witness  
10 who yesterday we erroneously identified as anonymous  
11 but is in fact Mr Gary Bennett. It's Mr John Peach  
12 next, then Mr Gary Bennett.

13 **SIR BRIAN LANGSTAFF:** Yes, we won't squeeze the coffee  
14 break any more than we need to. So it'll be five past  
15 12 we'll start, and I suspect that we may anticipate  
16 lunch probably around about 1.30 or thereabouts. But  
17 we'll see how it goes.

18 **MS RICHARDS:** Something like that. We'll take as much  
19 time as we need.

20 **SIR BRIAN LANGSTAFF:** Well, obviously. We won't rush his  
21 evidence.

22 Very well. Five past 12.

23 (11.38 am)

(A short break)

24  
25 (12.04 pm)

64



1 **SIR BRIAN LANGSTAFF:** It's John, isn't it?  
 2 **THE WITNESS:** It is, yeah.  
 3 **SIR BRIAN LANGSTAFF:** That's how you'd like to be called,  
 4 is it?  
 5 **THE WITNESS:** Yes, please, yeah.  
 6 **SIR BRIAN LANGSTAFF:** Mary will ask you to take the oath,  
 7 please, John.  
 8 **JOHN DAVID PEACH (sworn)**  
 9 **Questions by MS RICHARDS**  
 10 **MS RICHARDS:** John, I'm going to ask you some questions  
 11 about your sons, Leigh and Jason Peach.  
 12 **A.** Yes.  
 13 **Q.** They were both born with haemophilia A?  
 14 **A.** Yes, they were yes.  
 15 **Q.** Leigh was born in 1966 and Jason in 1969?  
 16 **A.** Correct.  
 17 **Q.** They were under the care, to start with, of the Oxford  
 18 Haemophilia Centre?  
 19 **A.** That's right.  
 20 **Q.** Can you recall which doctors you used to see there  
 21 generally when they were boys?  
 22 **A.** Mainly Dr Rizza and Dr Matthews.  
 23 **Q.** Your statement recalls them receiving cryoprecipitate  
 24 in hospital there?  
 25 **A.** Yes, they did, yeah.

65

1 **Q.** But there then came a point in time at which they had  
 2 home treatment with concentrates?  
 3 **A.** They did, yes.  
 4 **Q.** Your late wife, the boys' mother, would administer  
 5 that treatment at home?  
 6 **A.** Yes, she did, yes.  
 7 **Q.** Am I right in thinking that was, as far as you can  
 8 recall, NHS concentrates, Lister, you knew it as?  
 9 **A.** Yeah. The Lister product, yeah. Even when it was  
 10 freeze-dried, it's still got "Lister" on it. Yes,  
 11 I do, because we used to keep that at home.  
 12 **Q.** You referred to it in your statement as seeing it as  
 13 a godsend?  
 14 **A.** Oh, exactly, yeah. Yeah, without it -- I mean, when  
 15 the freeze-dried stuff come out they did nothing --  
 16 put on a drip and stopped for hours at hospital, or at  
 17 home. It was sort of instant, yeah, definite.  
 18 **Q.** In those years when they were receiving the treatment  
 19 at home with the Lister freeze-dried product, do you  
 20 recall Dr Rizza or Dr Matthews, or anyone else at  
 21 Oxford, ever telling you or your wife about any risks  
 22 associated with treatment with concentrates?  
 23 **A.** No, not at all.  
 24 **Q.** Now, there came a point in time at which the boys went  
 25 to Treloar's, Leigh first of all and then Jason. How

66

1 did it come about that they went to Treloar's?  
 2 **A.** Well, they both attended normal school but quite often  
 3 you'd get a call from the school headmaster, one of  
 4 them might have had a bleed, and the nearest centre  
 5 from us was Oxford, which was 100 miles round trip.  
 6 So when they got a little bit older, I said to June,  
 7 "We've got to do something about" -- not June, it was  
 8 Sue at that time. And it was the local council at  
 9 Northampton that suggested Treloar's. So we went  
 10 down, took the boys and had a look, and it went from  
 11 there.  
 12 **Q.** We'll look in more detail about the treatment that  
 13 each of them received for their haemophilia at  
 14 Treloar's but before we do that, I think you used to  
 15 visit them regularly at Treloar's?  
 16 **A.** Most weekends. Most weekends.  
 17 **Q.** What can you recall about the school and their time  
 18 there?  
 19 **A.** I think they enjoyed it. You know, and -- you know,  
 20 we had no complaints at all. No, not at all. You  
 21 know, they was getting a good education -- I mean  
 22 Leigh was there, I say, before Jason. But Jason had  
 23 it harder than Leigh because he had -- Leigh was quite  
 24 academic, a lot more academic than Jason, and he made  
 25 a lot of friends. He made friends very easily, Leigh

67

1 did. But Jason I don't think did. So Jason had it  
 2 a little bit harder.  
 3 **Q.** On those weekend visits, do you recall ever talking to  
 4 any of the nursing or medical staff at the centre?  
 5 **A.** Not particularly, no.  
 6 **Q.** What about the teaching staff? Did you ever have much  
 7 interaction with the teaching staff?  
 8 **A.** Oh yes, yeah. I can't remember the names now though.  
 9 **Q.** Don't worry.  
 10 **A.** I'm sorry.  
 11 **Q.** When you went at weekends, would you sometimes see  
 12 a teacher or the headteacher or a housemaster?  
 13 **A.** Yes, we was on first name terms with most of them,  
 14 because you'd see them in the grounds. You'd chat  
 15 with them, you know, take Leigh out for dinner, and  
 16 what have you, and then come back. And a lot of his  
 17 friends used to come with us too.  
 18 **Q.** But in terms of the clinical and medical and nursing  
 19 staff, you didn't really have anything to do with them  
 20 when you visited?  
 21 **A.** No, not really. No, not really, no.  
 22 **Q.** We're going to look at some of the Treloar's records  
 23 for each of the boys --  
 24 **A.** Okay.  
 25 **Q.** -- and we're going to start with Leigh. Am I right in

68

1 thinking he joined Treloar's in the autumn of 1978?  
 2 **A.** I think he did, yes.  
 3 **Q.** He was 11, or going on 12?  
 4 **A.** Yeah, he was born in '66, yeah, just turned 12.  
 5 **Q.** So if we have first up on screen, please, Soumik,  
 6 TREL0000242\_013. I'm just going to show you a couple  
 7 of documents first, John, and then we'll talk about  
 8 them. So, this is a letter from Dr Aronstam who was a  
 9 doctor at the Treloar's Haemophilia Centre to Dr Rizza  
 10 at Oxford, 5 September 1980. It's about Leigh. He  
 11 said:  
 12 "This boy, who is registered with you, is, as  
 13 you know, a pupil in at the Lord Mayor Treloar  
 14 College. We feel that he is now ready for training in  
 15 self therapy and if you agree, could you let me know  
 16 with which material you would like us to train him."  
 17 If you look at the response from Dr Rizza,  
 18 TREL0000242\_012. We can see a letter dated 11 September  
 19 from Dr Rizza back to Dr Aronstam, which says:  
 20 "As far as I can see Leigh has received only NHS  
 21 factor concentrate and it would be nice if he could be  
 22 supplied with that when you get him trained to treat  
 23 himself. As you know he has been on home therapy for  
 24 many years now, the material being administered by his  
 25 mother. He is a very sensible boy and I am sure you'll

69

1 If we go to the last page, please, Soumik,  
 2 page 7, it's in reverse date order.  
 3 John, what we've got here are records of  
 4 treatments from 1978 through to 1980 and, by way of  
 5 example, if we go to the bottom of the page -- I'm so  
 6 sorry, Soumik, if we go to the top of the page. You  
 7 were in the right place. Apologies.  
 8 We can see this is September 1978, this is Leigh's  
 9 first term.  
 10 **A.** Right.  
 11 **Q.** The first concentrate we see recorded there, Koate,  
 12 then Hemofil, then Factorate, then Koate again. If we  
 13 go down the bottom of the page, Hemofil, Koate,  
 14 Hemofil Hemofil, Hemofil, Koate, Factorate.  
 15 If we go, just by way of example, to one further  
 16 page, page 6, please, Soumik. We can then see Lister,  
 17 that's the NHS product, Koate, Lister, Koate, Hemofil,  
 18 and so on. We won't go through all the pages, John, but  
 19 this document shows Leigh being treated with, as well  
 20 as, from time to time, the Lister product, being treated  
 21 with Factorate, Kryobulin, Hemofil and Koate, all of  
 22 which were commercial concentrates.  
 23 **A.** Mm.  
 24 **Q.** Were you and your wife ever told that Leigh was being  
 25 treated with commercial concentrate?

71

1 find no difficulties whatsoever with his training."  
 2 **A.** Mm.  
 3 **Q.** We can see there Dr Rizza saying Leigh had only  
 4 received NHS factor concentrates, so that's the Lister  
 5 product, and that again was your recollection?  
 6 **A.** Yes, it was. Yeah.  
 7 **Q.** We can see the reference here to Leigh being trained  
 8 to administer the product to himself. Do you recall  
 9 that happening?  
 10 **A.** Yes, I do, yes.  
 11 **Q.** What would happen?  
 12 **A.** Well, as I say, I think he got the training at school,  
 13 at Treloar's. You know, I mean there are times when  
 14 I went down there and Leigh -- we was going to take  
 15 Leigh out and he would say, "Oh, I'm going to go and  
 16 have a dose because, you know, this -- the elbow hurts  
 17 or a knee hurts", or what have you. And I'd go into  
 18 the hospital with him or the hospital wing with him  
 19 and he'd just open the fridge and get the paperwork  
 20 out, weigh himself, and do it himself, which I was  
 21 quite impressed with, actually.  
 22 **Q.** Then, so we can see there the encouragement from  
 23 Dr Rizza that Leigh be supplied with NHS concentrate,  
 24 and if we look at TREL0000242\_041, these are some  
 25 treatment records for Leigh.

70

1 **A.** No.  
 2 **Q.** Were a ever told --  
 3 **A.** No.  
 4 **Q.** -- given any information about any risks associated  
 5 with the use of concentrates?  
 6 **A.** No. This is the first time I've ever seen this.  
 7 **Q.** You saw this this morning and you'd never been shown  
 8 this before?  
 9 **A.** No, no. No, not at all. So the only one I recognise  
 10 on that is the Lister.  
 11 **Q.** I think I'm right in understanding, John, that, as far  
 12 as you can recall, you and your wife never received  
 13 any medical information from Treloar's whatsoever?  
 14 **A.** No. No. We weren't even informed when they was in --  
 15 you know, got a bleed or anything like that, really.  
 16 **Q.** Can we look next at TREL0000242\_034, please. This is  
 17 a document which, again, you'd not seen before giving  
 18 your evidence -- sorry, not seen until -- in preparing  
 19 for giving your evidence today, I think. It says:  
 20 "Please complete and return to Dr Aronstam.  
 21 "I ..."  
 22 Then that's your late wife, the boys' mother's  
 23 signature.  
 24 **A.** Yeah, it's Susan, yeah.  
 25 **Q.** "... agree to Leigh Peach taking part in a trial as

72

1 explained by Dr Aronstam."

2 She's signed it and we've redacted the  
3 signature. Do you know anything about this document  
4 or what she'd been asked to agree to?

5 **A.** No, not at all. Not at all.

6 **Q.** It's not dated but we know, I think, from your  
7 statement that the boys' mum died in was it 198 --

8 **A.** '84, yeah.

9 **Q.** So it's from sometime before that but you don't know  
10 when?

11 **A.** No. Definitely not.

12 **Q.** There are records -- well, we'll look at one example.  
13 TREL0000241\_017, please. So this is a letter, a later  
14 letter in time. Again, it's from Treloar's to the  
15 Oxford Haemophilia Centre. This is 11 December 1984.  
16 If we go a little further down the page, please. If  
17 we look at the second paragraph, it talks about:

18 "Almost all of Leigh's bleeds so far this term  
19 were into his right ankle. He has also had 5 bleeds  
20 into this joint during the summer holiday. We have  
21 started him on another course of prophylaxis 20% raise  
22 on alternate days on 28.11.84."

23 Were you ever made aware by Treloar's that Leigh  
24 was being treated prophylactically?

25 **A.** No, no, not as I recall.

73

1 happens to have Leigh's name redacted. But it's about  
2 Leigh, it's from his records. It says:

3 "Recently I have seen [Leigh] in Oxford. You  
4 probably know he has persistently abnormal liver  
5 function tests since 1976. I took the opportunity to  
6 repeat these tests."

7 Then the last part of that paragraph says:

8 "... I am more or less sure that he has some  
9 chronic liver disease."

10 Then the last paragraph asks Treloar's to keep  
11 an eye on his liver function.

12 Can you recall either Oxford or Treloar's ever  
13 informing you about this --

14 **A.** No, this is the first time I've ever seen it.

15 **Q.** Then if we go to the second page of this bundle,  
16 please, Soumik. We can see Dr Aronstam's response,  
17 14 February 1980, again it is concerning Leigh,  
18 although the name is redacted on these copies. It  
19 says:

20 "We are well aware of his liver function tests and  
21 for your information, I enclose a copy of our records so  
22 far. We keep a very close watch on the liver function  
23 tests on all the boys at this College.

24 "I am inclined to take issue with you on the  
25 significance of his marginally elevated SGOTs. If this

75

1 **Q.** If we look at the very last paragraph of this letter,  
2 we can see there's a reference there to a change to  
3 heat-treated Factor VIII, for patients who were taking  
4 commercial Factor VIII. Was there ever any discussion  
5 with you in late 1984, or any other time, about  
6 a switch to heat-treated concentrates for Leigh?

7 **A.** No. We knew it was available but we didn't know that  
8 the boys were getting it, "Lister remain unchanged".

9 **Q.** If we look then at TREL0000242\_043, we can see here  
10 a record for Leigh, and on the left-hand column is  
11 headed "Serum hepatitis", and then there's a reference  
12 in 1979 to positive tests for antibody. Was that  
13 something that was ever drawn to your attention or  
14 discussed with you or your wife?

15 **A.** Not at all, no.

16 **Q.** Then we know, if we look at TREL0000241\_037, we know  
17 from an exchange of correspondence here about liver  
18 function tests. I'm going to just read some little  
19 extracts from each of the three letters and then ask  
20 you about it, John.

21 Soumik, could we go to the third page, please.

22 So we can see that is a letter from a Dr Ghosh at  
23 Oxford Haemophilia Centre, to Dr Aronstam at the --

24 **A.** Haemophilia Centre at Treloar's.

25 **Q.** Treloar's Centre. It's 4 February 1980. This copy

74

1 small degree of elevation is significant, then  
2 approximately 95% of the boys at this college and by  
3 implication of all severe haemophiliacs in this country  
4 have chronic liver disease."

5 Again, this is from Dr Aronstam, in whose care  
6 Leigh was at Treloar's. Was this issue ever explored  
7 with or raised with you or your wife?

8 **A.** No, not at all. Not at all.

9 **Q.** Just for the sake of completeness, if we just go to  
10 the first page, we can see Dr Ghosh at Oxford writing  
11 back to Dr Aronstam on 19 February 1980 saying:  
12 "Truly speaking, I do not know what these  
13 marginally elevated liver function tests in  
14 haemophiliacs mean, particularly in the absence of any  
15 other stigmata of chronic liver disease but as you  
16 know invasive investigations in this group of patients  
17 more often than not show some liver changes suggestive  
18 of chronic liver disease."

19 As I understand it, no -- none of the clinicians  
20 involved in Leigh's care ever spoke to you or your wife  
21 about the possibility of liver disease?

22 **A.** Not to my knowledge no.

23 **Q.** Can we then, please, Soumik, have TREL0000241\_016.

24 This is another letter, John, from Treloar's to  
25 Oxford. It's dated 19 March 1985. It says:

76

1 "For your information, I enclose copies of:  
 2 "(1) His bleeding episodes [that's Leigh's] and  
 3 transfusions so far this term  
 4 "(2) Laboratory results  
 5 "He was requested for Anti HTLV-3 for the first  
 6 time on 23.1.84 and was found to be positive."  
 7 **SIR BRIAN LANGSTAFF:** I think that must be '85?  
 8 **MS RICHARDS:** Well, sir, possibly. We see this  
 9 terminology used in multiple letters, so --  
 10 **SIR BRIAN LANGSTAFF:** Oh, I see what you mean. So you  
 11 think it's a back test?  
 12 **MS RICHARDS:** It's very puzzling wording, sir. We  
 13 discussed this with John this morning so I'm sure he  
 14 will forgive us for talking about this.  
 15 We know that HTLV-III testing was not available  
 16 in January 1984. The language used here could either  
 17 be explained by a mistake in the year, but it appears  
 18 in relation to different patients as well, in  
 19 different sets of records, on different dates; or it  
 20 could be a reference to retrospective testing. But  
 21 those would be the two ways of making sense of it.  
 22 We can see, the bottom of the page, it tells us  
 23 Leigh will be leaving the sixth form college -- oh,  
 24 that's just for the holidays, sorry.  
 25 This is a record in March of 1985, Treloar's

77

1 I'm going to ask you to look now at some records  
 2 relating to Jason.  
 3 Jason joined his brother at Treloar's I think in  
 4 the autumn of 1981.  
 5 **A.** Mm-hm.  
 6 **Q.** And if we look at TREL0000239\_137, please.  
 7 We can see here again, this is --  
 8 **A.** It's Jason.  
 9 **Q.** These are records from Jason's first term, the autumn  
 10 term of 1981.  
 11 If we go first of all, Soumik, because they're  
 12 in, I think, reverse date order, to page 10.  
 13 If we look down the left-hand side we can see an  
 14 entry just over halfway down the page "Units  
 15 Material". And we see there the reference to 530  
 16 units of Lister.  
 17 So we can see Jason being treated with a Lister  
 18 product on 4 November.  
 19 If we go back to page 9, Soumik. The same  
 20 column, again, we've got a treatment on 9 November  
 21 with the Lister product.  
 22 **A.** 520, yeah.  
 23 **Q.** If we go then to page 7, we can see, if we look at  
 24 that same reference, "Units Material: 550 Factorate".  
 25 So by 15 November Jason's been treated with an

79

1 telling Oxford that Leigh had been tested for HTLV-III  
 2 and the test result was positive.  
 3 Did Treloar's share that information with you,  
 4 Leigh's father --  
 5 **A.** No, definitely not.  
 6 **Q.** -- then or at any time?  
 7 **A.** No, it was -- it's got to have been two or three years  
 8 later than that, that we found out that Leigh was  
 9 positive.  
 10 **Q.** We'll look at some correspondence about that in  
 11 a little while, but you -- as I understand it, John,  
 12 you were never told by Treloar's --  
 13 **A.** No, definitely not.  
 14 **Q.** -- that he had tested positive for HTLV-III?  
 15 **A.** No.  
 16 **Q.** And as far as you were aware, was Leigh ever told by  
 17 Treloar's that he had tested positive?  
 18 **A.** Well, if he had have been, he would have discussed it  
 19 with us. He was that kind of lad. And Jason.  
 20 I'm sure they weren't.  
 21 **Q.** Leigh left Treloar's in the summer of 1985, and at  
 22 that point, you had no idea, and as far as you  
 23 understand it Leigh had no idea --  
 24 **A.** No, that's right.  
 25 **Q.** -- that he was HTLV-III positive.

78

1 American concentrate?  
 2 **A.** Mm.  
 3 **Q.** Factorate.  
 4 If we go to page 6, it's Lister again, in that  
 5 entry.  
 6 If we go to page 5, we're now on the 26th or so  
 7 of November, and the entry there is Hemofil. So  
 8 that's another commercial concentrate that Jason is  
 9 treated with.  
 10 **A.** Hmm.  
 11 **Q.** Then if we go to page 2, please, Soumik, we can see in  
 12 the same entry a reference to something called  
 13 Interhem?  
 14 **A.** Yeah.  
 15 **Q.** This another commercial concentrate.  
 16 Were you told that Jason was going to be treated  
 17 not simply with NHS Lister product but with other  
 18 concentrates?  
 19 **A.** As far as we are, as parents -- I mean, I just thought  
 20 that was one product. Just called freeze-dried. It  
 21 was the product that they'd always had at home. I  
 22 didn't realise all this was on the market.  
 23 **Q.** So no one at Treloar's ever told you about different  
 24 products and no one --  
 25 **A.** No.

80

1 Q. -- told you the boys were going to be treated with  
 2 them?  
 3 A. No, definitely not.  
 4 Q. Did anyone at Treloar's ever tell you any risks  
 5 associated with --  
 6 A. No.  
 7 Q. -- the treatment?  
 8 A. No, we knew there was a risk of jaundice. Because  
 9 Leigh had -- you know, he'd go back and he'd -- you  
 10 just look at him and you say: well, why are you so  
 11 yellow? You know. And then they explain it, you  
 12 know, he'd got a bit of jaundice in the product.  
 13 Apart from that, nothing else.  
 14 Q. So Leigh would occasionally go a bit yellow and you  
 15 understood that to be something mild?  
 16 A. Well, yeah, something -- something that was just --  
 17 you know, they couldn't avoid.  
 18 Q. And then if we go next to TREL0000239\_126, these are  
 19 some treatment records for Jason from March of 1983,  
 20 and we can take them in the correct order this time.  
 21 So we can see the first product here -- again, it's in  
 22 the same column, "Unit Materials" -- is Lister.  
 23 A. Mm.  
 24 Q. And there are various dates on this page if we read  
 25 across three occasions when he's given Lister.

81

1 enclosed AIDS related tests. We are repeating these  
 2 tests before the end of term and will let you have the  
 3 results when they are available."  
 4 A. Mm.  
 5 Q. Were you told, John, that your son was having AIDS  
 6 related investigations and tests undertaken at  
 7 Treloar's?  
 8 A. No. Especially not that early, 1983. Christ.  
 9 Q. Then if we turn to TREL0000239\_105.  
 10 These are some extracts from Jason's medical  
 11 notes at Treloar's.  
 12 If we go to page 4, please, Soumik, there's an  
 13 entry, it's the third entry down, for 1 July 1984. So  
 14 we'll just go slightly up, thank you.  
 15 We can see there, John, it says, "L. Nodes", so  
 16 that's lymph nodes, and various examinations recorded.  
 17 And then it says:  
 18 "AIDS stigmata:  
 19 "Exhibits none of the stigmata of AIDS."  
 20 So we can see there is a further examination, this  
 21 is the following year, July '84, looking for the signs  
 22 of AIDS. Again, was anything being said to you, had  
 23 anything --  
 24 A. No.  
 25 Q. -- been said to you about the risk of AIDS?

83

1 But if we then go to page 6, please, Soumik.  
 2 We can see in the same month --  
 3 A. That's right.  
 4 Q. -- so 14 March 1983, Jason was given Factorate, which  
 5 was a commercial product.  
 6 And if we go to the next page we've got a bleed  
 7 on 25 April 1983 and Jason was given 600 units of  
 8 Koate.  
 9 So, again, the various different products were  
 10 continuing to be given to Jason in 1983. And still  
 11 nothing being --  
 12 A. No, nothing at all, no. That's the first time I've  
 13 ever seen these.  
 14 Q. Soumik can we have TREL0000239\_037.  
 15 We've got a letter here, John, 7 July 1983,  
 16 about Jason. Again, is from Treloar's to Dr Matthews  
 17 at the Oxford Haemophilia Centre.  
 18 If we go towards the bottom of the page, we can  
 19 see a heading there, in July '83, "AIDS related  
 20 investigations":  
 21 "Clinically he exhibits none of the stigmata of  
 22 AIDS. Examination of his superficial lymph nodes on  
 23 14.3.83 revealed palpable small left axillary  
 24 lymph nodes.  
 25 "For your information we have undertaken the

82

1 A. No, not at all.  
 2 Q. If we go on to page 6, please. Can we zoom in,  
 3 Soumik, on the bottom right-hand corner.  
 4 So you'll see there, John, in the bottom  
 5 right-hand corner something called "Medical Report",  
 6 28 November 1984.  
 7 A. Yeah, yeah.  
 8 Q. And it talks about:  
 9 "Average number of bleeds mainly into his left  
 10 elbow ... several courses of prophylaxis ..."  
 11 And then there's some further information about  
 12 the frequency of the bleeds. But it's about the  
 13 bleeds and the position in relation to treatment for  
 14 the elbow. And then it says:  
 15 "Has had a good term."  
 16 A. That's right.  
 17 Q. Do you recall whether you ever received these medical  
 18 reports?  
 19 A. I could never remember seeing one, no. Not at all.  
 20 Q. If we go on to page 11, please, Soumik.  
 21 The second entry looks like it's 3 July 1985.  
 22 There's a reference there to "Lymphadenopathy/AIDS", and  
 23 then it looks like, about four lines down:  
 24 "Has had some thrush and difficulty in  
 25 swallowing ..."

84

1 Then the last line says:  
 2 "Apart from this no other stigmata of AIDS."  
 3 **SIR BRIAN LANGSTAFF:** Over seven weeks.  
 4 **MS RICHARDS:** Sorry, sir?  
 5 **SIR BRIAN LANGSTAFF:** "7/52", so seven weeks?  
 6 **MS RICHARDS:** Yes, sir, you're right.  
 7 Were you told at this stage by Treloar's, July of  
 8 '85, that some symptoms consistent with the possibility  
 9 of AIDS had been identified by Treloar's in Jason?  
 10 **A.** No, no.  
 11 **Q.** I think Jason left college in May of 1986; is that  
 12 right?  
 13 **A.** Yeah, that sounds right.  
 14 **Q.** You can take that down.  
 15 Your recollection in your witness statement, and  
 16 your recollection today, as I understand it, John, is  
 17 that you learnt of both boys being infected with HIV --  
 18 **A.** At the same time, yes.  
 19 **Q.** -- at the same time and from the Oxford Haemophilia  
 20 Centre?  
 21 **A.** Exactly.  
 22 **Q.** You were never told by Treloar's about either of your  
 23 sons' infections?  
 24 **A.** No, no.  
 25 **Q.** And as far as you're aware, were your sons, either of

85

1 them, ever told by Treloar's about their infections?  
 2 **A.** No, I'm sure they weren't.  
 3 **Q.** Because they'd have spoken to you?  
 4 **A.** They would have done.  
 5 **Q.** Can we look at JPEA0000001\_038.  
 6 So we can see here it's a document -- it's not  
 7 one that you would be expected to see, and this is  
 8 from the Oxford records, not the Treloar's records.  
 9 But we've got there "HTLV-III RISK". There's a date,  
 10 it looks like, top left-hand corner, 20 August 1985.  
 11 Your recollection, as I understand it, is that you  
 12 were not, even at this point in time, August 1985, aware  
 13 of any --  
 14 **A.** No.  
 15 **Q.** -- HIV test results?  
 16 **A.** No.  
 17 **Q.** And then if we go to JPEA0000001\_031, please.  
 18 There'd been a letter, I don't have it available  
 19 for display, but we looked at it this morning, John,  
 20 before you gave your evidence. There had been  
 21 a letter from Dr Rizza, undated, talking about having  
 22 tests available now in relation to Jason, and asking  
 23 if you wanted to know. And this is a letter from you,  
 24 18 November 1985, to Dr Rizza:  
 25 "Thank you for your recent letter relating the

86

1 AIDS related virus tests carried out on Jason.  
 2 "As mentioned you have had 3 test results for  
 3 Jason and I would appreciate it if you would please drop  
 4 me a line with the findings."  
 5 If we go to Dr Rizza's response and then I'll ask  
 6 you about it John, JPEA0000001\_030.  
 7 This is a letter dated 12 December 1985 from  
 8 Dr Rizza addressed to you:  
 9 "Thank you for your letter. The results of tests  
 10 on Jason show that he is HTLV-III antibody positive  
 11 which means that he has at some time been in contact  
 12 with the virus and has made antibodies to it. It does  
 13 not mean that he has AIDS or is going to get it. The  
 14 vast majority of people who are antibody positive are in  
 15 good health and remain in good health. Only a very  
 16 small number have any health problems. I suggest that  
 17 you come to the Centre with or without Jason to discuss  
 18 in more detail what this all means."  
 19 I think, John, in your statement your recollection  
 20 was that you'd been told about the boys' results later  
 21 than this. You thought it was about --  
 22 **A.** I thought it was later than this, but, as I say, these  
 23 letters must be right.  
 24 **Q.** And you've got a recollection, I think, of going into  
 25 the Centre and talking to Dr Rizza?

87

1 **A.** Yeah, we received a call. I was doing the gardening.  
 2 June was with me then. And she said, "I've just had  
 3 a call from the Oxford Haemophilia Centre about the  
 4 boys had tested positive". I said "Well, we'd better  
 5 go down and see them". So we went down to Oxford and  
 6 spoke to Dr Rizza.  
 7 **Q.** Can you recall, were the boys with you, both of them?  
 8 **A.** I think they were. I'm sure they were.  
 9 **Q.** And can you remember anything about what you were  
 10 told?  
 11 **A.** Well, they were quite well. This was before the AZT  
 12 was ever mentioned, or anything like that. We were  
 13 just told to carry on taking the Factor VIII, or the  
 14 treatment. And it may not -- it don't mean to say  
 15 that they're going to get full-blown AIDS.  
 16 **Q.** And then just one last document. JPEA0000001\_043.  
 17 We can see that exchange of correspondence in  
 18 that letter from Dr Rizza, December '85. This is  
 19 March 1985. So some months earlier Dr Wassef, at  
 20 Treloar's, had written to Oxford, saying, in relation  
 21 to Jason, he was tested for anti-HTLV-III for the  
 22 first time on 13 January '84 and was found to be  
 23 positive.  
 24 **A.** Mm.  
 25 **Q.** So you'll see why I said that wording appears in

88

1 a number of letters.

2 **A.** Yeah, mm.

3 **Q.** And not just in relation to the boys.

4 Whether or not that date is wrong or reflects

5 retrospective testing, it clearly shows Oxford being

6 told by Treloar's Jason was HTLV-III positive in

7 March 1985. But you were never told that?

8 **A.** No. No. No.

9 **Q.** You told us -- we can take that down. Thank you. You

10 told us in your witness statement that both boys were

11 working after they left college?

12 **A.** Yes, they were.

13 **Q.** I think Leigh as a graphic designer and Jason with the

14 local estate agent?

15 **A.** That's right.

16 **Q.** You've said that after the diagnosis for both of them

17 you talked about your world falling apart for all of

18 you.

19 **A.** When it came out in the papers, you know, and -- they

20 were stigmatised then. I mean, they couldn't get

21 dental treatment, they couldn't travel abroad, like

22 Leigh used to do with his job. Yeah, quite tough

23 then.

24 **Q.** I think they were treated, both of them, with AZT?

25 **A.** Pardon?

89

1 **A.** Yes, they did. I mean once they got -- I mean, they

2 got the initial payment, they decided that they'd like

3 to -- well, we went down to see Dr Matthews, and he

4 basically told us that if they'd got any -- once the

5 symptoms start, it'll probably be ... it'll probably

6 be an irritating cough, and they wouldn't last

7 four years. So they decided they'd like to ... well,

8 Leigh got married.

9 **Q.** He bought his wedding forward, I think.

10 **A.** And Jason moved in with his girlfriend. We still kept

11 very close, but ...

12 **Q.** Jason's health deteriorated, and --

13 **A.** Yeah.

14 **Q.** -- he died in 1993 aged 23 years old.

15 **A.** Yeah.

16 **Q.** Just five months later Leigh died, aged 27.

17 **A.** He did. Leigh was more concerned that when he died,

18 he didn't want to -- he knew it was a -- they called

19 it a gay plague, and they -- most of the gay lads that

20 died got very bad skin lesions and Leigh didn't want

21 that, and the doctors virtually told him when he was

22 going to die --

23 **Q.** Would you like a five-minute break, John?

24 **A.** -- I'll be all right in a minute -- that his lungs

25 wouldn't take any more oxygen in. And I was ... I was

91

1 **Q.** Were they treated, both of them, with AZT?

2 **A.** Yes, they put them on -- I've got another note. They

3 put them on it -- I think June made me a note when

4 they actually put them on it, AZT. It's put it on.

5 We did keep some notes when they was actually put on

6 that. Leigh was. Yeah, Leigh -- this is Leigh,

7 not -- we don't -- I can't remember Jason, but Leigh

8 was -- started AZT in 1990. And he was on it --

9 I mean, we didn't want him to take it because he

10 was -- he was fine. He was -- if you looked at a

11 picture when -- the three of us together, he looked

12 perfectly well. But after being on it seven months,

13 he was absolutely a shadow of himself. If you

14 looked at the side effects of AZT, I think Leigh had

15 every single one. Every single one. And they took

16 him off it. And they started -- but it got so bad

17 that they put him back on it in July '91. Yeah.

18 **Q.** And you don't know the dates for Jason but he too was

19 on AZT?

20 **A.** He was on AZT as well, yeah. I mean, I don't think

21 Jason had the same resistant -- side effects that

22 Leigh did. Leigh had it really, really bad.

23 **Q.** You told us in your statement both of your boys tried

24 to make the best of things. They found happiness with

25 their respective girlfriends?

90

1 holding Leigh's hand when he died. I just couldn't

2 believe he'd even gone. I couldn't believe he'd gone.

3 Sorry.

4 **SIR BRIAN LANGSTAFF:** I've stopped the broadcast.

5 **MS RICHARDS:** Just take a minute, John ...

6 **A.** They said he'd died from pneumocystis pneumonia,

7 that's what they'd told him he'd die from, that this

8 pneumonia would get worse. He'd had nebulisers before

9 that for quite a long time. He had to spent lots of

10 time on a nebuliser to keep himself breathing, but to

11 see somebody just go like that ... it's horrendous.

12 **Q.** One of the things you mentioned in your statement had

13 been about the waiver they'd had to sign --

14 **A.** Yes.

15 **Q.** -- in order to receive some money. And you talked

16 about it in terms of feeling like it was blackmail?

17 **A.** Well, it was. I mean, all the lads will tell you and

18 they'll all say the same story. And we went and

19 actually sat in the solicitors office, and the papers

20 were in front of them, and they said, "If you don't

21 sign it -- if every one of the 1,200" -- I think it

22 was about 1,200 at the time -- didn't sign it, then

23 nobody would get anything. And Leigh was more

24 concerned that the people that really needed the

25 money, you know -- so he said, "It's going to do no

92

1 harm, Dad. In four years I might not be here anyway".  
 2 So that's what they did. They signed it.  
 3 **Q.** If we just think back to the time that they were at  
 4 Treloar's, it sounds from your evidence, John, as  
 5 though throughout the period that both your boys were  
 6 at Treloar's, you never received any medical or  
 7 clinical information about their progress, their  
 8 bleeds, their treatment --  
 9 **A.** No.  
 10 **Q.** -- or risks whatsoever?  
 11 **A.** No, I can honestly say we didn't. No, not at all.  
 12 **Q.** John, I'm going to, in a moment, just put some photos  
 13 up of the boys. Before I do that I'm just going to  
 14 ask Mr Snowden if there's anything further he wants me  
 15 to ask.  
 16 So we've got three photos you've shared with us.  
 17 Soumik, JPEA0000004.  
 18 It's you and the boys.  
 19 **A.** Yeah, it was. And that was about 1986/87, I think.  
 20 '87, that's when I married my second wife. That was  
 21 at the wedding. You can see how well they were then.  
 22 They looked really well.  
 23 **Q.** Then we've got a couple of photos of them from  
 24 childhood, JPEA0000005, please.  
 25 **A.** Yeah.

93

1 **SIR BRIAN LANGSTAFF:** Yes. Thank you very much.  
 2 **MS RICHARDS:** John, is there anything else you'd like to  
 3 add?  
 4 **A.** Yeah, I'll just read out the ...  
 5 I miss these boys every day, every day. Yeah,  
 6 every day. I just want to thank you all and especially  
 7 all of the witnesses. I don't know how they got through  
 8 it, some of them. Thank you for the time, the Inquiry.  
 9 It's been a long time coming. But my own thoughts is  
 10 this whole scenario could have been avoided if  
 11 David Owen's commitment had been carried out.  
 12 I think, you know, when you think there was  
 13 a commitment by a minister, and it didn't get --  
 14 somebody cancelled it some way along the line. They  
 15 just cancelled the whole thing. It never went through  
 16 Parliament. And to me, that was a criminal act. That  
 17 should be a criminal act. The people responsible for  
 18 distribution and regulation of blood products have a lot  
 19 to answer for.  
 20 All I ever wanted was the truth, and I hope this  
 21 Inquiry delivers it. Thank you.  
 22 **MS RICHARDS:** Thank you, John.  
 23 [Applause]  
 24 **A.** Thank you all.  
 25 **SIR BRIAN LANGSTAFF:** Thank you, John. You said at the

95

1 **Q.** Then one last photo, 06, please, Soumik.  
 2 **A.** Yeah, yeah.  
 3 **Q.** John, those are the questions I have for you.  
 4 **A.** Pardon?  
 5 **MS RICHARDS:** Those are the questions I have for you,  
 6 John.  
 7 Sir Brian, is there anything you have to ask?  
 8 **Questions from SIR BRIAN LANGSTAFF**  
 9 **SIR BRIAN LANGSTAFF:** Just the one question. When you  
 10 learned that the boys -- I think it was Leigh --  
 11 had -- yellow skin, had jaundice, who did you find out  
 12 that it was jaundice from? From him or anybody else?  
 13 **A.** From -- it would be one of the doctors. We knew  
 14 what -- well, the wife is pretty medical. She's got  
 15 a medic, a trained in medicine, but she knew exactly  
 16 what it was. She said it was jaundice.  
 17 **SIR BRIAN LANGSTAFF:** So you weren't actually told by  
 18 anyone, she just knew?  
 19 **A.** Yes.  
 20 **SIR BRIAN LANGSTAFF:** I see. Thank you very much.  
 21 **A.** And we were just told eventually that would clear up,  
 22 you know. Which it did but, you know, every now and  
 23 again, they'd get it back. And during their whole  
 24 lifetime they'd had it more than once and then it  
 25 would clear up and then they'd probably get it again.

94

1 end there that you don't know how the other witnesses  
 2 did it. I have the sense that you must have  
 3 approached giving evidence with some dread but felt  
 4 you just had to do it.  
 5 **A.** Yeah.  
 6 **SIR BRIAN LANGSTAFF:** Am I right?  
 7 **A.** I know a lot of these lads from school, you know, and  
 8 remember a lot of them that have gone.  
 9 **SIR BRIAN LANGSTAFF:** It seems to be against the natural  
 10 order that any child should die before parent.  
 11 **A.** Exactly.  
 12 **SIR BRIAN LANGSTAFF:** All I would like to say to you is  
 13 that I think you've given a fitting tribute to your  
 14 two sons --  
 15 **A.** Thank you.  
 16 **SIR BRIAN LANGSTAFF:** -- from start to finish. Thank you  
 17 very much.  
 18 **A.** Thank you.  
 19 **MS RICHARDS:** Sir, if we break for lunch and then we'll  
 20 resume with the evidence of Gary this afternoon.  
 21 **SIR BRIAN LANGSTAFF:** Well, back at two.  
 22 **MS RICHARDS:** Yes, sir.  
 23 **SIR BRIAN LANGSTAFF:** Two o'clock.  
 24 (12.51 pm)  
 25 (The luncheon adjournment)

96



1 (2.00 pm)  
 2 **SIR BRIAN LANGSTAFF:** Our next witness is happy to be  
 3 called Gary, I understand.  
 4 Gary, would you come forward, please. Mary, would  
 5 you ask Gary to take the oath.  
 6 **GARY BENNETT (sworn)**  
 7 **Questions by MS FRASER BUTLIN**  
 8 **MS FRASER BUTLIN:** Gary, you have severe haemophilia A?  
 9 **A.** Yes.  
 10 **Q.** Your younger brother, Tony, also had severe  
 11 haemophilia A?  
 12 **A.** Yes, he did.  
 13 **Q.** In terms of your schooling, you went off to boarding  
 14 school at age 5 --  
 15 **A.** I did.  
 16 **Q.** -- a different school to Treloar's --  
 17 **A.** Yes.  
 18 **Q.** -- it wasn't a very happy experience?  
 19 **A.** No, it wasn't, no.  
 20 **Q.** So you returned home at nine?  
 21 **A.** Yes.  
 22 **Q.** Then you went to some other local schools --  
 23 **A.** Yes.  
 24 **Q.** -- which were also not particularly --  
 25 **A.** Brilliant.

97

1 **Q.** -- successful?  
 2 **A.** No.  
 3 **Q.** It was then decided that you'd go to Treloar's. Can  
 4 you tell us how that came about?  
 5 **A.** I actually had a place in Treloar's, I think, in '79  
 6 and, for whatever reason, I lost my slot and I went to  
 7 a local disabled school that took me in for a year,  
 8 and when I eventually went up to Treloar's, I already  
 9 met other people with disabilities. And it was --  
 10 I'll be honest, it was quite amazing. And the only  
 11 difference was, there was 80 of us -- 89 haemophiliacs  
 12 there. And I met a lot of different people and a lot  
 13 of friends and a lot of haemophiliacs.  
 14 **Q.** You went up together with Tony. He was in the year  
 15 behind you?  
 16 **A.** Yes, I was first, yeah.  
 17 **Q.** You've said that going to Treloar's opened your eyes  
 18 even more to disabilities?  
 19 **A.** Yes, it did.  
 20 **Q.** What else can you tell us about being a pupil at  
 21 Treloar's?  
 22 **A.** Oh, God. Because of my younger years, the actual  
 23 Treloar's School with sick bay and the treatment room,  
 24 was a godsend for all of us at the time because, yes,  
 25 we all missed school. I missed loads of school, my

98

1 younger years, I missed loads. So to walk in there  
 2 with my parents, this is sick bay, this is where the  
 3 boys will come and hopefully get onto factor, and  
 4 everything will be good, and go back to class, or if  
 5 need be, stay in sick bay and prep and the homework  
 6 would come up and carry on schooling. Brilliant,  
 7 really good.  
 8 **Q.** You've said you can remember the treatment room. What  
 9 can you tell us about how it was set up, what it was  
 10 like?  
 11 **A.** Oh God, it's a long time ago. I remember Dr Wassef's  
 12 office. I remember the brown bench. I remember  
 13 laying on the bench and having joints checked. The  
 14 treatment room, it's slightly vague, I remember the  
 15 tables. We'll probably come to this in a minute but  
 16 I remember putting the bottles on the table and, at  
 17 the moment, until you remind me, that's basically all  
 18 I can remember. I know where it is. If it's still  
 19 there today I could probably show you. But that's  
 20 roughly all I've got in the back of my head.  
 21 **Q.** Can I just ask you, Gary, just to shuffle in slightly  
 22 just so you're picked up by the microphones a little  
 23 bit better?  
 24 **A.** Yeah, sure, yeah.  
 25 **Q.** Thank you.

99

1 Now, until you went to Treloars, I think you just  
 2 received cryoprecipitate; is that right?  
 3 **A.** Yeah.  
 4 **Q.** Then once you arrived at Treloar's, when you started  
 5 receiving Factor VIII concentrates?  
 6 **A.** Yeah, mm-hm.  
 7 **Q.** Do you remember any discussion, either with you or  
 8 your parents, about changing over to factor?  
 9 **A.** I think, I think it was my dad. My dad dropped me, or  
 10 as a hint, that there's a new factor from the general  
 11 that they want to try us on, and it's easier than my  
 12 mum sitting up the hospital for four or five hours  
 13 defrosting the famous cryo. And I think it was my  
 14 dad, but we were really young, really young when we  
 15 went on Treloar's -- Factor VIII.  
 16 **Q.** So that was before you went to Treloar's?  
 17 **A.** Yeah.  
 18 **Q.** Do you recall if there was any discussion of any risks  
 19 involved in changing over?  
 20 **A.** No.  
 21 **Q.** I want to look at some Treloar's records with you?  
 22 **A.** Sure.  
 23 **Q.** They'll come up on the screen in front of you.  
 24 **A.** Okay.  
 25 **Q.** Could we have TREL000110\_137, please, Soumik.

100

1 What we've got here, we can see that it's  
2 a nursing report. So they seem to be your nursing  
3 records. And if we look through, we can see some of the  
4 products you received. If we start off on  
5 14 September 1980, it seems that you were transfused  
6 with Inter Hemofil; and then if we carry on to the  
7 22 September 1980, transfused 50% Inter Hem; and at the  
8 bottom, the 1 October 1980, Hemofil. Then over the  
9 page, please.

10 On 18 October, at the top of the page we can see  
11 50% increase Hemofil; 5 May 1981, what seems to read  
12 "Interhem" although it's not entirely clear, "Transfused  
13 10 pm"; and then 6 May 1981 "Transfused Kryobulin";  
14 31 May 1981 we just see "Transfused @ 9.30" but no note  
15 of the product that was used; then 6 July 1981  
16 "Transfused Factorate".

17 They appear to be at least some of the products  
18 you received --

19 **A.** Yeah.

20 **Q.** -- during 1980 and 1981. Do you recall any discussion  
21 about which products you'd be given?

22 **A.** No.

23 **Q.** Do you think your parents were told anything about the  
24 products you were being given?

25 **A.** I can't remember. I don't know.

101

1 when you needed treatment, when you realised you had  
2 a bleed? Can you tell us what you did?

3 **A.** If I remember, I think we used to wake up with arm or  
4 a knee, make our way to sick bay, get checked. They  
5 used to -- I think we mentioned this yesterday. We  
6 used to get a bit of paper and then take it down to  
7 the treatment nurse. And that's all I can remember.

8 **Q.** Can I take you back to another document.

9 **A.** Yeah.

10 **Q.** HHFT0001430.

11 This is headed "DDAVP Trial May 1982". We can  
12 see, on the left-hand side, your name. You're one of  
13 the seven who were to be in the trial. And it says:

"Eligibility for trial:

"AT LEAST 3 DAY[S] should elapse between the  
16 latest [Factor] VIII transfusion and the trial dose"

Then:

"(A) The trial will involve 2 boys at a time.

"(B) There will be three stages in the trial which  
20 will start at 8.30 am preferably during week days:

"(i) Trial dose of 50% [Factor] VIII.

"(ii) Trial dose of 50% [Factor] VIII following  
23 20 minutes later by DDAVP.

"(iii) Trial dose of 50% [Factor] VIII followed  
25 24 hours later by DDAVP."

103

1 **Q.** Could we then turn to TREL0000110\_041, please.

2 This is a letter from 9 May 1981 from

3 Dr Chisholm to Dr Aronstam, saying:

4 "Thank you for your letter about [Gary -- it's  
5 been redacted erroneously] being ready to be trained  
6 in self-therapy. He's been on self-administered home  
7 treatment for well over a year during the holiday  
8 period and in fact before he went to Lord Mayor  
9 Treloar College so there should be no problem. All my  
10 patients on home treatment start off with the NHS  
11 concentrate and most seem to manage very well with  
12 this."

13 Do you recall receiving NHS concentrate, Lister,  
14 from Dr Chisholm at home?

15 **A.** I don't. I don't.

16 **Q.** And do you recall any discussion with Dr Chisholm  
17 about the product you were being given either by her  
18 or when you were at Treloar's?

19 **A.** No.

20 **Q.** From this letter it looks like you were being trained  
21 in self-therapy --

22 **A.** Yeah.

23 **Q.** -- at Treloar's, and I think you were.

24 **A.** Yeah, I can't remember.

25 **Q.** And do you recall what the process was at Treloar's

102

1 If we just go to one more document then I'll ask  
2 you something about this, Gary.

3 If we could look at TREL0000110\_135, please.

4 We can see your name in the second row. And if we  
5 look across, we can see the word "Interhem", and then at  
6 the very bottom of the page:

7 "Boys should have the Same Material in the 3  
8 stages of the Trial."

9 Then over the page, again your name is second  
10 down, we've got a date under "stage I" as being  
11 22 June 1982 and "stage II", 28 June 1982.

12 Were you aware, Gary, at all, of this DDAVP trial?

13 **A.** No.

14 **Q.** And as far as you know, did your parents know about  
15 the DDAVP trial?

16 **A.** Not as far as I know, no.

17 **Q.** You've talked in your statement about remembering  
18 prophylaxis and receiving prophylactic treatment?

19 **A.** Yeah.

20 **Q.** When you were put on prophylactic treatment, do you  
21 remember whether that was something that was ever  
22 discussed with your parents, first of all?

23 **A.** Vaguely. There's an odd -- in the back of the head.

24 Dad -- it was Dad, really. Dad used to say, "They  
25 want to put you on prophylaxis". Until recently

104

1 I forgot, and I didn't realise I was on prophylaxis.  
 2 And I've seen some information, and I was, so ... But  
 3 I do remember Dad saying, "They want to inject you  
 4 every couple of days, every day, with prophylaxis."  
 5 **Q.** And do you remember if there was any more discussion  
 6 than just that that was going to happen, any  
 7 discussion --  
 8 **A.** That was going to happen, and that's all I can  
 9 remember, really.  
 10 **Q.** Could we turn to TREL0000110\_080, please, and we'll go  
 11 to the last page. The heading of this document, we've  
 12 seen it with other witnesses as well, "Transfusion  
 13 requirements (Not related to Current Bleeds)" and the  
 14 indication here is:  
 15 "Long Term prophylaxis for swollen [right] knee  
 16 and plus physiotherapy until further notice."  
 17 The frequency was to be alternate days.  
 18 We can see a series of entries from November 1982.  
 19 Looking at the "Material" column, it looks like -- could  
 20 we see the whole page, please, Soumik, all at the same  
 21 time? Thank you.  
 22 We can see that for that whole month you received  
 23 Factor VIII, apart from in relation to one entry, which  
 24 is Interhem, and the note is "At home". Again, when you  
 25 were put on prophylaxis, do you remember any discussion

105

1 Was this something you were keen to have?  
 2 **A.** No.  
 3 **Q.** What did you do about that?  
 4 **A.** I remember saying that I never want to go on  
 5 prophylaxis. Something with us haemophiliacs, we  
 6 don't like needles.  
 7 **Q.** Can you just shuffle forward?  
 8 **A.** Yeah, sure. We just don't like needles so I didn't  
 9 want prophylaxis, and I'm getting on a bit now. I've  
 10 had some major operations, and I still don't like  
 11 prophylaxis. I do it in my own way, so ...  
 12 **Q.** Did you see say that to the doctor --  
 13 **A.** Yeah.  
 14 **Q.** -- who was treating you --  
 15 **A.** Many times.  
 16 **Q.** -- at Treloar's? What was their response?  
 17 **A.** It was a long time ago. "You need it, Gary, you're  
 18 getting probably bad knees and it's to help your  
 19 knees". I probably relented because we were only  
 20 young. So ...  
 21 **Q.** Tony was also up at Treloar's with you?  
 22 **A.** Yes, he was, yeah.  
 23 **Q.** You recall -- your statement tells us that he received  
 24 a lot more treatment than you.  
 25 **A.** Yes, he did.

107

1 about which product you'd be receiving during that time?  
 2 **A.** No.  
 3 **Q.** Then if we turn back a page to page 3, please, Soumik.  
 4 Again, we're in December 1982 and throughout the month  
 5 you were just given Factorate in relation to the  
 6 prophylaxis, and there seems to be a handwritten note  
 7 that suggests "48 days, No bleeds". Do you remember  
 8 anything about that?  
 9 **A.** No. No.  
 10 **Q.** Having had Factorate for two months -- if we then go  
 11 to the January 1983 part of it, which is the second  
 12 page, please -- you then, in the January, only had  
 13 Lister. You're still on alternate days of  
 14 prophylaxis.  
 15 **A.** Yeah.  
 16 **Q.** Do you remember any discussion? Was there ever  
 17 a discussion about the product?  
 18 **A.** No.  
 19 **Q.** Then in February, so the first page of the document,  
 20 please. This time with the prophylaxis we see  
 21 Interhem, Interhem, Interhem, Factorate, Lister,  
 22 Lister, Lister, Lister, Lister, Lister.  
 23 Now, in terms of -- then it says at the end "Stop  
 24 prophylaxis" in the February.  
 25 Was prophylaxis something you wanted to receive?

106

1 **Q.** What's your recollection about that? What can you  
 2 tell us?  
 3 **A.** We were young lads, all of us. And to have your  
 4 brother at the same school -- he's my brother, so we  
 5 were brought up together and we would -- we would  
 6 knock each other. And many a times -- many a times, I  
 7 would walk past the treatment room just to go up to --  
 8 with somebody, a friend of ours, and I'd say, "What  
 9 are you doing?" Say, "Ah, they've put me in  
 10 prophylaxis again". And he was in there more times  
 11 than I was.  
 12 **Q.** I think it's right that you obviously don't know what  
 13 products --  
 14 **A.** No, I don't.  
 15 **Q.** -- he was receiving? Just a sense of him being in the  
 16 sick bay, in the treatment room a lot more --  
 17 **A.** He was always in there. Always. Just messing about  
 18 and I'd be, I don't know, talking to somebody, look  
 19 around and there he was. "What are you doing?"  
 20 "More prophylaxis."  
 21 "More prophylaxis."  
 22 I hate that word.  
 23 **Q.** And when you were at home I think you remember  
 24 sometimes using each other's products, factor  
 25 concentrates?

108

1 **A.** I was naughty. If the truth be known, I was very  
 2 naughty. And I used to run out. I used to run out.  
 3 I was never, never on time for any of my appointments.  
 4 I'm not ashamed. That's not the word I want to  
 5 use. But I put this to one side back in the eighties.  
 6 I knew I was a haemophiliac and I needed my factor.  
 7 But the hospitals, I don't know, they done the damage  
 8 and I put it to one side. And it was over 10 years  
 9 when I had -- my liver's checked, certain parts of  
 10 your body's checked. Yeah, checking for lumps or  
 11 bumps, groin pains, whatever. Now I can honestly say  
 12 I'm on top of my therapy and I go every six, four  
 13 months. I'm on top of it. But at the time I didn't  
 14 want to go to hospital so, yes, I did get caught a few  
 15 times.  
 16 "What's the matter?"  
 17 This is Tony.  
 18 "Ain't got no treatment."  
 19 "Well, you're stupid, ain't you? You're stupid.  
 20 Good job I've got a bootful in the car."  
 21 And, yes, he used to give me -- see, I was only on  
 22 2,000, maybe 4. He was on 10,000, 8,000 a bottle.  
 23 "Here, you can have one of them."  
 24 I don't know -- I don't know if it was  
 25 psychological or what but I used to have one and I used

109

1 statement that you remember being called into  
 2 a classroom at the end of dinner time with other --  
 3 **A.** Yes.  
 4 **Q.** -- presumably haemophiliacs?  
 5 **A.** Yeah.  
 6 **Q.** What can you tell us about that?  
 7 **A.** It was one -- I think it was a breakfast morning. And  
 8 we had our regular tables like we usually do. Our  
 9 group of lads on our table, and then -- am I allowed  
 10 to say the name? Am I allowed to say the doctor's  
 11 name?  
 12 **Q.** Oh, the doctor's name, absolutely.  
 13 **A.** I think it was Dr Wassef and one of the heads come  
 14 into the middle of the dining room and said, can  
 15 a certain group of haemophiliacs at that age group go  
 16 to a certain room, can the others go to -- I think --  
 17 I think at the time it was 2B. If you walked us back  
 18 in there now, I could tell you where I sat and which  
 19 classroom it was.  
 20 We all walked in, I can't even remember who was  
 21 behind me, who was in front of me. They walked in and  
 22 they stood there and they said, "Have you all got  
 23 a pen and paper?" We all said, "Yes sir". "I need  
 24 you to write down these numbers". It turned out to be  
 25 certain batch numbers. "You've got permission now to

111

1 to fall asleep for an hour. They were strong. But  
 2 I did wake up with no bleed. So ... But I was naughty.  
 3 I was very naughty. I know I was.  
 4 **Q.** Just taking you back to Treloar's.  
 5 If we can turn then to hepatitis. Could we have  
 6 TREL0000110\_094, please.  
 7 We can see across the top of this table the  
 8 dates, and if we look at the column dated  
 9 4 March 1981, and we follow the column down to where  
 10 it deals with hepatitis B surface antibody. Just  
 11 towards the bottom. And we can see the word "POS" --  
 12 positive.  
 13 And we can also see the row called "SGOT". The  
 14 column next to the letters is the reference range  
 15 that -- the range that it should be in, and we can see  
 16 the numbers are much higher: 76, 105, 62, 55, 64 and  
 17 68.  
 18 Were you told anything in 1981 about having the  
 19 hepatitis B antibody?  
 20 **A.** Not as far as I can remember, no.  
 21 **Q.** Do you know if your parents were told anything about  
 22 hepatitis?  
 23 **A.** Truthfully, I'm not sure.  
 24 **Q.** Again, in about 1981, 1982, I'm not quite sure when,  
 25 but when you were about 13 or 14, you've said in your

110

1 go to your dorm to use the private house line to ring  
 2 home and ask your parents, have the boys got this  
 3 certain batch number? If so, please stop, send it  
 4 back to the hospital", and we did.  
 5 **Q.** Looking back now, what do you think that was all  
 6 about?  
 7 **A.** At the time, I don't know. I asked Dad, I asked Mum.  
 8 I don't know. Was it a machine mess up? I don't  
 9 know. Not long after that, the truth come out but,  
 10 yeah, at the time, no. It all went back. Me and my  
 11 brother, we had a little corner in a downstairs  
 12 toilet. That was safe from being -- quite stacked, to  
 13 having three or four left, with not that batch number  
 14 on. That's what we had left. So they took all the  
 15 rest back.  
 16 **Q.** Because you'd had a large number of that batch number?  
 17 **A.** Yeah, we did, because there was two of us and Tone was  
 18 already on -- he was already on proph at home and he'd  
 19 go up the general and "Put you on proph, Tone".  
 20 **Q.** I think you then remember being home for holidays and  
 21 seeing Dr Chisholm in the early 1980s, and you have  
 22 described her changing her tune with you.  
 23 **A.** Yeah.  
 24 **Q.** What do you mean by that?  
 25 **A.** We used to live in -- not in the country, a lot of the

112

1 guys would know where I'm on about, but we used to  
2 live in -- slightly out of the way of Southampton and  
3 Dad and Mum heard of the famous General Hospital being  
4 built, and it's got a haemophiliac centre coming. And  
5 so to make life easier for them, we moved a bit closer  
6 to the hospital.

7 Dr Chisholm had known us since we were -- oh, God,  
8 '74? I was little, five, six. Tony, when he was  
9 a baby, right up until he moved from the area. And she  
10 always bantered with us, always. We got kicked out of  
11 wheelchairs. "You boys, the Bennett boys, are going to  
12 be parted, you can sleep in that bed, you can sleep in  
13 that bed".

14 And that was Dr Chisholm. When everyone -- "Which  
15 one is it?" Mum, [redacted], "It's Gary", "Which one is  
16 it?" "Oh, it's Tony today."

17 But because we were young, we all used to go, talk  
18 to the nurses, the regular lot. And then I do remember  
19 having a meeting with Dr Chisholm. I think it was  
20 Factor VIII, might be a check-up, and her attitude had  
21 changed, to be polite, to professional. There was no  
22 banter. There was no "How's the other one? How are  
23 they doing?" There was none of that. It was  
24 professional.

25 Q. I think you think that was sort of early 1980s --

113

1 A. No.

2 Q. Do you think your parents were aware?

3 A. No.

4 SIR BRIAN LANGSTAFF: It may be that they began in  
5 February --

6 MS FRASER BUTLIN: Indeed --

7 SIR BRIAN LANGSTAFF: -- given the dates --

8 MS FRASER BUTLIN: -- given the dates.

9 SIR BRIAN LANGSTAFF: -- on the second page.

10 MS FRASER BUTLIN: Yes, indeed.

11 SIR BRIAN LANGSTAFF: The second line.

12 MS FRASER BUTLIN: 28 February 1983. Thank you, sir.

13 You left the college in 1984.

14 A. Yeah.

15 Q. I think around that time you met a girl called  
16 Lorraine?

17 A. I did, I did meet Lorraine.

18 Q. Can you tell us what happened?

19 A. It was my first proper girlfriend when I left college.

20 We just met and we clicked, and we were getting  
21 serious. I was 16, 17, and Mum and Dad could see us  
22 getting closer but questions were being asked from my  
23 mum and dad. And it turned out that eventually my mum  
24 and dad went round to meet her mum and dad, and they  
25 spoke about me. And let's just say that was the end

115

1 A. I think she knew.

2 Q. -- before you were diagnosed?

3 A. Yeah, I think she knew.

4 Q. You think she knew that there was something --

5 A. Wrong.

6 Q. -- wrong?

7 A. Yeah.

8 Q. If we just carry on the timeline?

9 A. Yeah, sure.

10 Q. Could we have TREL0000110\_055, please. A letter from  
11 Dr Wassef to Dr Chisholm dated June 1983 and at the  
12 bottom of the letter we can see the heading "AIDS  
13 related investigations":

14 "Clinically he exhibits none of the stigmata of  
15 AIDS. Examination of his superficial lymph nodes on  
16 28.2.83 revealed palpable bilateral shotty inguinal  
17 lymph nodes. There was no change when re-examined on  
18 9.6.83 apart from a palpable tiny left cervical lymph  
19 node.

20 "For your information we have undertaken the  
21 enclosed AIDS related tests. We are repeating these  
22 before the end of term and will let you have a copy of  
23 the results when they are available."

24 Were you aware, in June 1983 that AIDS-related  
25 investigations were being undertaken?

114

1 of the relationship.

2 I've seen her since and I've seen her mum and dad  
3 since, and they regret everything that happened that  
4 day. But that's the way it was.

5 Q. Your understanding is the relationship came to an end  
6 because they were worried --

7 A. Worried --

8 Q. -- you might have --

9 A. -- Lorraine's mum and dad was worried, which I suppose  
10 if you ask me, if it was here now and it was my  
11 daughter, I'd probably be the same. Yeah.

12 Q. You think you were told that you were HIV positive in  
13 about 1986.

14 A. I think so, yeah.

15 Q. How were you told?

16 A. Again, I think I had a meeting with Dr Chisholm. And  
17 she said, "Gary" -- oh, it's a long time ago. I think  
18 I had a meeting and she said, "Gary, I've got some bad  
19 news for you, you've been infected".

20 No, "Do you know what's been happening  
21 recently?" Because it was just starting to come up.  
22 "Have you been listening and reading the telly?" And  
23 I said, "Yes", and she said "I'm really sorry but  
24 you're also infected with HIV". Something like that.

25 Q. At that stage, what was your reaction? What were your

116

1 thoughts?

2 **A.** Why me? I went home and hibernated for a year.

3 Didn't want to see anybody. Didn't want to go out.

4 Mum and Dad used to talk to me. I'd say, "You'll

5 never have -- you'll never see me get married, Mum,

6 and have grandchildren", how wrong I was. But ...

7 And I hibernated for about a year. They were bad

8 times.

9 **Q.** At some point you then met Renee. A bit later you

10 told her and her friend that you had something to tell

11 them?

12 **A.** God.

13 **Q.** What happened?

14 **A.** What happened? There was no mobile phones in them

15 days, and everybody was ringing up "Where's Gaz?"

16 "He's upstairs, he don't want to see nobody."

17 Towards the end of the year, it was about a year,

18 I just didn't want to do nothing. Nothing. Nothing at

19 all. My dad said to some well-known friends, and they

20 know who they are, "You need to come round and get him

21 out. You need to physically walk in the house and drag

22 him out."

23 They know who they are. And I love them to

24 pieces. And they did. And then through them and some

25 other friends, I met Renee. I knew Renee anyway but we

117

1 infection risk?

2 **A.** Yeah. Oh, we've all been there. Yellow stickers on

3 everything. She was virtually walking down the

4 corridor with her "Hazardous" stickers wrapped around

5 her. She had blood tests once a week, twice a week.

6 Dr Chisholm said, "Gary, it can go either way,

7 would you like us to do a test? I think you're doing

8 enough with your blood tests."

9 Looking back, I was very lucky. I've been married

10 twice and Renee is fine, and my son's mum is fine, so

11 ...

12 **Q.** You've described that during the eighties your

13 relationship with Renee was -- it ultimately broke

14 down?

15 **A.** It did.

16 **Q.** And that she went through hell and back with you?

17 **A.** Probably. Yeah.

18 **Q.** That's how you've described it in your statement?

19 **A.** Yes, probably. Looking back, yes.

20 **Q.** Can you tell us about that time?

21 **A.** I was angry, I think. Many a times. Many a times I'd

22 probably end up drunk. I wasn't violent, I don't

23 think, but I used to get into a state where I was just

24 a mess, in the gutter.

25 I loved her to pieces but I couldn't handle what

119

1 weren't close. I knew her through somebody else. In my

2 role back then, because I didn't want a girlfriend,

3 I wanted to pick them all up. So I picked Renee up and

4 at the time a friend of Renee's straight away, "Where

5 have you been? Where have you been?"

6 "Oh I've just been home."

7 "Why?"

8 "There's something I need to tell you."

9 And Renee went over my shoulder and went, "Ah,

10 you're going to tell us you got AIDS."

11 And that's how Renee found out about me. We sat

12 there, all three of us, on that summer's day, crying our

13 eyes out.

14 I said, "I haven't got AIDS. I'm still here. And

15 we're going to out to meet the others and have a good

16 night."

17 But Renee and her mate wouldn't leave me alone all

18 night. Oh dear, it was a good time.

19 **Q.** You married Renee?

20 **A.** I did marry Renee; yeah. We can have a giggle, but

21 yes, I did. Yes.

22 **Q.** You said that your diagnosis really hit home again

23 when she was pregnant with your daughter?

24 **A.** Oh god, yeah.

25 **Q.** And that was largely because she was treated as an

118

1 was going on with ... all of it, I suppose, the

2 hospital -- I worked nights. During the day, getting

3 up, going to the hospital. And it did break down. It

4 did break down. Yeah.

5 **Q.** During that time, what was your physical health like?

6 **A.** As far as I know, apart from a right knee that really

7 got bad, I was quite well. As far as I know, yeah.

8 **Q.** You've referred to your second wife, and you remarried

9 in 2004.

10 **A.** Yes.

11 **Q.** You've described in your statement a particular day

12 with your second wife and some friends of hers, where

13 your diagnosis --

14 **A.** Yeah.

15 **Q.** -- your infection was a particular issue. Do you want

16 to tell us what happened?

17 **A.** I met -- can I mention her name? Is that all right?

18 **Q.** I think that might be redacted, actually. Sorry, your

19 second wife's name?

20 **A.** Yeah.

21 **Q.** That's fine.

22 **A.** I met Jan, and we were just starting out. By this

23 time we had -- we had Kerry, and she loved her mum and

24 she loved me. And I did say to Jan, "If you don't

25 like my daughter, that's the end of our relationship."

120

1 How wrong I was. They got on really well. And  
 2 I'm slowly meeting people Jan met in her life. Certain  
 3 friends. We're still very close now. And we'd had an  
 4 invite to somebody's house to have a bite to eat.  
 5 "He's into classic cars. You'll get on well with  
 6 him."  
 7 And I did. I thought he was a nice guy. Spent  
 8 half the afternoon underneath one of the cars talking  
 9 about old cars. A few years later down the line, that  
 10 relationship between them two was over and the person in  
 11 question met somebody else. She told me that the minute  
 12 I left, he ransacked the kitchen and binned everything  
 13 that I'd touched, and he was just speaking to me an hour  
 14 ago outside.  
 15 **Q.** In terms of your personal relationships, that marriage  
 16 broke down?  
 17 **A.** It did, yeah.  
 18 **Q.** And you've been back together with Renee again  
 19 since 2010?  
 20 **A.** I don't know if that's a good thing, but yes, I have.  
 21 Yes, I have. Yes, I have.  
 22 **Q.** I just want to talk with you a little bit about Tony.  
 23 **A.** Yeah, sure.  
 24 **Q.** Tony was also diagnosed as being HIV positive?  
 25 **A.** Mm-hm.

121

1 the hospital on his own and he'd come home on his own.  
 2 That was it, that was the end of the conversation.  
 3 **Q.** You and Tony both also had hepatitis C.  
 4 **A.** Mm-hm.  
 5 **Q.** What's your recollection of how you were told that you  
 6 had been infected with hepatitis C?  
 7 **A.** I think -- I'm not 100 per cent sure on dates, I think  
 8 it's around about '95, '96. Me and Jan went to a --  
 9 we were invited to a party, that morning I had  
 10 a letter. I've no idea where that letter is. And in  
 11 that letter it stated that, "I'm really sorry,  
 12 Mr Bennett, but I have some bad news, you are now  
 13 infected with hepatitis C."  
 14 We went to the party and we'd stood out of the  
 15 way a little bit and people were coming up and saying  
 16 to Jan, "What's the matter with Gary?"  
 17 "He's just found out he's got hep C."  
 18 That sticks in my head. I can remember that.  
 19 **Q.** Tony underwent treatment for hepatitis C in 2004?  
 20 **A.** He did.  
 21 **Q.** What can you tell us about how Tony was during that  
 22 treatment?  
 23 **A.** As far as I know, a lot better. And I believe  
 24 a certain drug was working. But, in my eyes right  
 25 now: but he's not here.

123

1 **Q.** Do you know how he was told of his infection?  
 2 **A.** I don't personally. Probably like me. Maybe in  
 3 a room. But I can't remember. He was slightly  
 4 younger than me so I don't know if mum and dad went  
 5 with him up the General, I'm not sure.  
 6 **Q.** Did he ever tell you about how he was diagnosed or how  
 7 he was told of his diagnosis?  
 8 **A.** He probably did but I can't remember now. I can't  
 9 remember.  
 10 **Q.** What was Tony's reaction to knowing that he was  
 11 infected? How did he deal with it?  
 12 **A.** He was angry. Was he angry! He was very angry. He  
 13 wouldn't -- he wouldn't talk like we are now. He  
 14 would -- he locked himself away for years. He would  
 15 talk to me. If it was a family event, and we were  
 16 stood in the corner, "Gar, have you tried this  
 17 treatment yet?"  
 18 "No."  
 19 "Oh, it's good, it works."  
 20 But he wouldn't tell his partner or anybody.  
 21 Wouldn't tell mum and dad, nothing. But he'd talk to  
 22 me.  
 23 **Q.** You said in your statement that, other than talking to  
 24 you, he really shut down?  
 25 **A.** He did. He did shut down. So much that he went to

122

1 **Q.** Tony died in 2005.  
 2 **A.** He did.  
 3 **Q.** Your understanding was that he'd had a stroke.  
 4 **A.** Yeah.  
 5 **Q.** In some other documents you've seen that it might have  
 6 been an encephalopathy, but you've said in your  
 7 statement you think it was just build-up of  
 8 everything.  
 9 **A.** Everything. Stress. Never spoke to anybody. Nobody,  
 10 not even his partner, towards the end. No, nobody.  
 11 **Q.** Shortly after Tony died, your father also died.  
 12 **A.** Yes, he did.  
 13 **Q.** You said your dad had no hope at all after Tony died?  
 14 **A.** It was mentioned by Sir Brian earlier that my dad  
 15 couldn't get it in his head that he was burying his  
 16 son first, and my dad got cancer, and you could have  
 17 given him the cure drug but he could not get round his  
 18 head that he buried Tony first, and he did die. He  
 19 did die, and he was my best friend.  
 20 **Q.** You said that after your father died your life just --  
 21 **A.** Yeah.  
 22 **Q.** -- went to pieces.  
 23 **A.** He was my best friend. He worked. I got him a job  
 24 with me. We all do things in life but my dad actually  
 25 worked with me at our company, and it was my dad

124

1 driving a lorry, and you hear all the guys say, "Alan,  
2 Alan", but I had to still stand there and go "Dad,  
3 Dad". It was weird. It was weird. We had a good  
4 time, a good few months together before he fell ill.  
5 And we were friends, we were mates, not father and  
6 son.  
7 **Q.** You describe in your statement the effect of both  
8 Tony's death and then your dad's death --  
9 **A.** Yeah.  
10 **Q.** -- was enormous on you emotionally?  
11 **A.** Yeah.  
12 **Q.** When Tony died, you'd been having treatment for your  
13 own hepatitis C infection?  
14 **A.** Yeah.  
15 **Q.** It was with -- seems to be interferon, the  
16 injections --  
17 **A.** Yeah.  
18 **Q.** -- into your stomach.  
19 **A.** Yeah, it was, yeah.  
20 **Q.** What were the side effects that you felt from that  
21 treatment?  
22 **A.** I can't remember having side effects. I got very  
23 tired. And apparently, so I've been told, I got quite  
24 moody. And I've been told I've still got it some  
25 days, but hey, that's the way it is.

125

1 place at that point?  
2 **A.** I was. I was.  
3 **Q.** And that you were encouraged by Jan and by Kerry to  
4 attend the Macfarlane Trust weekends?  
5 **A.** Yeah.  
6 **Q.** Can you tell us how you found those weekends, what  
7 those weekends were like for you?  
8 **A.** I was hearing people from college -- ooh, I don't want  
9 to sound bad but people we all knew were slowly  
10 getting ill and passing away. And losing my dad and  
11 my brother, and home life and jobs, I suppose, yes, I  
12 needed to get away. I needed to do something  
13 different. I've always been a bit of an outsider.  
14 I've heard through the grapevine that certain people  
15 are still with us, not with us. So I've always had an  
16 ear but I've never really been involved. And I went.  
17 I got in contact and I went.  
18 I come out -- I come out that weekend and  
19 I cried. Did I cry. And I didn't kick myself but  
20 I thought, I had no problems. I had no problems.  
21 Listening to some -- some of us lads and their  
22 stories, virtually dragging their backsides down the  
23 hospitals, and there's me walking around going, "What  
24 are you moping for?"  
25 That was a hard weekend, the very first one.

127

1 **Q.** Not long after Tony's death, not long after your  
2 father's death, you were then told that the treatment  
3 was unsuccessful.  
4 **A.** Yeah, yeah, it was.  
5 **Q.** Can you tell us about how you were at that point?  
6 **A.** I think physically I was okay. I was getting over the  
7 loss of Tone and Dad, and I was doing my injections  
8 and, as far as I knew, all the blood tests were good  
9 and it was working. Tony was in front of me. He was  
10 about 12 months, just about to come to the end, and  
11 I'd just started. And yeah, we were talking, "My  
12 belly's bruised, Tone". "Yeah, it will get better, it  
13 will get better".  
14 When we lost Dad and Tony, yeah, I remember the  
15 phone call, standing in the garage and my nurse from the  
16 hospital rung me and said, "Hiya Gary, it's so and so".  
17 I said "Hello". "Gary, you sound really quiet, are you  
18 all right?" I said, "No, not really", I said "Christmas  
19 Day I lost my brother, and I've just found out my dad's  
20 died of cancer". "Oh, Gary, oh my God", she said, "I've  
21 got more bad news for you, I need you to stop your jabs  
22 because it's not working."  
23 And I don't know why but I still think: I'm here,  
24 Tony's not here.  
25 **Q.** Your statement describes that you were in quite a bad

126

1 I remember there was somebody else new. I don't know  
2 his name anyway. And we sat out the back a bit -- like,  
3 the conference was that end, and I sat out the back, out  
4 of the way listening to Joe Bloggs, blah, blah, blah.  
5 After that, it all closed down, we're both in the  
6 toilet.  
7 "God, that was a hard one."  
8 "Yeah, you're telling me."  
9 Looked around, and we're both crying. Both  
10 crying.  
11 He said, "I haven't been involved at all."  
12 And I said, "I have a little bit but not as bad as  
13 these guys. They've been from day one."  
14 And we both -- oh, that was clear as a bell. But  
15 we ended up cuddling and a guy come in and, like you do,  
16 being the blokes, "Shall I go out of the room?"  
17 "No, you're all right."  
18 And that was the way we broke the ice, yes. But  
19 that was my first time away.  
20 **Q.** And I think you've described going to three weekends?  
21 **A.** I did go, yes.  
22 **Q.** And finding them very helpful?  
23 **A.** Oh, I did, yes. Yeah. Just hearing bits and pieces.  
24 I mean, even now we've -- we've spoken last night,  
25 a few of us. I still run between two hospitals. And

128



1 they've all gone, eh? I still run -- I've seen the  
2 document and it was a problem back in '85 and it's  
3 still a problem today. Why do I have to run to two  
4 hospitals? Can please somebody tell me why I've got  
5 to run to two hospitals?

6 **Q.** One for your haemophilia care --

7 **A.** Yes.

8 **Q.** -- and one for the HIV clinic?

9 **A.** The clinic, yes.

10 **Q.** Going forwards in time, you then had further treatment  
11 for your hepatitis C from the end of 2016 until the  
12 end of May 2017.

13 **A.** Mm-hm.

14 **Q.** What do you recall of the side effects of that  
15 treatment?

16 **A.** You see, I can't ... unless you say something  
17 different, I can't remember any side effects.  
18 Probably still moody, probably still grumpy. But  
19 actually going out the hospital to say I've got a lump  
20 or a rash, as far as I know, no, I never did.

21 **Q.** Your statement recalls that while you were on those  
22 tablets you were quite depressed and you were arguing  
23 a lot with Renee.

24 **A.** There you go, then. There you go. Yeah.

25 **Q.** And you've -- I'll read the part of the statement --

129

1 I go. When they're due, I go. Definitely.

2 **Q.** Just one final matter. In terms of finances, I just  
3 want to ask you about one thing. You remember, a long  
4 time earlier, going with Tony to receive --

5 **A.** I know exactly.

6 **Q.** -- the first lump sum payment.

7 **A.** I know exactly what you're going to say, yes.

8 **Q.** What can you tell us about that first --

9 **A.** That was mentioned earlier today and it's a ...  
10 exactly the same as earlier. But yes, I remember Dad  
11 coming in, "Boys, we've got a -- we've got to go to  
12 London. There's a little matter of a little payout  
13 for you boys, and we need to go up to London and see  
14 this gentleman and we'll go from there."

15 And being excited, you are going to laugh, you are  
16 going to laugh. I always fancied being a typical  
17 English guy with a newspaper and to flag down a black  
18 cab. I've achieved that goal. We were young, all of  
19 us. I think we'd come up by train, got the cab, went to  
20 a certain building. And then the doors opened,  
21 I remember it being a big room, marble floors. We were  
22 young, all of us. I think we were even sliding on the  
23 marble floor. And this certain gentleman said to my mum  
24 and dad, and to us, "If you sign the bit of paper you'll  
25 walk out of here with 20 grand. If you don't, you won't

131

1 **A.** Yeah, please do.

2 **Q.** -- of the statement if I may.

3 "We were arguing ... we don't normally argue.

4 I became inward and laid back, I was really laid back.

5 Renee said it was the tablets. I was really low and

6 I kept crying. I said Renee should leave and I would

7 help her get a flat. Her reaction was, if you think

8 I have waited for you for nineteen years to walk out" --

9 **A.** Yes, she did. She did.

10 **Q.** And that treatment was successful in clearing --

11 **A.** Yes, it did.

12 **Q.** -- the hep C?

13 **A.** Yeah.

14 **Q.** What's the condition of your liver now?

15 **A.** Absolutely, shot to pieces. No, I'm not sure. I'm  
16 not a hundred per cent sure. I know it's damaged.

17 I know it is. They can take it out, scrape off the

18 mould and put it back in. So as far as I know it

19 hasn't got worse, it ain't got better, but I'm all

20 right.

21 **Q.** You've described in your statement that they've said  
22 it looks a bit like a cauliflower?

23 **A.** Yes, yes. Basically, yes, they have, yeah.

24 **Q.** And do they monitor your liver now?

25 **A.** Yes, they do. And I'm really good at my appointments.

130

1 get nothing again."

2 We were so -- I was 17, 18, and Tony was a bit  
3 younger. We signed it, we went out, and we had a good  
4 time. That's the end of that.

5 **MS FRASER BUTLIN:** Sir Brian, they're the questions I have  
6 for Gary. I'm just going to look behind in case  
7 anything has come through.

#### 8 Questions from SIR BRIAN LANGSTAFF

9 **SIR BRIAN LANGSTAFF:** Well, just two questions. One is,  
10 are you aware that as you've sat there, your voice has  
11 gone from being quiet and slow to you're entertaining  
12 the room with your anecdotes?

13 **A.** Sir Brian, I've turned my life around. I'm okay with  
14 my life. I've got lots of things happening. I've got  
15 lots of adult children -- now they're adults -- and  
16 I've got four grandchildren, and they keep me going.  
17 I've got a good job, a very good job, and I love, I do  
18 love -- I love my life now. And we were supposed to  
19 get married this year but next year it's going to  
20 happen. I think the world of her and she knows that.  
21 She's my soul mate.

22 **SIR BRIAN LANGSTAFF:** The only other thing that I want to  
23 ask. I don't want to put you back into the quiet  
24 miserable mode --

25 **A.** No, not at all.

132

1 **SIR BRIAN LANGSTAFF:** -- but what do you reckon was the  
2 worst thing about your experiences? Apart from losing  
3 your dad.

4 **A.** It's got to be Tony, I think. Even though his death  
5 certificate don't say that, but I think it was all the  
6 stress, all the build-up. And we saw him because he  
7 moved just down the road from here, funnily enough, so  
8 we had an hour's drive that night, Christmas Eve. And  
9 when we got to the hospital -- no, we knew, all of us  
10 know, Alton quite well and we know the A3, all of us.  
11 And I remember coming down that road that we'd done  
12 for years with Dad driving us back to college. And at  
13 three minutes past one, out of nowhere, there was  
14 a gust of leaves around the car, just out of nowhere.  
15 Just going up.

16 When we got to the hospital, "Mr and  
17 Mrs Bennett, boys, come in the side room. I'm really  
18 sorry, Tony passed away at three minutes passed one.  
19 And he is exactly how we've left him because we know  
20 you've just done an hour-and-a-half drive. Mum, you  
21 are going to see some tubes, drips still in him", and  
22 he was, apart from being asleep, he was dead. So  
23 Tony -- I think tony will always haunt me.

24 **SIR BRIAN LANGSTAFF:** That memory of the leaves at the  
25 same time?

133

1 name. I think it's still on there, but I'm still here.  
2 So maybe that paper might just be screwed up. I don't  
3 know. And hopefully, as somebody said to me half  
4 an hour, I'll lose that chip off my shoulder. You know,  
5 I know you're listening. And I love all of you to  
6 pieces. And I'll be home in a few days.

7 Thank you, Sir Brian, and thank you, team.  
8 [Applause]

9 **SIR BRIAN LANGSTAFF:** Thank you, Gary. It's obviously --  
10 it wasn't when you started -- a task you were  
11 enjoying, particularly, giving evidence. I think, as  
12 I've already indicated, you got much happier about  
13 that towards the end.

14 **A.** Yes, I did. Yeah, and I think it's listening out  
15 there yesterday, because we were early, and I want to  
16 listen to a couple. I'm well out of my comfort zone  
17 sat here. I drive a digger for a living. And for all  
18 us guys, if it makes you guys feel better, I pull dirt  
19 around all day and I pick that bucket of dirt up, and  
20 I've hurt a lot of medical team staff that hurt us  
21 back in the 1980s, but that's my job and I love it.  
22 So yesterday helped. I was nervous when I got here  
23 again, and I'm quite relaxed. I've done my bit. And  
24 you listened, and I thank you for that.

25 **SIR BRIAN LANGSTAFF:** Well, it is important to us to hear

135

1 **A.** Yeah, yeah, it just happened. Just happened out of  
2 the blue. All of us know that road like the back of  
3 our hands. I know that road like the back of my hand.  
4 I've driven it many a time since leaving college, and  
5 I could take you, I could take you to that spot with  
6 them leaves just nowhere, no trees around, just went  
7 up like that. At three minutes passed one, he passed  
8 away.

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

10 **MS FRASER BUTLIN:** Gary, is there anything else you'd like  
11 to say?

12 **A.** What would I like to say? Probably loads. I'll  
13 probably regret saying some things when I leave this  
14 bench in a minute. I think these guys in front of me,  
15 past and present, are amazing. I didn't think this  
16 would ever happen, and it is, and people are  
17 listening. We didn't ask for it but we got it. Some  
18 of us managed it, some of us haven't.

19 I've got some great support from family, friends  
20 now. They pushed me outside earlier. I had hundreds  
21 come through.

22 I'd like to say thank you for Sir Brian for  
23 listening and of course you guys, the team, the Inquiry  
24 team. I honestly thought for a long time my name was on  
25 a bit of paper out of all of us, and on there was my

134

1 a number of very different people give evidence about  
2 very much the same thing, how it affects them in  
3 different ways. As you said, it takes all sorts.

4 **A.** Yeah.

5 **SIR BRIAN LANGSTAFF:** That's why it is so important that  
6 you, amongst others, have given your evidence. Thank  
7 you.

8 **A.** Thank you.

9 **MS FRASER BUTLIN:** Tomorrow, sir, we will be hearing from  
10 Mr BC, an anonymous witness, followed by Lee Stay.  
11 And then in the afternoon we anticipate that the  
12 presentation will be continued.

13 **SIR BRIAN LANGSTAFF:** Very well, ten o'clock tomorrow.  
14 Ten o'clock.

15 **(3.02 pm)**

16 **(Adjourned until 10.00 am the following day)**  
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18  
19  
20  
21  
22  
23  
24  
25

136

1	<b>INDEX</b>	
2	NICHOLAS SAINSBURY (affirmed) .....	1
3	Questions by MS RICHARDS .....	1
4	Questions from SIR BRIAN LANGSTAFF .....	55
5	JOHN DAVID PEACH (sworn) .....	65
6	Questions by MS RICHARDS .....	65
7	Questions from SIR BRIAN LANGSTAFF .....	94
8	GARY BENNETT (sworn) .....	97
9	Questions by MS FRASER BUTLIN .....	97
10	Questions from SIR BRIAN LANGSTAFF .....	132

11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25

<b>MS FRASER BUTLIN:</b> [8] 97/8 115/6 115/8 115/10 115/12 132/5 134/10 136/9 <b>MS RICHARDS:</b> [26] 1/25 14/20 36/2 36/5 36/8 36/17 37/15 54/15 54/18 55/16 56/19 57/3 57/12 64/5 64/18 65/10 77/8 77/12 85/4 85/6 92/5 94/5 95/2 95/22 96/19 96/22 <b>SIR BRIAN</b> <b>LANGSTAFF:</b> [60] 1/3 1/6 1/8 1/11 1/14 12/16 12/20 14/1 14/4 35/25 36/3 36/7 36/12 37/14 54/16 55/15 55/21 56/7 56/13 56/16 56/25 57/8 63/11 63/15 63/17 64/13 64/20 65/1 65/3 65/6 77/7 77/10 85/3 85/5 92/4 94/9 94/17 94/20 95/1 95/25 96/6 96/9 96/12 96/16 96/21 96/23 97/2 115/4 115/7 115/9 115/11 132/9 132/22 133/1 133/24 134/9 135/9 135/25 136/5 136/13 <b>THE WITNESS:</b> [6] 1/5 1/7 1/10 1/12 65/2 65/5 * '66 [1] 69/4 '74 [1] 113/8 '75 [1] 11/15 '79 [1] 98/5 '83 [1] 82/19 '84 [3] 73/8 83/21 88/22 '85 [5] 30/6 77/7 85/8 88/18 129/2 '85 and [1] 129/2 '86 [1] 30/5 '87 [1] 93/20 '89 [1] 30/7 '91 [1] 90/17 '95 [1] 123/8 '96 [1] 123/8 'Your [1] 48/17 * -- and [1] 35/3 -- hard [1] 49/23 -- into [1] 125/18	<b>0</b> 003 [1] 23/19 006 [1] 21/3 012 [1] 69/18 013 [1] 69/6 016 [1] 76/23 017 [1] 73/13 018 [2] 22/17 55/24 020 [1] 19/7 021 [1] 15/22 022 [2] 10/25 11/2 023 [1] 18/9 028 [1] 25/7 030 [1] 87/6 031 [1] 86/17 034 [1] 72/16 037 [2] 74/16 82/14 038 [1] 86/5 041 [2] 70/24 102/1 043 [2] 74/9 88/16 055 [1] 114/10 06 [1] 94/1 067 [1] 24/17 06M6575 [1] 25/18 080 [1] 105/10 094 [1] 110/6 <b>1</b> 1 July 1984 [1] 83/13 1,000 [1] 48/11 1,200 [2] 92/21 92/22 1.30 [1] 64/16 10 [2] 14/7 79/12 10 pm [1] 101/13 10 years [2] 35/17 109/8 10,000 [1] 109/22 10.00 [2] 1/2 136/16 100 [1] 67/5 100 per cent [1] 123/7 105 [2] 83/9 110/16 10ml [1] 25/23 11 [4] 3/2 14/8 69/3 84/20 11 December 1984 [1] 73/15 11 March 1977 [1] 19/9 11 September [1] 69/18 11.38 [1] 64/23 12 [5] 64/15 64/22 69/3 69/4 87/7 12 December 1979 [1] 23/20 12 months [1] 126/10 12.04 [1] 64/25 12.51 [1] 96/24 126 [1] 81/18 13 [2] 29/14 110/25 13 January '84 [1]	88/22 13 July 1990 [1] 33/9 135 [1] 104/3 137 [2] 79/6 100/25 14 [2] 82/4 110/25 14 February 1980 [1] 75/17 14 June 2018 [2] 28/22 28/25 14 September 1980 [1] 101/5 14.3.83 [1] 82/23 15 [1] 5/6 15 November [1] 79/25 15 years [1] 51/8 16 [3] 14/15 62/20 115/21 16th [1] 53/20 17 [3] 41/20 115/21 132/2 17 August 1989 [1] 29/19 18 [3] 3/15 101/10 132/2 18 November 1985 [1] 86/24 19 [1] 76/11 19 haemophilia [1] 61/7 19 March 1985 [1] 76/25 1966 [1] 65/15 1969 [1] 65/15 1970s [2] 6/25 56/11 1974 [5] 2/16 2/22 3/1 13/17 57/19 1975 [8] 5/2 5/24 5/25 11/4 14/22 18/12 25/7 25/18 1976 [3] 5/24 15/24 75/5 1977 [3] 13/17 19/7 19/9 1978 [7] 13/12 22/21 24/22 59/14 69/1 71/4 71/8 1978/79 [1] 13/14 1979 [5] 7/17 8/17 22/22 23/20 74/12 198 [1] 73/7 1980 [13] 3/24 21/13 21/15 26/25 69/10 71/4 74/25 75/17 76/11 101/5 101/7 101/8 101/20 1980s [3] 112/21 113/25 135/21 1981 [11] 79/4 79/10 101/11 101/13 101/14 101/15 101/20 102/2 110/9 110/18 110/24	1982 [6] 103/11 104/11 104/11 105/18 106/4 110/24 1983 [10] 81/19 82/4 82/7 82/10 82/15 83/8 106/11 114/11 114/24 115/12 1984 [6] 73/15 74/5 77/16 83/13 84/6 115/13 1985 [12] 29/23 30/13 76/25 77/25 78/21 84/21 86/10 86/12 86/24 87/7 88/19 89/7 1986 [3] 29/21 85/11 116/13 1986/87 [1] 93/19 1989 [2] 29/19 32/18 1990 [5] 29/10 29/14 33/9 36/13 90/8 1990 I was [1] 34/3 1991 [1] 34/4 1991 settlement [1] 33/17 1993 [3] 29/15 33/10 91/14 1996 [1] 39/1 1997 [1] 39/5 <b>2</b> 2 July 1986 [1] 29/21 2,000 [1] 109/22 2.00 [1] 97/1 20 [3] 9/12 23/6 73/21 20 August 1985 [1] 86/10 20 grand [1] 131/25 20 minutes [1] 103/23 20,000 [3] 35/18 47/13 47/14 200 [1] 48/6 200,000 [1] 35/16 2003 [1] 34/25 2004 [2] 120/9 123/19 2005 [1] 124/1 2010 [1] 121/19 2016 [1] 129/11 2017 [1] 129/12 2018 [2] 28/22 28/25 2021 [1] 1/1 21 September 1993 [1] 29/15 21,000 [1] 35/14 22 June 1982 [1] 104/11 22 June 2021 [1] 1/1 22 September 1980 [1] 101/7 22,000 [1] 35/15 23 years [1] 91/14 23.1.84 [1] 77/6 24 hours [1] 103/25	25 April 1983 [1] 82/7 26th [1] 80/6 27 [1] 91/16 27 February 1976 [1] 15/24 27 June 1975 [1] 25/18 27th July 1990 [1] 29/10 28 February 1983 [1] 115/12 28 June 1982 [1] 104/11 28 November 1984 [1] 84/6 28.11.84 [1] 73/22 28.2.83 [1] 114/16 29th [1] 46/11 2B [1] 111/17 <b>3</b> 3 DAY [1] 103/15 3 July 1985 [1] 84/21 3 miles [1] 4/12 3.02 [1] 136/15 30 December 1985 [1] 29/23 30 years [3] 49/13 51/21 60/23 31 May 1981 [1] 101/14 32 [1] 54/11 <b>4</b> 4 March 1981 [1] 110/9 4 November [1] 79/18 400 [1] 1/18 440 [1] 19/17 48 [1] 106/7 <b>5</b> 5 June 1978 [1] 24/22 50 [6] 22/12 101/7 101/11 103/21 103/22 103/24 50p [4] 13/18 13/24 58/16 59/8 52 [1] 85/5 520 [1] 79/22 530 [1] 79/15 55 [1] 110/16 550 [1] 79/24 550 units [1] 9/15 <b>6</b> 6 July 1981 [1] 101/15 6 May 1981 [1] 101/13 600 units [1] 82/7 62 [1] 110/16 64 [1] 110/16	66 per cent [1] 57/22 68 [1] 110/17 <b>7</b> 7 July 1983 [1] 82/15 7/52 [1] 85/5 70 [1] 59/25 76 [1] 110/16 79 [1] 13/14 <b>8</b> 8,000 [1] 109/22 8.30 [1] 103/20 80 [2] 47/16 98/11 87 [1] 93/19 89 [2] 62/19 98/11 <b>9</b> 9 May 1981 [1] 102/2 9 November [1] 79/20 9.30 [1] 101/14 9.6.83 [1] 114/18 95 [1] 76/2 <b>A</b> A, [2] 56/10 56/18 A3 [1] 133/10 able [8] 1/16 8/19 10/9 28/1 46/23 48/10 55/23 57/19 abnormal [1] 75/4 about [155] about 1985 [1] 30/13 above [2] 25/16 29/23 abroad [1] 89/21 absence [1] 76/14 absolutely [7] 10/14 28/24 33/23 42/14 90/13 111/12 130/15 academic [2] 67/24 67/24 accept [1] 61/15 access [1] 36/20 accessed [1] 29/8 accompanied [1] 58/25 achieved [2] 8/10 131/18 across [4] 50/1 81/25 104/5 110/7 act [3] 10/18 95/16 95/17 acting [1] 41/16 action [4] 33/19 33/21 33/22 40/16 active [1] 55/15 actual [1] 98/22 actually [22] 11/9 13/11 14/17 17/11 30/11 38/6 44/3 48/18 50/15 53/20 55/22 59/23 63/14 70/21
--	---	--	--	---	--

<p><b>A</b></p> <p><b>actually... [8]</b> 90/4 90/5 92/19 94/17 98/5 120/18 124/24 129/19</p> <p><b>add [1]</b> 95/3</p> <p><b>addressed [1]</b> 87/8</p> <p><b>Adjourned [1]</b> 136/16</p> <p><b>adjournment [1]</b> 96/25</p> <p><b>administer [3]</b> 8/20 66/4 70/8</p> <p><b>administered [2]</b> 69/24 102/6</p> <p><b>adult [1]</b> 132/15</p> <p><b>adults [1]</b> 132/15</p> <p><b>advance [1]</b> 42/19</p> <p><b>advisable [1]</b> 16/14</p> <p><b>affect [1]</b> 8/3</p> <p><b>affected [2]</b> 5/17 16/12</p> <p><b>affects [2]</b> 43/22 136/2</p> <p><b>affirmed [2]</b> 1/23 137/2</p> <p><b>afraid [1]</b> 48/13</p> <p><b>after [39]</b> 6/24 6/25 7/10 8/11 10/8 13/2 20/9 20/14 21/24 23/7 23/15 27/6 32/18 33/16 35/15 40/7 42/25 45/6 45/7 45/16 49/20 59/19 60/14 61/7 61/11 62/25 63/1 63/3 63/9 89/11 89/16 90/12 112/9 124/11 124/13 124/20 126/1 126/1 128/5</p> <p><b>afternoon [4]</b> 64/9 96/20 121/8 136/11</p> <p><b>afterwards [1]</b> 5/18</p> <p><b>again [43]</b> 22/2 22/17 23/20 24/1 24/20 25/8 25/25 27/2 27/24 29/15 34/17 42/9 43/10 43/11 52/5 55/11 57/5 63/2 70/5 71/12 72/17 73/14 75/17 76/5 79/7 79/20 80/4 81/21 82/9 82/16 83/22 94/23 94/25 104/9 105/24 106/4 108/10 110/24 116/16 118/22 121/18 132/1 135/23</p> <p><b>against [6]</b> 9/11 34/24 40/16 41/9 41/25 96/9</p> <p><b>age [8]</b> 2/11 3/1 8/3 14/7 39/7 54/11 97/14 111/15</p> <p><b>age 5 [1]</b> 97/14</p> <p><b>aged [3]</b> 52/10 91/14</p>	<p>91/16</p> <p><b>agent [1]</b> 89/14</p> <p><b>ago [11]</b> 12/12 37/7 44/13 51/8 52/7 52/18 61/13 99/11 107/17 116/17 121/14</p> <p><b>agree [4]</b> 33/21 69/15 72/25 73/4</p> <p><b>Ah [2]</b> 108/9 118/9</p> <p><b>AIDS [25]</b> 41/2 41/18 47/20 50/6 50/9 82/19 82/22 83/1 83/5 83/18 83/19 83/22 83/25 84/22 85/2 85/9 87/1 87/13 88/15 114/12 114/15 114/21 114/24 118/10 118/14</p> <p><b>AIDS-related [1]</b> 114/24</p> <p><b>ain't [3]</b> 109/18 109/19 130/19</p> <p><b>air [1]</b> 46/8</p> <p><b>Alan [2]</b> 125/1 125/2</p> <p><b>alcohol [1]</b> 34/13</p> <p><b>all [155]</b></p> <p><b>allowed [2]</b> 111/9 111/10</p> <p><b>Allsup [1]</b> 29/1</p> <p><b>almost [6]</b> 2/20 20/10 40/10 52/3 52/23 73/18</p> <p><b>alone [1]</b> 118/17</p> <p><b>along [6]</b> 20/18 31/5 38/10 43/3 60/10 95/14</p> <p><b>already [10]</b> 11/10 33/15 41/22 50/14 52/25 60/23 98/8 112/18 112/18 135/12</p> <p><b>also [29]</b> 2/8 13/16 17/17 18/15 18/22 18/23 20/16 31/9 33/20 34/15 35/9 38/19 38/19 45/14 48/9 48/24 51/5 51/9 52/2 62/14 73/19 97/10 97/24 107/21 110/13 116/24 121/24 123/3 124/11</p> <p><b>alt [1]</b> 21/6</p> <p><b>alternate [6]</b> 19/18 20/9 20/20 73/22 105/17 106/13</p> <p><b>alternative [2]</b> 21/7 21/8</p> <p><b>although [5]</b> 3/18 11/6 62/7 75/18 101/12</p> <p><b>Alton [2]</b> 61/6 133/10</p> <p><b>always [21]</b> 13/4 14/6 23/2 26/20 27/19 39/9 42/23 47/9 48/3 49/7 58/16 60/14 80/21</p>	<p>108/17 108/17 113/10 113/10 127/13 127/15 131/16 133/23</p> <p><b>am [19]</b> 1/2 1/12 10/21 16/15 28/10 39/23 62/3 62/20 64/23 66/7 68/25 69/25 75/8 75/24 96/6 103/20 111/9 111/10 136/16</p> <p><b>am I [1]</b> 39/23</p> <p><b>amazing [2]</b> 98/10 134/15</p> <p><b>ambulance [1]</b> 46/8</p> <p><b>America [1]</b> 4/24</p> <p><b>American [4]</b> 34/24 36/24 51/10 80/1</p> <p><b>amongst [1]</b> 136/6</p> <p><b>amount [4]</b> 35/11 58/6 58/15 59/11</p> <p><b>an AIDS [1]</b> 41/2</p> <p><b>an aphyllactic [1]</b> 16/25</p> <p><b>an emergency [1]</b> 2/25</p> <p><b>an end [1]</b> 116/5</p> <p><b>an entry [1]</b> 24/20</p> <p><b>an exchange [1]</b> 74/17</p> <p><b>an eye [1]</b> 75/11</p> <p><b>an hour [1]</b> 135/4</p> <p><b>an infection [2]</b> 41/10 41/24</p> <p><b>an interview [1]</b> 50/19</p> <p><b>an irritating [1]</b> 91/6</p> <p><b>anaphylactic [1]</b> 16/11</p> <p><b>Andy [2]</b> 62/7 63/24</p> <p><b>anecdotes [1]</b> 132/12</p> <p><b>angry [4]</b> 119/21 122/12 122/12 122/12</p> <p><b>ankle [1]</b> 73/19</p> <p><b>Anna [1]</b> 51/17</p> <p><b>Anna Soubry [1]</b> 51/17</p> <p><b>Anne [2]</b> 51/16 51/18</p> <p><b>Annie [1]</b> 8/10</p> <p><b>annoyed [2]</b> 8/18 30/20</p> <p><b>annual [1]</b> 53/18</p> <p><b>anonymous [2]</b> 64/10 136/10</p> <p><b>another [25]</b> 14/10 15/24 17/14 17/15 19/8 20/9 21/1 30/16 31/10 31/16 33/3 34/8 44/5 45/6 46/5 52/20 58/13 58/23 61/20 73/21 76/24 80/8 80/15 90/2 103/8</p> <p><b>answer [2]</b> 26/7 95/19</p> <p><b>answers [3]</b> 51/6</p>	<p>60/20 60/21</p> <p><b>anti [5]</b> 41/5 43/8 43/11 77/5 88/21</p> <p><b>anti-depressants [2]</b> 43/8 43/11</p> <p><b>anti-HTLV-III [1]</b> 88/21</p> <p><b>anti-retroviral [1]</b> 41/5</p> <p><b>antibodies [1]</b> 87/12</p> <p><b>antibody [13]</b> 22/20 22/22 25/19 25/24 36/15 56/9 56/10 57/6 74/12 87/10 87/14 110/10 110/19</p> <p><b>anticipate [2]</b> 64/15 136/11</p> <p><b>antigen [8]</b> 22/21 22/23 22/24 25/15 25/24 56/9 56/10 57/6</p> <p><b>any [61]</b> 6/7 6/8 12/1 12/14 14/22 14/24 19/19 19/22 22/25 23/11 24/25 26/11 27/14 27/17 27/17 28/3 32/3 33/22 34/13 34/19 36/14 37/24 47/20 47/21 49/16 55/18 56/10 56/16 56/17 56/23 60/13 61/18 61/23 64/14 66/21 68/4 72/4 72/4 72/13 74/4 74/5 76/14 78/6 81/4 86/13 87/16 91/4 91/25 93/6 96/10 100/7 100/18 100/18 101/20 102/16 105/5 105/6 105/25 106/16 109/3 129/17</p> <p><b>anybody [6]</b> 24/12 54/22 94/12 117/3 122/20 124/9</p> <p><b>anyone [3]</b> 66/20 81/4 94/18</p> <p><b>anything [32]</b> 14/5 14/5 15/4 15/13 16/25 22/24 26/6 26/8 27/20 34/2 35/7 42/4 55/14 55/19 57/12 68/19 72/15 73/3 83/22 83/23 88/9 88/12 92/23 93/14 94/7 95/2 101/23 106/8 110/18 110/21 132/7 134/10</p> <p><b>anyway [7]</b> 26/23 32/4 37/11 48/21 93/1 117/25 128/2</p> <p><b>apart [9]</b> 26/5 81/13 85/2 89/17 105/23 114/18 120/6 133/2 133/22</p> <p><b>apathetic [1]</b> 31/21</p> <p><b>apathy [1]</b> 15/15</p> <p><b>aphyllactic [1]</b> 16/25</p>	<p><b>Apologies [1]</b> 71/7</p> <p><b>apparently [2]</b> 17/7 125/23</p> <p><b>appear [1]</b> 101/17</p> <p><b>appearing [1]</b> 24/25</p> <p><b>appears [2]</b> 77/17 88/25</p> <p><b>applause [4]</b> 63/12 63/13 95/23 135/8</p> <p><b>application [1]</b> 48/21</p> <p><b>applied [3]</b> 40/19 47/18 48/24</p> <p><b>apply [3]</b> 47/17 47/21 47/24</p> <p><b>appointment [3]</b> 3/17 9/19 43/4</p> <p><b>appointments [2]</b> 109/3 130/25</p> <p><b>apportion [1]</b> 60/12</p> <p><b>appreciate [1]</b> 87/3</p> <p><b>approachable [1]</b> 47/10</p> <p><b>approached [1]</b> 96/3</p> <p><b>approximately [2]</b> 61/7 76/2</p> <p><b>April [3]</b> 21/15 22/22 82/7</p> <p><b>April 1979 [1]</b> 22/22</p> <p><b>are [58]</b> 1/11 1/14 1/16 5/10 5/12 6/5 20/12 21/23 22/1 28/20 35/4 38/1 45/5 46/2 49/3 53/10 56/3 56/21 57/3 57/6 63/23 70/13 70/24 71/3 73/12 75/20 79/9 80/19 81/10 81/18 81/24 83/1 83/3 83/10 87/14 87/14 94/3 94/5 108/9 108/19 110/16 113/11 113/22 114/21 114/23 117/20 117/23 122/13 123/12 126/17 127/15 127/24 131/15 131/15 132/10 133/21 134/15 134/16</p> <p><b>are much [1]</b> 110/16</p> <p><b>area [1]</b> 113/9</p> <p><b>argue [1]</b> 130/3</p> <p><b>arguing [2]</b> 129/22 130/3</p> <p><b>arises [1]</b> 55/25</p> <p><b>arm [4]</b> 8/13 8/13 54/4 103/3</p> <p><b>armchair [1]</b> 47/18</p> <p><b>army [1]</b> 31/22</p> <p><b>Aronstam [11]</b> 6/20 6/23 26/21 69/8 69/19 72/20 73/1 74/23 76/5 76/11 102/3</p> <p><b>Aronstam's [1]</b> 75/16</p> <p><b>around [17]</b> 5/24 8/6</p>	<p>10/16 13/13 29/17 38/22 64/16 108/19 115/15 119/4 123/8 127/23 128/9 132/13 133/14 134/6 135/19</p> <p><b>arrange [1]</b> 25/22</p> <p><b>arrangements [1]</b> 7/13</p> <p><b>arrived [1]</b> 100/4</p> <p><b>as [128]</b> 1/16 1/16 4/13 4/14 7/24 9/14 9/14 9/16 10/2 10/2 10/4 11/9 11/10 13/1 13/3 14/5 14/15 16/20 20/5 22/4 22/7 22/21 22/22 23/1 24/10 24/10 24/12 26/4 28/5 28/9 29/24 32/25 33/1 33/16 34/14 34/14 35/19 36/8 36/17 36/17 39/4 41/14 47/22 48/19 51/1 51/7 51/25 53/14 53/21 56/25 56/25 57/2 59/20 59/23 62/16 62/20 62/21 63/19 64/10 64/18 64/19 66/7 66/7 66/8 66/12 66/12 69/12 69/20 69/20 69/23 70/12 71/19 71/20 72/11 72/12 72/25 73/25 76/15 76/19 77/18 78/11 78/16 78/16 78/22 78/22 80/19 80/19 80/19 85/16 85/25 85/25 86/11 87/2 87/22 89/13 90/20 93/4 100/10 104/10 104/14 104/14 104/16 104/16 105/12 110/20 110/20 118/25 120/6 120/6 120/7 120/7 121/24 123/23 123/23 126/8 126/8 128/12 128/12 128/14 129/20 129/20 130/18 130/18 131/10 132/10 135/3 135/11 136/3</p> <p><b>ashamed [1]</b> 109/4</p> <p><b>ask [28]</b> 1/20 5/12 10/21 26/4 28/10 35/21 47/2 52/24 55/16 55/19 57/9 57/10 65/6 65/10 74/19 79/1 87/5 93/14 93/15 94/7 97/5 99/21 104/1 112/2 116/10 131/3 132/23 134/17</p> <p><b>asked [15]</b> 11/18 12/22 17/9 17/9 17/10 28/15 29/4 30/18 48/6</p>
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<b>A</b>	90/19 90/20	69/21 69/21 70/23 77/6 77/7 77/17 77/20 77/21 77/23 80/16 81/1 81/15 82/10 86/7 87/23 88/22 91/5 91/6 91/24 93/1 94/13 95/17 96/9 97/2 98/10 99/4 99/5 101/2 101/17 101/21 102/5 102/9 103/13 103/19 105/17 106/1 106/6 108/18 109/1 110/15 111/24 113/12 113/20 113/21 115/4 116/11 120/18 125/15 133/4 135/2 135/6 136/9 136/12	46/20 48/17 48/25 49/12 50/23 51/18 51/19 51/20 51/20 52/5 52/17 52/20 53/7 57/18 58/17 60/22 61/23 62/8 63/8 63/9 69/23 72/7 73/4 78/1 78/7 78/18 79/25 83/25 85/9 86/18 86/20 87/11 87/20 92/13 95/9 95/10 95/11 102/5 102/6 116/19 116/20 116/22 118/5 118/5 118/6 119/2 119/9 121/18 123/6 124/6 125/12 125/23 125/24 127/13 127/16 128/11 128/13	<b>better</b> [12] 7/6 7/8 7/14 40/14 45/25 88/4 99/23 123/23 126/12 126/13 130/19 135/18 <b>between</b> [7] 13/17 15/3 24/6 63/23 103/15 121/10 128/25 <b>beyond</b> [1] 1/18 <b>big</b> [3] 41/13 59/21 131/21 <b>Biggs</b> [1] 11/18 <b>bilateral</b> [1] 114/16 <b>binned</b> [1] 121/12 <b>Biochemically</b> [1] 23/23 <b>biopsy</b> [1] 44/11 <b>birthday</b> [3] 53/21 53/25 63/25 <b>bit</b> [46] 5/5 8/16 8/18 8/21 9/16 13/5 18/1 18/6 26/20 27/21 30/24 30/24 32/15 37/2 39/24 40/11 43/13 43/25 44/3 44/4 45/11 45/15 48/1 48/3 48/4 48/13 57/22 67/6 68/2 81/12 81/14 99/23 103/6 107/9 113/5 117/9 121/22 123/15 127/13 128/2 128/12 130/22 131/24 132/2 134/25 135/23 <b>bite</b> [1] 121/4 <b>bits</b> [1] 128/23 <b>black</b> [1] 131/17 <b>blackmail</b> [1] 92/16 <b>blackout</b> [1] 46/2 <b>blah</b> [3] 128/4 128/4 128/4 <b>blame</b> [2] 31/11 60/13 <b>blamed</b> [1] 61/18 <b>blank</b> [2] 11/16 26/8 <b>bled</b> [1] 3/13 <b>bleed</b> [16] 7/21 9/5 9/8 10/14 13/6 20/9 32/3 44/17 59/19 59/20 61/9 67/4 72/15 82/6 103/2 110/2 <b>bleeding</b> [1] 77/2 <b>bleeds</b> [13] 3/6 19/19 20/2 20/6 21/10 73/18 73/19 84/9 84/12 84/13 93/8 105/13 106/7 <b>bless</b> [1] 18/4 <b>blighted</b> [1] 61/4 <b>blocked</b> [2] 39/17 39/18 <b>Bloggs</b> [1] 128/4 <b>blokes</b> [1] 128/16 <b>blood</b> [18] 7/23 17/24 18/4 23/2 23/5 23/6	25/3 25/23 39/18 44/3 51/9 60/3 60/22 61/2 95/18 119/5 119/8 126/8 <b>blown</b> [1] 88/15 <b>blue</b> [1] 134/2 <b>boarding</b> [3] 12/24 58/23 97/13 <b>Body</b> [1] 62/3 <b>body's</b> [1] 109/10 <b>bombs</b> [1] 50/21 <b>book</b> [1] 18/18 <b>booked</b> [1] 8/17 <b>bootful</b> [1] 109/20 <b>boring</b> [1] 19/4 <b>born</b> [3] 65/13 65/15 69/4 <b>both</b> [24] 18/25 19/6 21/11 32/5 32/11 39/6 39/10 58/5 65/13 67/2 85/17 88/7 89/10 89/16 89/24 90/1 90/23 93/5 123/3 125/7 128/5 128/9 128/9 128/14 <b>bothered</b> [1] 13/4 <b>bottle</b> [4] 4/19 15/17 27/20 109/22 <b>bottles</b> [2] 9/13 99/16 <b>bottom</b> [11] 12/18 71/5 71/13 77/22 82/18 84/3 84/4 101/8 104/6 110/11 114/12 <b>bought</b> [1] 91/9 <b>boy</b> [1] 13/18 16/8 52/9 52/11 53/24 58/7 58/16 59/8 61/20 69/12 69/25 <b>boy's</b> [1] 58/18 <b>boys</b> [40] 4/6 5/6 5/17 10/15 16/15 16/16 50/15 52/8 61/7 61/15 62/15 62/19 65/21 66/24 67/10 68/23 74/8 75/23 76/2 81/1 85/17 88/4 88/7 89/3 89/10 90/23 93/5 93/13 93/18 94/10 95/5 99/3 103/18 104/7 112/2 113/11 113/11 131/11 131/13 133/17 <b>boys'</b> [4] 66/4 72/22 73/7 87/20 <b>brain</b> [2] 8/2 17/2 <b>brand</b> [1] 27/11 <b>break</b> [7] 64/5 64/14 64/24 91/23 96/19 120/3 120/4 <b>breakfast</b> [2] 7/10 111/7 <b>breathing</b> [1] 92/10
<b>B</b>	<b>baby</b> [2] 2/3 113/9 <b>back</b> [54] 14/1 17/25 18/11 25/7 33/7 36/18 40/6 40/21 46/10 48/15 49/2 50/8 52/9 55/24 58/8 58/25 68/16 69/19 76/11 77/11 79/19 81/9 90/17 93/3 94/23 96/21 99/4 99/20 103/8 104/23 106/3 109/5 110/4 111/17 112/4 112/5 112/10 112/15 118/2 119/9 119/16 119/19 121/18 128/2 128/3 129/2 130/4 130/4 130/18 132/23 133/12 134/2 134/3 135/21 <b>backside</b> [1] 127/22 <b>bad</b> [19] 10/14 13/6 31/24 39/7 42/12 44/9 47/25 90/16 90/22 91/20 107/18 116/18 117/7 120/7 123/12 126/21 126/25 127/9 128/12 <b>badly</b> [1] 39/6 <b>banned</b> [1] 59/13 <b>banners</b> [1] 52/16 <b>banter</b> [1] 113/22 <b>bantered</b> [1] 113/10 <b>barrier</b> [1] 50/13 <b>basically</b> [4] 42/24 91/4 99/17 130/23 <b>basis</b> [2] 20/11 40/10 <b>batch</b> [4] 111/25 112/3 112/13 112/16 <b>batches</b> [1] 7/19 <b>battle</b> [1] 48/23 <b>bay</b> [8] 4/7 4/7 4/14 98/23 99/2 99/5 103/4 108/16 <b>BBC</b> [1] 60/9 <b>BC</b> [1] 136/10 <b>be</b> [103] 1/3 1/13 1/16 4/4 4/12 4/20 4/20 5/2 7/2 7/13 8/18 8/18 9/9 9/18 9/21 10/9 11/24 12/2 14/8 14/24 14/25 15/25 16/17 16/18 17/24 20/6 25/14 25/22 25/23 29/5 35/16 38/4 40/12 42/8 42/21 44/10 46/15 46/21 46/22 46/23 48/10 49/5 50/11 53/9 55/23 56/20 57/1 57/25 64/14 65/3	77/6 77/7 77/17 77/20 77/21 77/23 80/16 81/1 81/15 82/10 86/7 87/23 88/22 91/5 91/6 91/24 93/1 94/13 95/17 96/9 97/2 98/10 99/4 99/5 101/2 101/17 101/21 102/5 102/9 103/13 103/19 105/17 106/1 106/6 108/18 109/1 110/15 111/24 113/12 113/20 113/21 115/4 116/11 120/18 125/15 133/4 135/2 135/6 136/9 136/12 <b>beautifully</b> [1] 60/5 <b>became</b> [4] 15/7 33/16 40/25 130/4 <b>because</b> [62] 3/6 3/21 4/24 6/14 8/16 8/19 11/9 16/13 17/21 26/20 30/17 30/20 31/6 31/13 31/18 31/22 32/20 33/24 35/12 36/22 37/23 38/18 38/19 39/11 40/16 42/3 42/12 43/21 43/25 44/21 47/19 50/12 51/22 51/24 56/3 56/8 57/10 58/4 58/22 61/15 66/11 67/23 68/14 70/16 79/11 81/8 86/3 90/9 98/22 98/24 107/19 112/16 112/17 113/17 116/6 116/21 118/2 118/25 126/22 133/6 133/19 135/15 <b>become</b> [3] 7/1 14/12 51/2 <b>becoming</b> [1] 25/21 <b>bed</b> [7] 13/5 13/7 45/23 59/19 59/20 113/12 113/13 <b>bedroom</b> [1] 45/20 <b>been</b> [106] 5/11 5/12 6/1 6/24 8/4 8/8 10/2 11/10 11/18 11/21 12/10 13/12 14/6 14/15 14/16 15/10 17/2 17/14 19/18 23/23 24/3 25/14 26/9 26/10 28/1 30/9 30/12 30/24 31/8 31/13 31/19 34/11 34/13 35/12 37/11 37/12 37/23 38/17 39/7 39/9 39/14 40/23 41/6 42/13 43/1 43/14 43/17 44/7 44/12	<b>before</b> [27] 2/6 2/16 3/7 10/16 23/5 27/17 37/6 45/19 51/25 55/19 61/21 67/14 67/22 72/8 72/17 73/9 83/2 86/20 88/11 92/8 93/13 96/10 100/16 102/8 114/2 114/22 125/4 <b>began</b> [3] 37/18 37/20 115/4 <b>beginning</b> [1] 23/1 <b>behalf</b> [1] 52/1 <b>behind</b> [6] 52/12 58/13 58/24 98/15 111/21 132/6 <b>being</b> [42] 3/19 4/13 4/14 6/5 6/8 6/18 17/19 19/11 23/10 29/22 30/5 37/17 45/9 47/9 50/25 69/24 70/7 71/19 71/20 71/24 73/24 79/17 82/11 83/22 85/17 89/5 90/12 98/20 101/24 102/5 102/17 102/20 104/10 108/15 111/1 112/12 112/20 113/3 114/25 115/22 121/24 128/16 131/15 131/16 131/21 132/11 133/22 <b>believe</b> [5] 60/15 61/24 92/2 92/2 123/23 <b>bell</b> [5] 17/5 17/6 25/2 25/5 128/14 <b>belly's</b> [1] 126/12 <b>bench</b> [3] 99/12 99/13 134/14 <b>Bennett</b> [7] 64/11 64/12 97/6 113/11 123/12 133/17 137/8 <b>best</b> [5] 53/25 62/7 90/24 124/19 124/23		

<p><b>B</b></p> <p><b>Brian</b> [15] 55/18 55/20 62/12 63/5 94/7 94/8 124/14 132/5 132/8 132/13 134/22 135/7 137/4 137/7 137/10 <b>bright</b> [1] 5/4 <b>Brilliant</b> [2] 97/25 99/6 <b>bring</b> [1] 14/1 <b>broadcast</b> [1] 92/4 <b>broke</b> [3] 119/13 121/16 128/18 <b>broken</b> [1] 35/19 <b>brother</b> [20] 14/13 17/21 17/25 18/4 18/16 19/4 27/25 41/1 41/15 46/10 54/8 62/6 62/22 79/3 97/10 108/4 108/4 112/11 126/19 127/11 <b>brought</b> [4] 27/9 27/10 27/24 108/5 <b>brown</b> [1] 99/12 <b>bruised</b> [1] 126/12 <b>bucket</b> [1] 135/19 <b>build</b> [2] 124/7 133/6 <b>build-up</b> [2] 124/7 133/6 <b>building</b> [1] 131/20 <b>builds</b> [1] 39/19 <b>built</b> [1] 113/4 <b>bullying</b> [4] 13/16 58/3 58/5 59/11 <b>bumps</b> [1] 109/11 <b>bundle</b> [1] 75/15 <b>buried</b> [3] 46/3 46/3 124/18 <b>burying</b> [2] 50/8 124/15 <b>but</b> [185] <b>BUTLIN</b> [2] 97/7 137/9 <b>by</b> [62] 1/24 3/7 6/5 6/19 10/13 11/18 11/22 13/18 13/20 16/7 18/16 25/15 26/2 32/4 32/9 39/1 39/6 40/4 40/8 42/19 50/12 50/25 53/18 58/22 59/25 60/22 62/16 62/22 63/24 65/9 69/24 71/4 71/15 73/1 73/23 76/2 77/17 78/12 78/16 79/25 85/7 85/9 85/22 86/1 89/6 94/17 95/13 97/7 99/22 102/17 103/23 103/25 112/24 120/22 124/14 127/3 127/3 131/19 136/10 137/3 137/6 137/9</p>	<p><b>C</b></p> <p><b>cab</b> [2] 131/18 131/19 <b>cabin</b> [1] 53/18 <b>call</b> [6] 24/16 37/10 67/3 88/1 88/3 126/15 <b>called</b> [13] 1/3 8/10 17/8 41/1 65/3 80/12 80/20 84/5 91/18 97/3 110/13 111/1 115/15 <b>calling</b> [1] 50/21 <b>came</b> [12] 30/13 40/7 40/13 45/19 48/15 50/8 58/8 66/1 66/24 89/19 98/4 116/5 <b>Cameron</b> [1] 52/14 <b>campaign</b> [3] 12/12 51/23 52/5 <b>campaigning</b> [4] 26/5 49/19 50/5 51/3 <b>campaigns</b> [1] 60/7 <b>can</b> [133] 1/6 1/6 1/7 1/8 1/8 1/16 1/25 2/1 2/21 7/5 9/2 10/12 11/3 11/14 12/16 14/1 15/20 19/9 20/14 21/1 21/3 21/13 21/16 21/18 22/20 23/22 24/19 26/24 29/11 31/3 32/7 35/21 36/19 40/9 52/6 53/21 54/16 54/18 54/18 55/24 58/15 58/19 62/10 63/21 64/9 65/20 66/7 67/17 69/18 69/20 70/3 70/7 70/22 71/8 71/16 72/12 72/16 74/2 74/9 74/22 75/12 75/16 76/10 76/23 77/22 79/7 79/13 79/17 79/23 80/11 81/20 81/21 82/2 82/14 82/18 83/15 83/20 84/2 85/14 86/5 86/6 88/7 88/9 88/17 89/9 93/11 93/21 98/3 98/20 99/8 99/9 99/18 99/21 101/1 101/3 101/10 103/2 103/7 103/8 103/11 104/4 104/5 105/8 105/18 105/22 107/7 108/1 109/11 109/23 110/5 110/7 110/11 110/13 110/15 110/20 111/6 111/14 111/16 113/12 113/12 114/12 115/18 118/20 119/6 119/20 120/17 123/18 123/21 126/5 127/6 129/4 130/17 131/8 <b>can't</b> [20] 1/13 11/1</p>	<p>17/17 27/10 41/24 44/15 44/16 48/14 51/12 68/8 90/7 101/25 102/24 111/20 122/3 122/8 122/8 125/22 129/16 129/17 <b>Canada</b> [2] 8/17 53/14 <b>cancelled</b> [2] 95/14 95/15 <b>cancer</b> [3] 44/11 124/16 126/20 <b>candida</b> [1] 38/7 <b>cannot</b> [2] 4/20 45/8 <b>canteen</b> [1] 5/19 <b>Cape</b> [2] 45/13 62/25 <b>Cape Verde</b> [1] 62/25 <b>car</b> [5] 45/4 47/25 48/10 109/20 133/14 <b>caravan</b> [3] 18/20 18/22 19/3 <b>care</b> [8] 27/2 40/23 59/6 61/8 65/17 76/5 76/20 129/6 <b>caring</b> [1] 61/9 <b>Caroline</b> [1] 54/10 <b>carried</b> [2] 87/1 95/11 <b>carry</b> [5] 49/21 88/13 99/6 101/6 114/8 <b>cars</b> [4] 50/5 121/5 121/8 121/9 <b>case</b> [4] 2/24 29/11 37/18 132/6 <b>cases</b> [1] 47/15 <b>casually</b> [2] 34/4 36/9 <b>catastrophe</b> [1] 62/18 <b>caught</b> [1] 109/14 <b>cauliflower</b> [1] 130/22 <b>causing</b> [1] 43/7 <b>CD4</b> [1] 41/19 <b>cells</b> [1] 38/23 <b>cellulitis</b> [2] 39/21 43/19 <b>cent</b> [4] 34/15 57/22 123/7 130/16 <b>Central</b> [1] 52/16 <b>centre</b> [32] 2/8 7/2 9/4 9/6 11/19 19/2 20/19 24/6 24/7 25/13 31/10 31/17 33/3 37/4 38/10 40/24 41/8 46/6 65/18 67/4 68/4 69/9 73/15 74/23 74/24 74/25 82/17 85/20 87/17 87/25 88/3 113/4 <b>centres</b> [1] 16/22 <b>certain</b> [10] 109/9 111/15 111/16 111/25 112/3 121/2 123/24 127/14 131/20 131/23 <b>certainly</b> [2] 2/1 20/13 <b>certificate</b> [1] 133/5 <b>cervical</b> [1] 114/18</p>	<p><b>chalk</b> [1] 41/13 <b>chalk-like</b> [1] 41/13 <b>chance</b> [2] 34/15 63/24 <b>change</b> [2] 74/2 114/17 <b>changed</b> [1] 113/21 <b>changes</b> [1] 76/17 <b>changing</b> [4] 38/4 100/8 100/19 112/22 <b>chapel</b> [1] 60/6 <b>charity</b> [2] 47/14 47/15 <b>Charles</b> [1] 3/16 <b>chart</b> [1] 9/10 <b>chat</b> [4] 7/20 44/25 59/1 68/14 <b>chatted</b> [1] 54/6 <b>check</b> [4] 9/7 23/7 55/10 113/20 <b>check-in</b> [1] 9/7 <b>checked</b> [4] 99/13 103/4 109/9 109/10 <b>checking</b> [1] 109/10 <b>chest</b> [1] 38/21 <b>child</b> [1] 96/10 <b>childhood</b> [2] 2/6 93/24 <b>children</b> [1] 132/15 <b>chip</b> [1] 135/4 <b>Chisholm</b> [10] 102/3 102/14 102/16 112/21 113/7 113/14 113/19 114/11 116/16 119/6 <b>choice</b> [3] 3/20 6/2 22/15 <b>Christ</b> [1] 83/8 <b>Christmas</b> [2] 126/18 133/8 <b>chronic</b> [5] 43/6 75/9 76/4 76/15 76/18 <b>Civil</b> [1] 32/23 <b>claim</b> [2] 35/1 42/2 <b>class</b> [3] 26/18 34/23 99/4 <b>classic</b> [1] 121/5 <b>classroom</b> [2] 111/2 111/19 <b>clean</b> [1] 6/17 <b>cleanliness</b> [1] 7/21 <b>clear</b> [8] 29/24 43/9 57/11 60/12 94/21 94/25 101/12 128/14 <b>cleared</b> [2] 43/12 43/13 <b>clearing</b> [1] 130/10 <b>clearly</b> [2] 57/7 89/5 <b>cleft</b> [2] 3/12 63/4 <b>clicked</b> [1] 115/20 <b>clinic</b> [12] 7/9 7/10 9/6 9/19 10/4 29/4 30/12 34/12 37/24</p>	<p>41/18 129/8 129/9 <b>clinical</b> [3] 43/6 68/18 93/7 <b>Clinically</b> [2] 82/21 114/14 <b>clinicians</b> [1] 76/19 <b>close</b> [6] 9/14 22/7 75/22 91/11 118/1 121/3 <b>closed</b> [1] 128/5 <b>closer</b> [2] 113/5 115/22 <b>clotted</b> [1] 25/23 <b>co</b> [3] 7/1 8/4 16/6 <b>co-operate</b> [1] 16/6 <b>co-ordination</b> [1] 8/4 <b>coffee</b> [1] 64/13 <b>coffin</b> [1] 52/7 <b>coincidence</b> [1] 10/13 <b>coincidentally</b> [1] 3/5 <b>cold</b> [2] 45/15 57/24 <b>Colin</b> [1] 52/9 <b>college</b> [16] 17/25 28/2 61/6 62/15 69/14 75/23 76/2 77/23 85/11 89/11 102/9 115/13 115/19 127/8 133/12 134/4 <b>Cologne</b> [1] 20/19 <b>colour</b> [1] 63/21 <b>column</b> [8] 22/24 74/10 79/20 81/22 105/19 110/8 110/9 110/14 <b>combination</b> [2] 9/13 9/14 <b>come</b> [30] 7/15 10/6 24/20 25/12 41/19 44/21 51/12 66/15 67/1 68/16 68/17 87/17 97/4 99/3 99/6 99/15 100/23 111/13 112/9 116/21 117/20 123/1 126/10 127/18 127/18 128/15 131/19 132/7 133/17 134/21 <b>comes</b> [1] 34/16 <b>comfort</b> [1] 135/16 <b>coming</b> [6] 9/5 95/9 113/4 123/15 131/11 133/11 <b>commemorated</b> [1] 60/4 <b>comment</b> [4] 29/22 30/6 33/9 55/23 <b>commented</b> [1] 29/15 <b>commercial</b> [6] 71/22 71/25 74/4 80/8 80/15 82/5 <b>commitment</b> [2] 95/11 95/13 <b>common</b> [2] 41/11</p>	<p>54/9 <b>communicated</b> [1] 26/2 <b>communicating</b> [1] 58/20 <b>companies</b> [1] 35/10 <b>company</b> [2] 34/24 124/25 <b>compassion</b> [3] 61/8 63/7 63/8 <b>complaint</b> [1] 41/25 <b>complaints</b> [1] 67/20 <b>complementary</b> [2] 48/5 48/7 <b>complete</b> [2] 15/15 72/20 <b>completeness</b> [1] 76/9 <b>compromised</b> [1] 39/2 <b>computer</b> [1] 1/12 <b>concentrate</b> [20] 2/24 4/17 6/10 9/21 9/24 14/13 14/17 18/16 25/17 27/22 60/17 69/21 70/23 71/11 71/25 80/1 80/8 80/15 102/11 102/13 <b>concentrates</b> [13] 2/17 6/9 27/18 66/2 66/8 66/22 70/4 71/22 72/5 74/6 80/18 100/5 108/25 <b>concern</b> [3] 7/23 20/1 50/20 <b>concerned</b> [4] 40/25 58/16 91/17 92/24 <b>concerning</b> [2] 12/1 75/17 <b>concluded</b> [1] 33/20 <b>condition</b> [2] 40/25 130/14 <b>conduct</b> [1] 11/19 <b>conference</b> [1] 128/3 <b>confusing</b> [1] 28/16 <b>connected</b> [1] 37/4 <b>conscious</b> [1] 54/20 <b>consensual</b> [2] 13/4 60/16 <b>consent</b> [6] 12/18 12/21 12/22 58/20 60/17 60/18 <b>consider</b> [2] 42/7 42/10 <b>consistent</b> [1] 85/8 <b>conspiracy</b> [1] 30/24 <b>consultant</b> [3] 16/1 29/1 42/19 <b>consumed</b> [1] 59/12 <b>contact</b> [3] 26/12 87/11 127/17 <b>contacted</b> [2] 46/6</p>
---	---	---	---	--	---

<p><b>C</b></p> <p><b>contacted...</b> [1] 46/7</p> <p><b>containing</b> [1] 11/23</p> <p><b>contaminated</b> [5] 60/1 60/3 60/22 61/1 61/17</p> <p><b>continue</b> [5] 19/21 20/11 43/16 60/7 60/9</p> <p><b>continued</b> [1] 136/12</p> <p><b>continuing</b> [1] 82/10</p> <p><b>contract</b> [1] 11/24</p> <p><b>contracted</b> [1] 5/7</p> <p><b>contrast</b> [1] 49/19</p> <p><b>conversation</b> [2] 59/15 123/2</p> <p><b>cope</b> [3] 45/5 48/14 58/2</p> <p><b>copies</b> [2] 75/18 77/1</p> <p><b>copy</b> [6] 26/8 26/8 36/25 74/25 75/21 114/22</p> <p><b>corner</b> [5] 84/3 84/5 86/10 112/11 122/16</p> <p><b>correct</b> [4] 1/5 2/4 65/16 81/20</p> <p><b>correspondence</b> [3] 74/17 78/10 88/17</p> <p><b>corridor</b> [3] 7/7 40/14 119/4</p> <p><b>cost</b> [3] 41/25 48/24 59/10</p> <p><b>cough</b> [1] 91/6</p> <p><b>could</b> [35] 8/20 10/24 16/18 20/18 25/22 34/13 41/17 41/25 42/8 42/13 47/17 49/2 54/10 58/1 69/15 69/21 74/21 77/16 77/20 84/19 95/10 99/19 100/25 102/1 104/3 105/10 105/19 110/5 111/18 114/10 115/21 124/16 124/17 134/5 134/5</p> <p><b>couldn't</b> [10] 45/23 50/16 52/4 81/17 89/20 89/21 92/1 92/2 119/25 124/15</p> <p><b>council</b> [1] 67/8</p> <p><b>counselling</b> [3] 44/19 45/2 61/23</p> <p><b>counsellor</b> [1] 45/1</p> <p><b>count</b> [1] 41/19</p> <p><b>countless</b> [1] 61/3</p> <p><b>country</b> [4] 22/13 60/3 76/3 112/25</p> <p><b>couple</b> [11] 4/15 18/23 18/25 24/14 31/6 35/17 43/9 69/6 93/23 105/4 135/16</p> <p><b>course</b> [14] 2/14 4/5</p>	<p>14/18 31/7 42/3 43/12 45/17 46/18 46/25 48/5 51/22 53/8 73/21 134/23</p> <p><b>courses</b> [1] 84/10</p> <p><b>court</b> [2] 33/18 33/20</p> <p><b>Covid</b> [1] 45/21</p> <p><b>crack</b> [1] 59/17</p> <p><b>crash</b> [2] 32/25 45/4</p> <p><b>crashing</b> [1] 45/17</p> <p><b>cried</b> [1] 127/19</p> <p><b>criminal</b> [2] 95/16 95/17</p> <p><b>crockery</b> [1] 5/20</p> <p><b>cropped</b> [1] 7/11</p> <p><b>cross</b> [1] 31/13</p> <p><b>cry</b> [1] 127/19</p> <p><b>crying</b> [4] 118/12 128/9 128/10 130/6</p> <p><b>cryo</b> [1] 100/13</p> <p><b>cryoprecipitate</b> [12] 2/10 2/14 2/19 2/21 4/8 6/12 14/10 16/19 18/14 27/23 65/23 100/2</p> <p><b>cuddling</b> [1] 128/15</p> <p><b>cure</b> [1] 124/17</p> <p><b>curious</b> [1] 12/16</p> <p><b>current</b> [3] 1/17 28/15 105/13</p> <p><b>cutlery</b> [1] 5/19</p> <p><b>D</b></p> <p><b>dad</b> [45] 12/13 30/14 30/23 31/1 31/11 32/7 32/14 32/21 38/4 58/22 58/25 93/1 100/9 100/9 100/14 104/24 104/24 104/24 105/3 112/7 113/3 115/21 115/23 115/24 115/24 116/2 116/9 117/4 117/19 122/4 122/21 124/13 124/14 124/16 124/24 124/25 125/2 125/3 126/7 126/14 127/10 131/10 131/24 133/3 133/12</p> <p><b>dad said</b> [1] 31/1</p> <p><b>dad's</b> [2] 125/8 126/19</p> <p><b>damage</b> [3] 43/14 43/22 109/7</p> <p><b>damaged</b> [2] 43/21 130/16</p> <p><b>date</b> [11] 24/21 25/18 29/6 29/10 29/13 29/18 71/2 79/12 86/9 89/4 104/10</p> <p><b>dated</b> [9] 11/15 28/22 28/25 69/18 73/6 76/25 87/7 110/8</p>	<p>114/11</p> <p><b>dates</b> [11] 21/15 28/13 29/5 29/24 77/19 81/24 90/18 110/8 115/7 115/8 123/7</p> <p><b>daubed</b> [1] 50/6</p> <p><b>daughter</b> [3] 116/11 118/23 120/25</p> <p><b>David</b> [4] 52/14 65/8 95/11 137/5</p> <p><b>David Cameron</b> [1] 52/14</p> <p><b>David Owen's</b> [1] 95/11</p> <p><b>day</b> [31] 1/18 4/10 5/2 7/11 12/7 13/24 14/11 19/1 21/6 21/7 30/23 34/5 40/9 41/13 47/16 55/5 59/9 63/24 95/5 95/5 95/6 103/15 105/4 116/4 118/12 120/2 120/11 126/19 128/13 135/19 136/16</p> <p><b>day one</b> [1] 128/13</p> <p><b>days</b> [26] 4/13 13/8 17/3 19/18 20/20 21/8 25/12 42/22 42/25 43/18 45/16 45/19 45/21 45/24 46/5 46/15 62/1 73/22 103/20 105/4 105/17 106/7 106/13 117/15 125/25 135/6</p> <p><b>DDAVP</b> [5] 103/11 103/23 103/25 104/12 104/15</p> <p><b>dead</b> [1] 133/22</p> <p><b>deal</b> [2] 35/25 122/11</p> <p><b>deals</b> [1] 110/10</p> <p><b>dealt</b> [1] 31/22</p> <p><b>dear</b> [5] 11/7 11/15 16/5 26/10 118/18</p> <p><b>death</b> [6] 61/21 125/8 125/8 126/1 126/2 133/4</p> <p><b>deaths</b> [1] 59/24</p> <p><b>decades</b> [1] 44/20</p> <p><b>December</b> [9] 11/4 11/15 23/20 29/23 30/6 73/15 87/7 88/18 106/4</p> <p><b>December '85</b> [2] 30/6 88/18</p> <p><b>December 1975</b> [1] 11/4</p> <p><b>December 1982</b> [1] 106/4</p> <p><b>December 1985</b> [1] 87/7</p> <p><b>decided</b> [5] 49/20 59/1 91/2 91/7 98/3</p>	<p><b>declined</b> [1] 39/6</p> <p><b>decorating</b> [1] 49/3</p> <p><b>dedicate</b> [2] 62/11 62/14</p> <p><b>dedicated</b> [1] 8/14</p> <p><b>dedication</b> [1] 63/6</p> <p><b>definite</b> [1] 66/17</p> <p><b>definitely</b> [6] 37/9 73/11 78/5 78/13 81/3 131/1</p> <p><b>defrosting</b> [1] 100/13</p> <p><b>degree</b> [2] 28/2 76/1</p> <p><b>delayed</b> [1] 60/24</p> <p><b>delivered</b> [1] 40/23</p> <p><b>delivers</b> [1] 95/21</p> <p><b>demand</b> [1] 19/25</p> <p><b>demanded</b> [1] 41/1</p> <p><b>denied</b> [1] 60/25</p> <p><b>dental</b> [1] 89/21</p> <p><b>deposit</b> [2] 47/25 48/11</p> <p><b>depressants</b> [2] 43/8 43/11</p> <p><b>depressed</b> [2] 43/2 129/22</p> <p><b>depression</b> [1] 43/6</p> <p><b>describe</b> [3] 9/23 39/4 125/7</p> <p><b>described</b> [6] 112/22 119/12 119/18 120/11 128/20 130/21</p> <p><b>describes</b> [1] 126/25</p> <p><b>describing</b> [1] 24/5</p> <p><b>description</b> [1] 63/17</p> <p><b>deserved</b> [1] 61/14</p> <p><b>designed</b> [1] 60/5</p> <p><b>designer</b> [1] 89/13</p> <p><b>detail</b> [2] 67/12 87/18</p> <p><b>deteriorated</b> [2] 41/14 91/12</p> <p><b>determine</b> [1] 29/16</p> <p><b>devastating</b> [1] 62/9</p> <p><b>develop</b> [1] 25/21</p> <p><b>developed</b> [4] 23/3 35/23 38/15 39/15</p> <p><b>diagnosed</b> [4] 2/2 114/2 121/24 122/6</p> <p><b>diagnoses</b> [1] 28/11</p> <p><b>diagnosis</b> [4] 89/16 118/22 120/13 122/7</p> <p><b>dialogue</b> [2] 24/6 24/9</p> <p><b>did</b> [90] 4/18 6/10 7/15 8/3 8/12 8/13 8/14 8/16 9/1 9/15 9/25 10/11 10/20 13/23 17/3 20/11 20/13 23/2 26/4 26/6 27/14 28/17 36/2 40/3 43/19 44/21 45/22 52/12 62/7 63/13 65/25 66/3 66/6 66/15 67/1 68/1 68/1 68/6</p>	<p>69/2 78/3 81/4 90/5 90/22 91/1 91/17 93/2 94/11 94/22 96/2 97/12 97/15 98/19 103/2 104/14 107/3 107/12 107/25 109/14 110/2 112/4 112/17 115/17 115/17 117/24 118/20 118/21 119/15 120/3 120/4 120/24 121/7 121/17 122/6 122/8 122/11 122/25 122/25 123/20 124/2 124/12 124/18 124/19 127/19 128/21 128/23 129/20 130/9 130/9 130/11 135/14</p> <p><b>didn't</b> [56] 2/10 2/25 3/18 3/20 5/5 13/19 13/19 13/20 15/4 15/17 15/18 22/11 26/19 31/11 31/19 32/3 33/24 34/1 35/3 36/20 38/3 38/4 40/6 40/21 42/4 42/6 42/9 43/9 47/20 47/21 48/12 51/19 55/4 58/22 59/3 59/5 63/14 68/19 74/7 80/22 90/9 91/18 91/20 92/22 93/11 95/13 105/1 107/8 109/13 117/3 117/3 117/18 118/2 127/19 134/15 134/17</p> <p><b>die</b> [6] 49/15 91/22 92/7 96/10 124/18 124/19</p> <p><b>died</b> [22] 32/11 46/1 46/11 52/10 54/11 60/4 60/23 62/24 73/7 91/14 91/16 91/17 91/20 92/1 92/6 124/1 124/11 124/11 124/13 124/20 125/12 126/20</p> <p><b>difference</b> [2] 15/3 98/11</p> <p><b>different</b> [15] 22/3 22/16 37/4 57/4 77/18 77/19 77/19 80/23 82/9 97/16 98/12 127/13 129/17 136/1 136/3</p> <p><b>differently</b> [1] 9/25</p> <p><b>difficult</b> [5] 8/1 8/24 18/10 40/1 64/2</p> <p><b>difficulties</b> [2] 27/24 70/1</p> <p><b>difficulty</b> [1] 84/24</p> <p><b>digger</b> [1] 135/17</p> <p><b>dining</b> [1] 111/14</p> <p><b>dinner</b> [2] 68/15 111/2</p> <p><b>dirt</b> [2] 135/18 135/19</p>	<p><b>disabilities</b> [2] 98/9 98/18</p> <p><b>disabled</b> [1] 98/7</p> <p><b>disaster</b> [1] 60/11</p> <p><b>disciplinary</b> [1] 40/16</p> <p><b>discipline</b> [1] 13/11</p> <p><b>discuss</b> [3] 12/2 51/10 87/17</p> <p><b>discussed</b> [4] 74/14 77/13 78/18 104/22</p> <p><b>discussion</b> [12] 19/22 26/22 74/4 100/7 100/18 101/20 102/16 105/5 105/7 105/25 106/16 106/17</p> <p><b>discussions</b> [1] 27/25</p> <p><b>disease</b> [5] 75/9 76/4 76/15 76/18 76/21</p> <p><b>display</b> [2] 24/15 86/19</p> <p><b>dissolve</b> [1] 19/5</p> <p><b>distribution</b> [1] 95/18</p> <p><b>District</b> [1] 51/10</p> <p><b>Disturbing</b> [1] 5/17</p> <p><b>divided</b> [1] 57/6</p> <p><b>do</b> [94] 2/16 6/10 8/7 9/2 9/5 10/9 12/3 12/7 12/8 12/11 12/18 13/1 15/8 16/14 16/25 17/18 17/23 18/6 18/24 19/22 22/24 23/4 23/10 24/17 26/1 27/5 28/2 28/4 28/4 31/13 32/3 32/19 43/16 43/17 51/15 52/4 55/18 57/18 57/19 59/18 60/12 62/10 66/11 66/19 67/7 67/14 68/3 68/19 70/8 70/10 70/20 73/3 76/12 84/17 89/22 92/25 93/13 96/4 100/7 100/18 101/20 101/23 102/13 102/16 102/25 104/20 105/3 105/5 105/25 106/7 106/16 107/3 107/11 110/21 111/8 112/5 112/24 113/18 115/2 116/20 117/18 119/7 120/15 122/1 124/24 127/12 128/15 129/3 129/14 130/1 130/24 130/25 132/17 133/1</p> <p><b>doctor</b> [14] 9/19 10/4 28/15 30/18 31/4 31/20 32/21 39/22 41/18 41/22 43/20 44/5 69/9 107/12</p> <p><b>doctor's</b> [2] 111/10 111/12</p> <p><b>doctors</b> [6] 6/19 12/14</p>
---	--	--	---	--	---



<p><b>D</b></p> <p><b>doctors... [4]</b> 63/1 65/20 91/21 94/13</p> <p><b>document [14]</b> 15/20 18/8 21/1 25/6 71/19 72/17 73/3 86/6 88/16 103/8 104/1 105/11 106/19 129/2</p> <p><b>documentation [2]</b> 29/11 29/24</p> <p><b>documents [6]</b> 20/12 24/14 56/19 57/4 69/7 124/5</p> <p><b>does [3]</b> 4/22 35/3 87/12</p> <p><b>doesn't [9]</b> 11/12 15/25 17/5 17/6 24/16 25/2 25/5 31/4 55/2</p> <p><b>doing [18]</b> 10/16 17/22 17/23 18/1 19/4 19/4 19/6 23/4 23/9 26/18 30/21 59/17 88/1 108/9 108/19 113/23 119/7 126/7</p> <p><b>don't [74]</b> 8/9 8/22 9/15 11/7 11/13 12/5 12/9 12/11 15/6 17/2 17/3 17/4 24/3 25/4 26/4 26/16 31/24 34/13 35/6 35/10 36/18 37/9 39/19 39/23 42/21 45/3 46/13 52/19 54/4 54/25 55/21 55/23 56/2 58/1 68/1 68/9 73/9 86/18 88/14 90/7 90/18 90/20 92/20 95/7 96/1 101/25 102/15 102/15 107/6 107/8 107/10 108/12 108/14 108/18 109/7 109/24 109/24 112/7 112/8 112/8 117/16 119/22 120/24 121/20 122/2 122/4 126/23 127/8 128/1 130/3 131/25 132/23 133/5 135/2</p> <p><b>done [13]</b> 9/17 14/16 39/11 39/25 43/15 44/10 44/12 48/25 86/4 109/7 133/11 133/20 135/23</p> <p><b>donors [1]</b> 15/18</p> <p><b>doors [3]</b> 7/8 50/7 131/20</p> <p><b>dorm [1]</b> 112/1</p> <p><b>dose [6]</b> 2/14 70/16 103/16 103/21 103/22 103/24</p> <p><b>doses [4]</b> 2/23 2/24</p>	<p>31/25 32/1</p> <p><b>double [2]</b> 48/24 49/1</p> <p><b>doubled [1]</b> 10/14</p> <p><b>doubt [1]</b> 64/2</p> <p><b>down [59]</b> 2/9 3/16 3/18 18/23 19/1 21/14 26/22 26/24 29/2 30/11 30/22 32/21 34/16 35/19 35/21 38/17 42/12 44/3 45/18 47/19 48/15 49/25 50/2 50/17 51/13 52/6 52/14 53/25 55/10 67/10 70/14 71/13 73/16 79/13 79/14 83/13 84/23 85/14 88/5 88/5 89/9 91/3 103/6 104/10 110/9 111/24 119/3 119/14 120/3 120/4 121/9 121/16 122/24 122/25 127/22 128/5 131/17 133/7 133/11</p> <p><b>downhill [2]</b> 40/8 45/16</p> <p><b>downstairs [1]</b> 112/11</p> <p><b>Dr [82]</b> 3/16 6/20 6/20 6/20 6/20 6/22 6/22 6/23 6/23 7/20 11/6 11/18 15/24 16/1 16/5 16/20 16/20 17/14 18/2 18/2 18/12 18/12 19/8 19/8 19/20 23/20 23/21 23/22 23/22 25/8 25/8 26/21 27/14 29/1 30/19 42/2 42/21 43/4 43/5 65/22 65/22 66/20 66/20 69/8 69/9 69/17 69/19 69/19 70/3 70/23 72/20 73/1 74/22 74/23 75/16 76/5 76/10 76/11 82/16 86/21 86/24 87/5 87/8 87/25 88/6 88/18 88/19 91/3 99/11 102/3 102/3 102/14 102/16 111/13 112/21 113/7 113/14 113/19 114/11 114/11 116/16 119/6</p> <p><b>Dr Allsup [1]</b> 29/1</p> <p><b>Dr Aronstam [11]</b> 6/20 6/23 26/21 69/8 69/19 72/20 73/1 74/23 76/5 76/11 102/3</p> <p><b>Dr Aronstam's [1]</b> 75/16</p> <p><b>Dr Charles [1]</b> 3/16</p> <p><b>Dr Chisholm [10]</b> 102/3 102/14 102/16</p>	<p>112/21 113/7 113/14 113/19 114/11 116/16 119/6</p> <p><b>Dr Ghosh [1]</b> 76/10</p> <p><b>Dr Kirk [9]</b> 6/20 6/22 11/6 15/24 16/20 18/12 19/8 19/20 25/8</p> <p><b>Dr Matthews [4]</b> 65/22 66/20 82/16 91/3</p> <p><b>Dr McHardy [2]</b> 6/20 6/22</p> <p><b>Dr Montgomery [2]</b> 42/21 43/5</p> <p><b>Dr Raper [13]</b> 16/1 16/5 16/20 17/14 18/2 18/2 18/12 19/8 23/21 23/22 25/8 27/14 42/2</p> <p><b>Dr Rizza [13]</b> 65/22 66/20 69/9 69/17 69/19 70/3 70/23 86/21 86/24 87/8 87/25 88/6 88/18</p> <p><b>Dr Rizza's [1]</b> 87/5</p> <p><b>Dr Rosemary Biggs [1]</b> 11/18</p> <p><b>Dr Shields [1]</b> 43/4</p> <p><b>Dr Wassef [8]</b> 6/20 6/23 7/20 23/20 23/22 88/19 111/13 114/11</p> <p><b>Dr Wassef's [1]</b> 99/11</p> <p><b>draconian [1]</b> 57/22</p> <p><b>drag [1]</b> 117/21</p> <p><b>dragging [1]</b> 127/22</p> <p><b>drain [3]</b> 39/17 39/17 39/18</p> <p><b>drawn [1]</b> 74/13</p> <p><b>dread [1]</b> 96/3</p> <p><b>dreadful [1]</b> 62/18</p> <p><b>dream [1]</b> 39/5</p> <p><b>dried [4]</b> 66/10 66/15 66/19 80/20</p> <p><b>drink [1]</b> 34/13</p> <p><b>drip [2]</b> 4/9 66/16</p> <p><b>drips [1]</b> 133/21</p> <p><b>drive [4]</b> 33/2 133/8 133/20 135/17</p> <p><b>driven [1]</b> 134/4</p> <p><b>driving [3]</b> 47/24 125/1 133/12</p> <p><b>drop [2]</b> 33/3 87/3</p> <p><b>dropped [1]</b> 100/9</p> <p><b>dropping [2]</b> 33/19 40/10</p> <p><b>drops [1]</b> 38/11</p> <p><b>drug [4]</b> 2/15 35/9 123/24 124/17</p> <p><b>drugs [1]</b> 38/18</p> <p><b>drunk [2]</b> 13/14 119/22</p> <p><b>due [3]</b> 48/9 62/17 131/1</p>	<p><b>during [19]</b> 1/18 4/10 7/11 17/23 18/13 20/16 42/3 46/1 56/11 73/20 94/23 101/20 102/7 103/20 106/1 119/12 120/2 120/5 123/21</p> <p><b>duty [1]</b> 9/7</p> <p><b>dying [1]</b> 41/12</p> <p><b>E</b></p> <p><b>each [11]</b> 10/12 10/20 16/23 23/1 28/11 41/13 67/13 68/23 74/19 108/6 108/24</p> <p><b>ear [3]</b> 13/18 58/14 127/16</p> <p><b>earlier [12]</b> 29/17 29/19 32/11 32/19 32/22 44/1 88/19 124/14 131/4 131/9 131/10 134/20</p> <p><b>early [7]</b> 40/19 49/20 62/1 83/8 112/21 113/25 135/15</p> <p><b>easier [3]</b> 11/24 100/11 113/5</p> <p><b>easily [1]</b> 67/25</p> <p><b>eat [1]</b> 121/4</p> <p><b>education [3]</b> 3/22 57/16 67/21</p> <p><b>educational [1]</b> 7/1</p> <p><b>effect [2]</b> 21/23 125/7</p> <p><b>effects [8]</b> 42/20 61/1 90/14 90/21 125/20 125/22 129/14 129/17</p> <p><b>effort [1]</b> 60/14</p> <p><b>efforts [1]</b> 60/9</p> <p><b>eh [1]</b> 129/1</p> <p><b>eight [1]</b> 3/10</p> <p><b>eighties [4]</b> 27/9 27/16 109/5 119/12</p> <p><b>either [11]</b> 3/20 4/8 9/20 19/23 75/12 77/16 85/22 85/25 100/7 102/17 119/6</p> <p><b>elapse [1]</b> 103/15</p> <p><b>elbow [8]</b> 9/8 10/14 19/10 19/19 59/20 70/16 84/10 84/14</p> <p><b>elbows [2]</b> 20/9 21/11</p> <p><b>election [1]</b> 51/23</p> <p><b>elevated [2]</b> 75/25 76/13</p> <p><b>elevation [1]</b> 76/1</p> <p><b>Eligibility [1]</b> 103/14</p> <p><b>else [12]</b> 14/5 44/7 59/4 66/20 81/13 94/12 95/2 98/20 118/1 121/11 128/1 134/10</p> <p><b>embarrassed [2]</b></p>	<p>58/22 59/2</p> <p><b>emergency [1]</b> 2/25</p> <p><b>emotionally [1]</b> 125/10</p> <p><b>encephalopathy [1]</b> 124/6</p> <p><b>enclose [2]</b> 75/21 77/1</p> <p><b>enclosed [2]</b> 83/1 114/21</p> <p><b>encouraged [1]</b> 127/3</p> <p><b>encouragement [1]</b> 70/22</p> <p><b>end [21]</b> 19/14 26/6 62/22 83/2 96/1 106/23 111/2 114/22 115/25 116/5 117/17 119/22 120/25 123/2 124/10 126/10 128/3 129/11 129/12 132/4 135/13</p> <p><b>ended [3]</b> 37/10 51/23 128/15</p> <p><b>endless [1]</b> 52/17</p> <p><b>endured [1]</b> 58/5</p> <p><b>English [2]</b> 48/12 131/17</p> <p><b>enhance [2]</b> 50/24 60/1</p> <p><b>enjoyed [1]</b> 67/19</p> <p><b>enjoying [1]</b> 135/11</p> <p><b>enormous [1]</b> 125/10</p> <p><b>enough [8]</b> 16/6 35/5 48/2 49/6 54/24 62/5 119/8 133/7</p> <p><b>entertaining [1]</b> 132/11</p> <p><b>entirely [2]</b> 2/20 101/12</p> <p><b>entries [1]</b> 105/18</p> <p><b>entry [10]</b> 23/18 24/20 79/14 80/5 80/7 80/12 83/13 83/13 84/21 105/23</p> <p><b>episode [1]</b> 18/7</p> <p><b>episodes [2]</b> 16/13 77/2</p> <p><b>equivalent [1]</b> 24/9</p> <p><b>erroneously [2]</b> 64/10 102/5</p> <p><b>error [1]</b> 52/1</p> <p><b>especially [2]</b> 83/8 95/6</p> <p><b>establishment [1]</b> 7/2</p> <p><b>estate [1]</b> 89/14</p> <p><b>Eve [1]</b> 133/8</p> <p><b>even [21]</b> 2/10 2/11 11/12 15/6 15/6 20/7 24/3 24/9 25/5 42/5 50/16 66/9 72/14 86/12 92/2 98/18 111/20 124/10 128/24</p>	<p>131/22 133/4</p> <p><b>evening [2]</b> 7/10 9/20</p> <p><b>event [3]</b> 45/4 45/6 122/15</p> <p><b>events [1]</b> 26/1</p> <p><b>eventually [4]</b> 27/11 94/21 98/8 115/23</p> <p><b>ever [38]</b> 5/8 6/7 8/9 12/3 12/13 23/10 24/1 26/2 26/6 39/13 44/19 55/3 58/11 66/21 68/3 68/6 71/24 72/2 72/6 73/23 74/4 74/13 75/12 75/14 76/6 76/20 78/16 80/23 81/4 82/13 84/17 86/1 88/12 95/20 104/21 106/16 122/6 134/16</p> <p><b>every [17]</b> 22/6 33/14 38/4 49/12 51/25 52/21 60/14 90/15 90/15 92/21 94/22 95/5 95/5 95/6 105/4 105/4 109/12</p> <p><b>everybody [3]</b> 5/21 59/4 117/15</p> <p><b>everyone [3]</b> 20/23 51/14 113/14</p> <p><b>everything [13]</b> 27/8 37/16 40/12 44/2 44/7 45/8 47/19 99/4 116/3 119/3 121/12 124/8 124/9</p> <p><b>evidence [17]</b> 24/13 53/8 56/1 62/11 63/22 64/3 64/8 64/21 72/18 72/19 86/20 93/4 96/3 96/20 135/11 136/1 136/6</p> <p><b>evil [1]</b> 51/1</p> <p><b>ex [4]</b> 31/22 33/18 33/18 57/25</p> <p><b>ex gratia [2]</b> 33/18 33/18</p> <p><b>Ex-army [1]</b> 31/22</p> <p><b>ex-military [1]</b> 57/25</p> <p><b>exactly [11]</b> 49/17 52/3 54/1 66/14 85/21 94/15 96/11 131/5 131/7 131/10 133/19</p> <p><b>examination [3]</b> 82/22 83/20 114/15</p> <p><b>examinations [1]</b> 83/16</p> <p><b>examined [1]</b> 114/17</p> <p><b>example [6]</b> 15/17 34/11 58/13 71/5 71/15 73/12</p> <p><b>examples [1]</b> 58/19</p> <p><b>Excellent [1]</b> 24/18</p> <p><b>exception [1]</b> 2/21</p> <p><b>exchange [2]</b> 74/17</p>
---	---	---	--	--	--

<p><b>E</b> exchange... [1] 88/17 excited [1] 131/15 excruciating [2] 39/13 40/4 exhibited [1] 28/12 exhibits [3] 82/21 83/19 114/14 expected [2] 13/13 86/7 experience [5] 37/20 47/3 47/11 49/8 97/18 experiences [1] 133/2 explain [2] 48/9 81/11 explained [6] 15/9 39/1 47/4 48/21 73/1 77/17 explanation [2] 5/8 26/16 explored [1] 76/6 Express [1] 60/8 expressly [1] 56/22 extended [1] 32/15 extracts [2] 74/19 83/10 eye [2] 13/8 75/11 eyes [4] 52/23 98/17 118/13 123/24</p>	<p>71/12 71/14 71/21 79/24 80/3 82/4 101/16 106/5 106/10 106/21 faff [1] 48/1 Failing [1] 16/18 fair [4] 35/5 48/2 51/6 54/24 fairly [1] 19/18 fairness [1] 36/21 fall [1] 110/1 falling [1] 89/17 families [1] 61/3 family [9] 18/17 18/18 26/19 40/24 49/21 50/3 53/16 122/15 134/19 famous [2] 100/13 113/3 fancied [1] 131/16 fancy [1] 3/19 far [25] 3/19 10/2 36/17 56/25 60/23 63/7 66/7 69/20 72/11 73/18 75/22 77/3 78/16 78/22 80/19 85/25 104/14 104/16 110/20 120/6 120/7 123/23 126/8 129/20 130/18 fatal [6] 5/13 5/14 6/6 6/6 56/4 56/4 father [5] 31/18 78/4 124/11 124/20 125/5 father's [1] 126/2 fault [1] 31/21 feared [1] 62/1 featured [1] 60/8 February [9] 15/24 19/16 74/25 75/17 76/11 106/19 106/24 115/5 115/12 February 1980 [1] 76/11 feel [6] 8/16 42/25 49/12 62/5 69/14 135/18 feeling [1] 92/16 feels [1] 22/10 fell [1] 125/4 felt [8] 9/1 9/5 40/5 43/1 52/4 61/16 96/3 125/20 few [27] 4/1 4/13 10/21 13/8 16/9 17/3 25/12 35/10 35/24 37/17 39/25 42/22 42/25 43/18 44/1 45/16 46/15 52/6 52/13 57/14 57/25 61/21 109/14 121/9 125/4 128/25 135/6</p>	<p>fibrosis [1] 44/3 fight [2] 49/12 52/21 fighting [2] 35/16 59/12 fill [1] 9/17 filled [1] 22/24 filling [1] 48/1 final [2] 23/18 131/2 finally [1] 63/5 finances [1] 131/2 financial [2] 47/3 47/3 find [6] 29/11 50/9 54/6 54/10 70/1 94/11 finding [1] 128/22 findings [1] 87/4 fine [14] 8/4 13/19 13/24 31/15 37/17 44/2 44/4 46/15 58/16 59/9 90/10 119/10 119/10 120/21 finish [2] 64/7 96/16 first [56] 2/14 4/15 4/18 10/24 14/11 14/15 14/17 18/14 19/9 19/15 27/16 28/12 29/10 29/13 29/15 29/18 30/3 32/17 33/7 34/22 35/24 36/13 37/17 38/6 39/11 41/5 41/11 47/17 51/9 54/3 55/6 66/25 68/13 69/5 69/7 71/9 71/11 72/6 75/14 76/10 77/5 79/9 79/11 81/21 82/12 88/22 98/16 104/22 106/19 115/19 124/16 124/18 127/25 128/19 131/6 131/8 firstly [1] 33/14 fitting [1] 96/13 five [9] 2/11 46/5 53/17 64/14 64/22 91/16 91/23 100/12 113/8 five hours [1] 100/12 fixed [2] 20/18 39/8 flag [1] 131/17 flat [1] 130/7 flew [1] 45/15 floods [1] 43/3 floor [2] 9/9 131/23 floors [1] 131/21 focus [1] 61/2 follow [3] 11/14 15/20 110/9 followed [2] 103/24 136/10 following [10] 13/22 25/18 29/3 35/23 48/6 50/18 61/14 83/21 103/22 136/16</p>	<p>follows [1] 63/17 food [1] 31/2 football [1] 59/14 Foreign [1] 46/7 forest [1] 53/19 forget [4] 13/21 27/12 48/14 63/18 forgive [1] 77/14 forgot [2] 16/23 105/1 forgotten [1] 10/17 form [7] 6/7 22/25 35/1 56/7 56/8 56/16 77/23 format [2] 29/3 41/24 formally [1] 29/25 format [1] 57/4 formed [1] 50/13 former [3] 32/10 59/25 61/15 forms [2] 18/13 48/1 fortnight [1] 44/12 fortunately [1] 25/19 forward [4] 44/21 91/9 97/4 107/7 forwards [1] 129/10 found [21] 8/1 8/23 13/21 26/8 28/3 28/11 28/16 29/5 38/21 41/6 54/9 55/4 61/24 77/6 78/8 88/22 90/24 118/11 123/17 126/19 127/6 four [15] 2/24 6/24 7/19 10/11 10/13 14/14 45/21 54/8 84/23 91/7 93/1 100/12 109/12 112/13 132/16 four days [1] 45/21 four years [5] 6/24 14/14 54/8 91/7 93/1 France [1] 2/23 FRASER [2] 97/7 137/9 free [1] 4/20 freeze [4] 66/10 66/15 66/19 80/20 freeze-dried [4] 66/10 66/15 66/19 80/20 frequency [3] 21/6 84/12 105/17 frequent [1] 21/10 Friday [1] 46/11 fridge [4] 9/23 9/24 18/21 70/19 friend [9] 5/3 44/21 45/14 62/7 108/8 117/10 118/4 124/19 124/23 friends [12] 53/25 61/3 67/25 67/25 68/17 98/13 117/19</p>	<p>117/25 120/12 121/3 125/5 134/19 from [129] 3/19 4/20 4/24 6/3 10/18 10/22 11/6 11/6 11/8 12/14 13/22 14/10 15/18 15/24 18/5 19/8 21/15 21/16 22/13 22/15 22/18 23/18 23/20 24/13 24/20 25/8 25/20 26/6 26/7 28/25 29/3 30/13 30/22 31/7 32/10 32/15 37/16 43/5 43/15 44/22 47/5 47/6 50/8 50/12 51/6 51/12 54/7 54/9 55/20 56/23 57/21 58/1 58/13 58/23 61/15 61/20 62/25 63/17 67/3 67/5 67/10 69/8 69/17 69/19 70/22 71/4 71/20 72/13 73/6 73/9 73/14 74/17 74/19 74/22 75/2 76/5 76/24 79/9 81/13 81/19 82/16 83/10 85/2 85/19 86/8 86/21 86/23 87/7 88/3 88/18 92/6 92/7 93/4 93/23 94/8 94/12 94/12 94/13 96/7 96/16 100/10 102/2 102/2 102/14 102/20 105/18 105/23 112/12 113/9 114/10 114/18 115/22 120/6 125/20 126/15 127/8 128/13 129/11 131/14 132/8 132/11 133/2 133/7 133/22 134/19 136/9 137/4 137/7 137/10 front [7] 5/21 50/9 92/20 100/23 111/21 126/9 134/14 full [4] 1/15 1/16 28/4 88/15 full-blown [1] 88/15 function [7] 56/21 74/18 75/5 75/11 75/20 75/22 76/13 funnily [1] 133/7 furious [2] 33/24 42/14 further [12] 13/10 25/6 26/15 26/15 55/14 71/15 73/16 83/20 84/11 93/14 105/16 129/10 future [2] 33/21 33/25</p>	<p>garage [1] 126/15 gardening [1] 88/1 Gary [25] 64/11 64/12 96/20 97/3 97/4 97/5 97/6 97/8 99/21 102/4 104/2 104/12 107/17 113/15 116/17 116/18 119/6 123/16 126/16 126/17 126/20 132/6 134/10 135/9 137/8 gather [1] 1/4 gave [7] 17/11 17/12 21/25 35/12 38/11 42/1 86/20 gay [3] 58/8 91/19 91/19 Gaz [1] 117/15 general [8] 16/2 27/15 47/10 49/10 100/10 112/19 113/3 122/5 generally [3] 4/1 47/9 65/21 gentleman [2] 131/14 131/23 Germany [1] 20/17 get [56] 3/22 4/16 6/11 8/5 8/6 9/14 10/5 10/9 13/20 18/3 22/7 22/15 26/6 28/3 32/2 33/4 34/1 40/2 40/3 45/18 45/25 46/13 48/2 48/11 49/24 50/17 54/5 58/23 60/20 67/3 69/22 70/19 87/13 88/15 89/20 92/8 92/23 94/23 94/25 95/13 99/3 103/4 103/6 109/14 117/5 117/20 119/23 121/5 124/15 124/17 126/12 126/13 127/12 130/7 132/1 132/19 getting [22] 2/12 9/3 21/17 23/8 26/17 31/2 31/7 37/23 40/5 42/8 47/23 51/7 62/24 67/21 74/8 107/9 107/18 115/20 115/22 120/2 126/6 127/10 Ghosh [2] 74/22 76/10 giggle [1] 118/20 girl [1] 115/15 girlfriend [3] 91/10 115/19 118/2 girlfriends [1] 90/25 give [14] 9/5 9/18 16/14 18/3 22/8 31/3 32/15 39/4 40/11 41/9 58/19 64/2 109/21 136/1</p>
<p><b>F</b></p>					
<p>face [3] 13/25 32/13 38/15 faces [1] 55/7 facial [1] 38/16 facilitator [1] 52/17 fact [9] 14/9 39/10 43/17 44/2 44/8 52/2 53/22 64/11 102/8 factor [37] 2/17 4/16 8/20 11/23 15/18 19/3 23/6 25/17 27/10 32/1 32/4 58/7 58/15 59/11 59/13 60/1 60/17 61/11 61/17 69/21 70/4 74/3 74/4 88/13 99/3 100/5 100/8 100/10 100/15 103/16 103/21 103/22 103/24 105/23 108/24 109/6 113/20 factor VIII [25] 4/16 8/20 11/23 15/18 19/3 23/6 25/17 27/10 32/1 32/4 58/7 58/15 59/11 59/13 60/1 60/17 61/11 61/17 74/3 74/4 88/13 100/5 100/15 105/23 113/20 Factorate [17] 21/17 21/17 21/19 21/20 21/20 21/20 27/7</p>	<p>fatal [6] 5/13 5/14 6/6 6/6 56/4 56/4 father [5] 31/18 78/4 124/11 124/20 125/5 father's [1] 126/2 fault [1] 31/21 feared [1] 62/1 featured [1] 60/8 February [9] 15/24 19/16 74/25 75/17 76/11 106/19 106/24 115/5 115/12 February 1980 [1] 76/11 feel [6] 8/16 42/25 49/12 62/5 69/14 135/18 feeling [1] 92/16 feels [1] 22/10 fell [1] 125/4 felt [8] 9/1 9/5 40/5 43/1 52/4 61/16 96/3 125/20 few [27] 4/1 4/13 10/21 13/8 16/9 17/3 25/12 35/10 35/24 37/17 39/25 42/22 42/25 43/18 44/1 45/16 46/15 52/6 52/13 57/14 57/25 61/21 109/14 121/9 125/4 128/25 135/6</p>	<p>five [9] 2/11 46/5 53/17 64/14 64/22 91/16 91/23 100/12 113/8 five hours [1] 100/12 fixed [2] 20/18 39/8 flag [1] 131/17 flat [1] 130/7 flew [1] 45/15 floods [1] 43/3 floor [2] 9/9 131/23 floors [1] 131/21 focus [1] 61/2 follow [3] 11/14 15/20 110/9 followed [2] 103/24 136/10 following [10] 13/22 25/18 29/3 35/23 48/6 50/18 61/14 83/21 103/22 136/16</p>	<p>France [1] 2/23 FRASER [2] 97/7 137/9 free [1] 4/20 freeze [4] 66/10 66/15 66/19 80/20 freeze-dried [4] 66/10 66/15 66/19 80/20 frequency [3] 21/6 84/12 105/17 frequent [1] 21/10 Friday [1] 46/11 fridge [4] 9/23 9/24 18/21 70/19 friend [9] 5/3 44/21 45/14 62/7 108/8 117/10 118/4 124/19 124/23 friends [12] 53/25 61/3 67/25 67/25 68/17 98/13 117/19</p>	<p>front [7] 5/21 50/9 92/20 100/23 111/21 126/9 134/14 full [4] 1/15 1/16 28/4 88/15 full-blown [1] 88/15 function [7] 56/21 74/18 75/5 75/11 75/20 75/22 76/13 funnily [1] 133/7 furious [2] 33/24 42/14 further [12] 13/10 25/6 26/15 26/15 55/14 71/15 73/16 83/20 84/11 93/14 105/16 129/10 future [2] 33/21 33/25</p>	<p>Germany [1] 20/17 get [56] 3/22 4/16 6/11 8/5 8/6 9/14 10/5 10/9 13/20 18/3 22/7 22/15 26/6 28/3 32/2 33/4 34/1 40/2 40/3 45/18 45/25 46/13 48/2 48/11 49/24 50/17 54/5 58/23 60/20 67/3 69/22 70/19 87/13 88/15 89/20 92/8 92/23 94/23 94/25 95/13 99/3 103/4 103/6 109/14 117/5 117/20 119/23 121/5 124/15 124/17 126/12 126/13 127/12 130/7 132/1 132/19 getting [22] 2/12 9/3 21/17 23/8 26/17 31/2 31/7 37/23 40/5 42/8 47/23 51/7 62/24 67/21 74/8 107/9 107/18 115/20 115/22 120/2 126/6 127/10 Ghosh [2] 74/22 76/10 giggle [1] 118/20 girl [1] 115/15 girlfriend [3] 91/10 115/19 118/2 girlfriends [1] 90/25 give [14] 9/5 9/18 16/14 18/3 22/8 31/3 32/15 39/4 40/11 41/9 58/19 64/2 109/21 136/1</p>
<p><b>G</b></p>					
<p>Gar [1] 122/16</p>					

<p><b>G</b></p> <p><b>given</b> [33] 1/20 2/23 5/8 5/16 6/8 10/25 18/15 18/16 24/21 25/14 28/7 38/13 38/18 41/4 41/7 46/8 50/23 59/8 63/20 72/4 81/25 82/4 82/7 82/10 96/13 101/21 101/24 102/17 106/5 115/7 115/8 124/17 136/6</p> <p><b>gives</b> [3] 21/1 24/12 28/13</p> <p><b>giving</b> [5] 63/22 72/17 72/19 96/3 135/11</p> <p><b>glass</b> [1] 60/5</p> <p><b>glasses</b> [1] 58/14</p> <p><b>glazing</b> [2] 48/24 49/1</p> <p><b>go</b> [97] 4/4 4/7 4/9 7/9 7/12 8/17 8/19 8/22 9/3 9/6 9/8 14/7 16/21 18/3 18/20 18/23 20/18 23/16 27/22 28/1 28/24 29/2 30/16 30/22 31/9 31/16 33/3 33/6 39/20 40/21 44/15 45/8 45/16 50/17 53/9 54/5 55/24 59/20 64/8 70/15 70/17 71/1 71/5 71/6 71/13 71/15 71/18 73/16 74/21 75/15 76/9 79/11 79/19 79/23 80/4 80/6 80/11 81/9 81/14 81/18 82/1 82/6 82/18 83/12 83/14 84/2 84/20 86/17 87/5 88/5 92/11 98/3 99/4 104/1 105/10 106/10 107/4 108/7 109/12 109/14 111/15 111/16 112/1 112/19 113/17 117/3 119/6 125/2 128/16 128/21 129/24 129/24 131/1 131/1 131/11 131/13 131/14</p> <p><b>goal</b> [1] 131/18</p> <p><b>god</b> [9] 41/20 55/5 98/22 99/11 113/7 117/12 118/24 126/20 128/7</p> <p><b>godsend</b> [2] 66/13 98/24</p> <p><b>goes</b> [1] 64/17</p> <p><b>going</b> [63] 5/8 5/11 8/20 9/24 10/21 13/8 13/16 20/25 24/15 25/6 26/1 28/10 31/3 33/24 35/25 39/22 40/8 47/2 52/6 52/11</p>	<p>52/18 52/24 54/13 55/13 65/10 68/22 68/25 69/3 69/6 70/14 70/15 74/18 79/1 80/16 81/1 87/13 87/24 88/15 91/22 92/25 93/12 93/13 98/17 105/6 105/8 113/11 118/10 118/15 120/1 120/3 127/23 128/20 129/10 129/19 131/4 131/7 131/15 131/16 132/6 132/16 132/19 133/15 133/21</p> <p><b>gone</b> [10] 39/12 44/3 45/7 51/13 58/12 92/2 92/2 96/8 129/1 132/11</p> <p><b>good</b> [26] 1/25 16/22 31/2 31/2 32/4 44/24 48/12 58/10 67/21 84/15 87/15 87/15 99/4 99/7 109/20 118/15 118/18 121/20 122/19 125/3 125/4 126/8 130/25 132/3 132/17 132/17</p> <p><b>got</b> [121] 3/17 3/23 4/12 5/14 6/3 6/18 8/24 9/7 12/6 13/14 13/18 13/22 13/23 18/7 19/2 20/2 21/14 22/19 24/15 24/16 24/23 30/20 31/25 32/22 34/6 35/6 35/18 36/9 37/22 38/8 38/13 39/17 39/18 41/18 42/14 43/2 43/5 43/19 43/22 48/13 48/22 48/22 49/3 51/22 52/1 52/21 53/6 56/3 56/5 57/16 57/16 57/16 57/17 57/17 58/16 63/2 66/10 67/6 67/7 70/12 71/3 72/15 78/7 79/20 81/12 82/6 82/15 86/9 87/24 90/2 90/16 91/1 91/2 91/4 91/8 91/20 93/16 93/23 94/14 95/7 99/20 101/1 104/10 109/18 109/20 111/22 111/25 112/2 113/4 113/10 116/18 118/10 118/14 120/7 121/1 123/17 124/16 124/23 125/22 125/23 125/24 126/21 127/17 129/4 129/19 130/19 130/19 131/11 131/11 131/19 132/14 132/14 132/16 132/17 133/4 133/9</p>	<p>133/16 134/17 134/19 135/12 135/22</p> <p><b>government</b> [5] 33/17 51/6 51/24 52/17 52/22</p> <p><b>governments</b> [1] 51/4</p> <p><b>GP</b> [1] 50/12</p> <p><b>gradually</b> [3] 4/16 16/15 27/9</p> <p><b>grand</b> [1] 131/25</p> <p><b>grandchildren</b> [2] 117/6 132/16</p> <p><b>grant</b> [1] 48/22</p> <p><b>grants</b> [3] 47/5 47/17 47/23</p> <p><b>grapevine</b> [1] 127/14</p> <p><b>graphic</b> [2] 32/12 89/13</p> <p><b>grateful</b> [1] 25/22</p> <p><b>gratia</b> [2] 33/18 33/18</p> <p><b>great</b> [3] 30/15 41/13 134/19</p> <p><b>Grenfell</b> [1] 52/2</p> <p><b>grim</b> [1] 59/24</p> <p><b>groin</b> [1] 109/11</p> <p><b>grounded</b> [1] 13/15</p> <p><b>grounds</b> [2] 40/19 68/14</p> <p><b>group</b> [6] 35/6 62/3 76/16 111/9 111/15 111/15</p> <p><b>grumpy</b> [1] 129/18</p> <p><b>guaranteed</b> [1] 4/20</p> <p><b>guardian</b> [1] 26/10</p> <p><b>guess</b> [1] 30/24</p> <p><b>guilt</b> [1] 61/16</p> <p><b>gust</b> [1] 133/14</p> <p><b>gutter</b> [1] 119/24</p> <p><b>guy</b> [3] 121/7 128/15 131/17</p> <p><b>guys</b> [7] 113/1 125/1 128/13 134/14 134/23 135/18 135/18</p> <p><b>H</b></p> <p><b>had</b> [195]</p> <p><b>had a</b> [3] 15/8 59/19 61/9</p> <p><b>hadn't</b> [5] 8/8 15/10 23/3 31/9 48/25</p> <p><b>haematologist</b> [3] 16/1 28/15 29/1</p> <p><b>haematology</b> [2] 29/4 41/22</p> <p><b>haemoglobin</b> [2] 38/20 38/20</p> <p><b>haemophilia</b> [31] 2/2 2/8 4/21 6/4 7/2 11/18 11/19 19/2 20/19 38/10 40/24 41/8 46/6 53/16 53/17 61/5 61/7 62/19 65/13 65/18</p>	<p>67/13 69/9 73/15 74/23 74/24 82/17 85/19 88/3 97/8 97/11 129/6</p> <p><b>haemophilia A</b> [4] 2/2 65/13 97/8 97/11</p> <p><b>haemophiliac</b> [3] 33/14 109/6 113/4</p> <p><b>haemophiliacs</b> [9] 31/24 47/13 76/3 76/14 98/11 98/13 107/5 111/4 111/15</p> <p><b>haemorrhage</b> [1] 8/2</p> <p><b>half</b> [7] 3/9 14/11 59/20 62/17 121/8 133/20 135/3</p> <p><b>halfway</b> [1] 79/14</p> <p><b>hammer</b> [1] 59/17</p> <p><b>Hampshire</b> [1] 61/6</p> <p><b>hand</b> [14] 5/18 5/21 8/4 22/12 22/14 22/19 74/10 79/13 84/3 84/5 86/10 92/1 103/12 134/3</p> <p><b>handle</b> [2] 41/24 119/25</p> <p><b>hands</b> [1] 134/3</p> <p><b>handwriting</b> [1] 11/1</p> <p><b>handwritten</b> [1] 106/6</p> <p><b>hanging</b> [1] 50/16</p> <p><b>happen</b> [9] 1/15 9/25 17/4 33/24 70/11 105/6 105/8 132/20 134/16</p> <p><b>happened</b> [24] 3/3 3/15 5/2 5/5 6/1 15/9 30/11 30/25 36/19 38/19 39/16 44/22 45/8 50/14 51/15 52/3 60/19 115/18 116/3 117/13 117/14 120/16 134/1 134/1</p> <p><b>happening</b> [5] 38/2 59/14 70/9 116/20 132/14</p> <p><b>happens</b> [1] 75/1</p> <p><b>happier</b> [1] 135/12</p> <p><b>happiness</b> [1] 90/24</p> <p><b>happy</b> [3] 12/2 97/2 97/18</p> <p><b>hard</b> [8] 28/3 38/22 45/13 49/23 52/5 63/6 127/25 128/7</p> <p><b>harder</b> [2] 67/23 68/2</p> <p><b>hardly</b> [1] 41/17</p> <p><b>harm</b> [1] 3/12</p> <p><b>harm</b> [1] 93/1</p> <p><b>harsh</b> [1] 57/20</p> <p><b>has</b> [39] 1/20 11/21 16/10 19/18 19/19 23/23 24/20 25/12 25/14 25/19 26/10</p>	<p>44/14 45/8 45/11 46/19 48/16 48/17 52/17 55/19 56/8 56/13 58/12 59/6 60/8 60/24 62/8 63/8 69/20 69/23 73/19 75/4 75/8 84/15 84/24 87/11 87/12 87/13 132/7 132/10</p> <p><b>hasn't</b> [1] 130/19</p> <p><b>hate</b> [1] 108/22</p> <p><b>hated</b> [2] 19/6 57/23</p> <p><b>haunt</b> [1] 133/23</p> <p><b>have</b> [158]</p> <p><b>haven't</b> [5] 24/16 43/17 118/14 128/11 134/18</p> <p><b>having</b> [20] 2/11 12/7 16/25 19/3 19/10 20/17 39/4 45/2 45/7 48/1 50/11 83/5 86/21 99/13 106/10 110/18 112/13 113/19 125/12 125/22</p> <p><b>having thought</b> [1] 12/7</p> <p><b>Hazardous</b> [1] 119/4</p> <p><b>he</b> [192]</p> <p><b>he did</b> [1] 45/22</p> <p><b>he'd</b> [14] 44/21 70/19 81/9 81/9 81/12 92/2 92/2 92/6 92/7 92/8 112/18 122/21 123/1 124/3</p> <p><b>he'll</b> [1] 46/15</p> <p><b>he's</b> [17] 13/7 14/14 26/17 26/17 31/1 31/1 31/2 31/2 63/25 81/25 102/6 108/4 117/16 121/5 123/17 123/17 123/25</p> <p><b>head</b> [5] 99/20 104/23 123/18 124/15 124/18</p> <p><b>headed</b> [2] 74/11 103/11</p> <p><b>heading</b> [4] 22/19 82/19 105/11 114/12</p> <p><b>headmaster</b> [5] 5/9 6/5 56/2 59/13 67/3</p> <p><b>heads</b> [1] 111/13</p> <p><b>headteacher</b> [1] 68/12</p> <p><b>health</b> [8] 35/22 37/16 39/2 87/15 87/15 87/16 91/12 120/5</p> <p><b>hear</b> [8] 1/8 1/9 1/25 61/13 61/20 63/13 125/1 135/25</p> <p><b>heard</b> [12] 9/23 44/22 45/2 47/22 50/3 50/11 50/14 52/20 56/12 63/15 113/3 127/14</p> <p><b>hearing</b> [4] 32/9 127/8</p>	<p>128/23 136/9</p> <p><b>hearse</b> [1] 52/7</p> <p><b>hearts</b> [1] 61/12</p> <p><b>heat</b> [3] 27/10 74/3 74/6</p> <p><b>heat-treated</b> [3] 27/10 74/3 74/6</p> <p><b>heightened</b> [1] 20/22</p> <p><b>hell</b> [2] 34/18 119/16</p> <p><b>Hello</b> [1] 126/17</p> <p><b>help</b> [9] 10/6 10/11 10/20 25/10 31/12 46/6 46/9 107/18 130/7</p> <p><b>helped</b> [5] 10/16 45/11 61/6 63/3 135/22</p> <p><b>helpful</b> [2] 47/10 128/22</p> <p><b>Hem</b> [1] 101/7</p> <p><b>Hemofil</b> [14] 16/16 19/17 27/7 71/12 71/13 71/14 71/14 71/14 71/17 71/21 80/7 101/6 101/8 101/11</p> <p><b>hep</b> [2] 123/17 130/12</p> <p><b>hep C</b> [2] 123/17 130/12</p> <p><b>hepatitis</b> [69] 5/1 5/7 5/11 5/13 5/24 6/6 11/17 11/25 14/21 14/22 14/24 15/2 15/4 15/5 15/7 16/7 17/8 20/22 22/20 22/25 23/15 24/23 25/10 25/15 25/20 28/9 29/6 29/9 29/13 33/6 33/13 33/16 33/22 34/6 34/21 34/22 35/4 35/11 35/13 36/1 36/2 36/3 36/4 36/5 36/6 36/8 42/4 42/12 42/16 43/21 44/14 56/3 56/8 56/14 56/24 57/2 57/5 57/7 74/11 110/5 110/10 110/19 110/22 123/3 123/6 123/13 123/19 125/13 129/11</p> <p><b>hepatitis A</b> [1] 15/4</p> <p><b>hepatitis B</b> [23] 5/1 5/7 5/24 15/2 25/10 25/15 25/20 29/6 29/9 34/21 35/4 35/11 36/1 36/2 36/4 36/5 36/6 36/8 56/14 57/2 57/7 110/10 110/19</p> <p><b>hepatitis C</b> [19] 28/9 29/13 33/6 33/13 33/16 34/6 35/13 36/3 42/4 42/12 42/16 43/21 44/14 123/3</p>
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<p><b>H</b></p> <p><b>hepatitis C...</b> [5] 123/6 123/13 123/19 125/13 129/11</p> <p><b>her</b> [35] 8/12 12/13 48/19 50/8 51/23 52/1 61/8 61/9 61/14 61/15 61/18 61/19 61/21 61/21 61/22 102/17 112/22 112/22 113/20 115/24 116/2 116/2 117/10 117/10 118/1 118/17 119/4 119/5 119/25 120/17 120/23 121/2 130/7 130/7 132/20</p> <p><b>here</b> [31] 1/15 21/14 37/3 46/12 50/9 52/1 54/5 55/8 70/7 71/3 74/9 74/17 77/16 79/7 81/21 82/15 86/6 93/1 101/1 105/14 109/23 116/10 118/14 123/25 126/23 126/24 131/25 133/7 135/1 135/17 135/22</p> <p><b>herpes</b> [2] 38/16 38/16</p> <p><b>hers</b> [1] 120/12</p> <p><b>hey</b> [1] 125/25</p> <p><b>HHFT0001430</b> [1] 103/10</p> <p><b>hibernated</b> [2] 117/2 117/7</p> <p><b>Higgins</b> [1] 44/24</p> <p><b>higher</b> [1] 110/16</p> <p><b>him</b> [51] 3/16 5/4 5/6 11/22 13/8 13/24 18/4 18/16 19/17 25/20 30/22 30/22 31/3 32/12 32/15 36/21 41/25 45/18 46/3 46/4 50/13 54/4 54/6 55/19 58/10 59/9 59/10 59/16 59/21 69/16 69/22 70/18 70/18 73/21 81/10 90/9 90/16 90/17 91/21 92/7 94/12 108/15 117/20 117/22 121/6 122/5 124/17 124/23 133/6 133/19 133/21</p> <p><b>himself</b> [8] 10/19 69/23 70/8 70/20 70/20 90/13 92/10 122/14</p> <p><b>hint</b> [1] 100/10</p> <p><b>hired</b> [1] 52/7</p> <p><b>his</b> [50] 10/17 13/25 18/16 23/23 23/24 26/17 28/2 32/13</p>	<p>42/11 46/10 50/12 50/12 52/15 53/25 54/4 54/7 56/1 58/10 62/8 63/25 64/7 64/20 68/16 69/24 70/1 73/19 75/2 75/11 75/20 75/25 77/2 79/3 82/22 84/9 89/22 91/9 91/10 91/24 114/15 122/1 122/7 122/20 123/1 123/1 124/10 124/15 124/15 124/17 128/2 133/4</p> <p><b>historic</b> [1] 29/20</p> <p><b>hit</b> [1] 118/22</p> <p><b>HIV</b> [20] 28/5 29/6 29/18 29/20 30/3 30/7 30/9 32/5 32/17 33/15 40/4 40/23 41/11 42/5 85/17 86/15 116/12 116/24 121/24 129/8</p> <p><b>Hiya</b> [1] 126/16</p> <p><b>hm</b> [5] 79/5 100/6 121/25 123/4 129/13</p> <p><b>Hmm</b> [1] 80/10</p> <p><b>Hobson's</b> [1] 3/20</p> <p><b>hold</b> [2] 8/5 8/6</p> <p><b>holding</b> [1] 92/1</p> <p><b>holiday</b> [8] 17/12 18/17 18/20 32/15 45/13 53/18 73/20 102/7</p> <p><b>holidays</b> [9] 2/22 16/21 17/10 17/23 18/13 19/21 20/16 77/24 112/20</p> <p><b>home</b> [48] 1/11 3/4 3/5 3/19 7/25 12/5 12/10 13/20 14/13 16/21 17/13 17/16 17/19 18/18 24/7 30/13 31/1 40/18 45/19 46/11 50/12 57/19 57/21 58/10 58/23 62/24 66/2 66/5 66/11 66/17 66/19 69/23 80/21 97/20 102/6 102/10 102/14 105/24 108/23 112/2 112/18 112/20 117/2 118/6 118/22 123/1 127/11 135/6</p> <p><b>homework</b> [1] 99/5</p> <p><b>honest</b> [2] 20/7 98/10</p> <p><b>honestly</b> [3] 93/11 109/11 134/24</p> <p><b>hooked</b> [1] 45/23</p> <p><b>hope</b> [4] 37/18 60/20 95/20 124/13</p> <p><b>hopefully</b> [3] 25/20 99/3 135/3</p> <p><b>hoping</b> [1] 53/6</p>	<p><b>horrendous</b> [2] 46/17 92/11</p> <p><b>horrible</b> [1] 6/13</p> <p><b>horrific</b> [1] 50/3</p> <p><b>hospital</b> [28] 4/11 14/10 16/2 20/18 27/3 27/15 30/14 30/16 41/1 42/1 43/18 45/20 65/24 66/16 70/18 70/18 100/12 109/14 112/4 113/3 113/6 120/2 120/3 123/1 126/16 129/19 133/9 133/16</p> <p><b>hospitals</b> [5] 109/7 127/23 128/25 129/4 129/5</p> <p><b>hotel</b> [1] 45/20</p> <p><b>hour</b> [4] 110/1 121/13 133/20 135/4</p> <p><b>hour's</b> [1] 133/8</p> <p><b>hours</b> [3] 66/16 100/12 103/25</p> <p><b>house</b> [8] 13/23 44/16 50/7 50/10 57/24 112/1 117/21 121/4</p> <p><b>housemaster</b> [5] 58/9 59/2 59/2 59/15 68/12</p> <p><b>how</b> [40] 3/23 4/3 7/22 8/14 17/4 18/3 20/14 28/11 30/8 33/12 35/19 35/22 41/20 42/22 45/5 58/2 64/17 65/3 66/25 93/21 95/7 96/1 98/4 99/9 113/22 116/15 117/6 118/11 119/18 121/1 122/1 122/6 122/6 122/11 123/5 123/21 126/5 127/6 133/19 136/2</p> <p><b>How's</b> [1] 113/22</p> <p><b>However</b> [1] 18/15</p> <p><b>HTLV</b> [13] 29/20 29/21 30/4 30/5 77/5 77/15 78/1 78/14 78/25 86/9 87/10 88/21 89/6</p> <p><b>HTLV-3</b> [3] 29/20 29/21 77/5</p> <p><b>HTLV-III</b> [9] 30/4 30/5 77/15 78/1 78/14 78/25 86/9 87/10 89/6</p> <p><b>huge</b> [1] 39/15</p> <p><b>Hull</b> [8] 2/7 3/10 14/7 14/16 19/8 27/3 27/15 32/25</p> <p><b>hundred</b> [2] 52/13 130/16</p> <p><b>hundreds</b> [1] 134/20</p> <p><b>hurt</b> [2] 135/20 135/20</p> <p><b>hurting</b> [1] 38/21</p> <p><b>hurts</b> [2] 70/16 70/17</p>	<p><b>husband</b> [1] 50/8</p> <p><b>I</b></p> <p><b>I accessed</b> [1] 29/8</p> <p><b>I actually</b> [1] 98/5</p> <p><b>I agree</b> [1] 33/21</p> <p><b>I allowed</b> [2] 111/9 111/10</p> <p><b>I already</b> [1] 98/8</p> <p><b>I also</b> [2] 48/9 52/2</p> <p><b>I always</b> [2] 26/20 131/16</p> <p><b>I am</b> [8] 1/12 10/21 16/15 28/10 62/3 69/25 75/8 75/24</p> <p><b>I applied</b> [2] 47/18 48/24</p> <p><b>I ask</b> [2] 55/19 57/10</p> <p><b>I asked</b> [4] 30/18 48/6 112/7 112/7</p> <p><b>I became</b> [1] 130/4</p> <p><b>I been</b> [1] 31/19</p> <p><b>I believe</b> [2] 61/24 123/23</p> <p><b>I both</b> [1] 58/5</p> <p><b>I came</b> [2] 30/13 48/15</p> <p><b>I can</b> [14] 2/21 10/12 29/11 32/7 36/19 52/6 58/19 69/20 93/11 99/18 103/7 105/8 109/11 110/20</p> <p><b>I can't</b> [15] 1/13 11/1 17/17 27/10 44/15 44/16 51/12 90/7 102/24 111/20 122/3 122/8 125/22 129/16 129/17</p> <p><b>I certainly</b> [1] 2/1</p> <p><b>I come</b> [2] 127/18 127/18</p> <p><b>I could</b> [9] 20/18 41/17 42/8 42/13 84/19 99/19 111/18 134/5 134/5</p> <p><b>I couldn't</b> [2] 92/2 119/25</p> <p><b>I cried</b> [1] 127/19</p> <p><b>I cry</b> [1] 127/19</p> <p><b>I deteriorated</b> [1] 41/14</p> <p><b>I developed</b> [1] 39/15</p> <p><b>I did</b> [16] 4/18 8/16 26/4 28/17 62/7 97/15 110/2 115/17 115/17 118/20 118/21 120/24 121/7 128/21 128/23 135/14</p> <p><b>I didn't</b> [21] 3/18 13/20 31/11 31/19 35/3 38/3 38/4 40/6 40/21 43/9 47/20</p>	<p>47/21 55/4 58/22 63/14 105/1 107/8 109/13 118/2 127/19 134/15</p> <p><b>I do</b> [21] 6/10 12/7 12/8 12/11 15/8 16/14 17/18 17/23 18/6 18/24 23/4 43/17 60/12 66/11 70/10 76/12 93/13 105/3 107/11 113/18 132/17</p> <p><b>I don't</b> [46] 8/9 9/15 11/13 12/5 12/9 12/11 15/6 17/2 17/3 17/4 24/3 25/4 26/4 26/16 35/6 35/10 36/18 39/19 39/23 45/3 52/19 54/4 55/21 55/23 68/1 86/18 90/20 95/7 101/25 102/15 102/15 108/14 108/18 109/7 109/24 112/7 112/8 112/8 119/22 121/20 122/2 122/4 127/8 128/1 132/23 135/2</p> <p><b>I drive</b> [1] 135/17</p> <p><b>I enclose</b> [2] 75/21 77/1</p> <p><b>I eventually</b> [1] 98/8</p> <p><b>I ever</b> [1] 95/20</p> <p><b>I explained</b> [1] 15/9</p> <p><b>I feared</b> [1] 62/1</p> <p><b>I feel</b> [1] 49/12</p> <p><b>I felt</b> [2] 9/5 43/1</p> <p><b>I first</b> [1] 55/6</p> <p><b>I forget</b> [1] 27/12</p> <p><b>I forgot</b> [1] 105/1</p> <p><b>I found</b> [5] 8/1 26/8 28/16 41/6 54/9</p> <p><b>I gather</b> [1] 1/4</p> <p><b>I go</b> [3] 109/12 128/16 131/1</p> <p><b>I got</b> [15] 3/23 8/24 13/22 30/20 37/22 38/8 43/2 43/19 48/13 49/3 124/23 125/22 125/23 127/17 135/22</p> <p><b>I had</b> [35] 2/13 2/13 8/2 13/18 14/18 20/15 30/25 31/9 32/25 33/2 38/16 38/22 39/10 39/11 39/16 39/20 39/21 39/25 42/3 42/6 42/12 44/25 46/6 48/4 59/14 59/21 63/4 109/9 116/16 116/18 123/9 125/2 127/20 127/20 134/20</p> <p><b>I hate</b> [1] 108/22</p> <p><b>I have</b> [14] 10/10 61/23 62/5 64/2 75/3</p>	<p>94/3 94/5 121/20 121/21 123/12 128/12 129/3 130/8 132/5</p> <p><b>I haven't</b> [3] 43/17 118/14 128/11</p> <p><b>I heard</b> [1] 47/22</p> <p><b>I hibernated</b> [1] 117/7</p> <p><b>I honestly</b> [1] 134/24</p> <p><b>I hope</b> [1] 95/20</p> <p><b>I imagine</b> [1] 21/7</p> <p><b>I improved</b> [1] 43/9</p> <p><b>I joined</b> [3] 4/5 57/19 62/2</p> <p><b>I just</b> [19] 5/22 14/1 36/2 37/9 38/5 40/10 40/18 45/1 48/13 55/4 58/1 63/21 80/19 92/1 95/6 99/21 117/18 121/22 131/2</p> <p><b>I kept</b> [1] 130/6</p> <p><b>I knew</b> [4] 37/22 109/6 117/25 126/8</p> <p><b>I know</b> [15] 54/23 96/7 99/18 104/16 110/3 120/7 123/23 129/20 130/16 130/17 130/18 131/5 131/7 134/3 135/5</p> <p><b>I leave</b> [1] 134/13</p> <p><b>I left</b> [2] 115/19 121/12</p> <p><b>I like</b> [1] 134/12</p> <p><b>I looked</b> [1] 5/4</p> <p><b>I lost</b> [3] 32/5 98/6 126/19</p> <p><b>I love</b> [5] 117/23 132/17 132/18 135/5 135/21</p> <p><b>I loved</b> [1] 119/25</p> <p><b>I made</b> [1] 41/24</p> <p><b>I managed</b> [1] 8/23</p> <p><b>I married</b> [1] 93/20</p> <p><b>I may</b> [1] 130/2</p> <p><b>I mean</b> [45] 7/17 9/22 10/2 10/5 10/10 10/20 12/10 13/2 13/18 14/6 14/14 15/3 20/1 23/1 23/15 27/25 31/12 32/8 34/11 34/16 35/7 38/7 41/7 46/21 47/17 52/6 57/15 58/7 58/19 58/21 59/8 59/10 59/13 59/23 66/14 67/21 70/13 80/19 89/20 90/9 90/20 91/1 91/1 92/17 128/24</p> <p><b>I mention</b> [1] 120/17</p> <p><b>I mentioned</b> [2] 23/16 53/15</p> <p><b>I met</b> [4] 98/12 117/25 120/17 120/22</p> <p><b>I might</b> [2] 12/10 93/1</p>
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<p><b>I</b></p> <p><b>I miss [1]</b> 95/5</p> <p><b>I missed [2]</b> 3/14 98/25</p> <p><b>I must [1]</b> 61/4</p> <p><b>I need [3]</b> 111/23 118/8 126/21</p> <p><b>I needed [5]</b> 30/16 36/23 37/1 109/6 127/12</p> <p><b>I never [1]</b> 129/20</p> <p><b>I ought [1]</b> 42/10</p> <p><b>I pick [1]</b> 135/19</p> <p><b>I picked [1]</b> 118/3</p> <p><b>I probably [1]</b> 107/19</p> <p><b>I proceeded [1]</b> 7/25</p> <p><b>I pull [1]</b> 135/18</p> <p><b>I put [2]</b> 109/5 109/8</p> <p><b>I rang [3]</b> 35/2 36/24 37/1</p> <p><b>I recall [1]</b> 7/24</p> <p><b>I received [1]</b> 22/5</p> <p><b>I recognise [1]</b> 72/9</p> <p><b>I remember [24]</b> 2/11 10/2 18/22 19/4 19/6 20/16 23/1 27/7 32/20 33/23 38/21 52/13 59/14 99/11 99/12 99/14 99/16 103/3 107/4 126/14 128/1 131/10 131/21 133/11</p> <p><b>I right [3]</b> 66/7 68/25 96/6</p> <p><b>I said [27]</b> 4/21 4/21 6/12 12/13 31/14 34/6 35/2 35/5 37/5 39/21 40/11 40/17 45/2 45/5 46/2 48/13 48/18 58/10 59/22 67/6 88/4 88/25 116/23 126/17 126/18 126/18 128/12</p> <p><b>I sat [2]</b> 111/18 128/3</p> <p><b>I saw [5]</b> 13/24 35/1 43/4 54/3 59/9</p> <p><b>I say [6]</b> 10/4 26/4 41/14 51/7 70/12 87/22</p> <p><b>I see [2]</b> 77/10 94/20</p> <p><b>I seem [1]</b> 17/15</p> <p><b>I shouldn't [1]</b> 21/24</p> <p><b>I sought [1]</b> 62/2</p> <p><b>I spent [2]</b> 3/8 43/18</p> <p><b>I spoke [2]</b> 44/5 54/3</p> <p><b>I started [2]</b> 47/24 51/7</p> <p><b>I still [5]</b> 33/3 48/10 107/10 126/23 128/25</p> <p><b>I suddenly [2]</b> 30/21 55/5</p> <p><b>I suppose [3]</b> 116/9 120/1 127/11</p>	<p><b>I suspect [3]</b> 22/6 39/18 64/15</p> <p><b>I sweat [1]</b> 38/8</p> <p><b>I talk [1]</b> 62/6</p> <p><b>I talked [1]</b> 50/1</p> <p><b>I tended [1]</b> 32/3</p> <p><b>I tested [1]</b> 45/21</p> <p><b>I thank [1]</b> 135/24</p> <p><b>I think [128]</b> 2/12 2/20 2/23 3/8 4/16 5/1 5/20 5/25 6/16 6/18 11/10 12/13 14/8 14/11 14/16 17/11 17/17 18/2 18/4 18/7 18/24 20/7 20/12 20/16 20/23 21/13 22/5 22/9 23/2 23/8 24/11 24/12 26/16 30/12 31/5 31/8 31/23 32/13 34/6 35/8 35/8 35/13 36/21 38/6 38/23 39/9 39/16 39/21 40/23 42/7 45/24 46/19 47/15 49/19 51/8 51/9 52/10 52/21 53/1 53/2 53/15 54/3 54/9 55/4 55/11 57/10 63/18 67/14 67/19 69/2 70/12 72/11 72/19 73/6 79/3 79/12 85/11 87/19 87/24 89/13 89/24 90/3 90/14 91/9 92/21 93/19 94/10 95/12 96/13 98/5 100/1 100/9 100/9 100/13 102/23 103/3 103/5 108/12 108/23 111/7 111/13 111/16 111/17 113/19 113/25 114/1 114/3 115/15 116/14 116/16 116/17 119/7 119/21 120/18 123/7 123/7 126/6 128/20 131/19 131/22 132/20 133/4 133/5 133/23 134/14 135/1 135/11 135/14</p> <p><b>I thought [18]</b> 4/24 8/21 12/9 17/11 30/15 31/18 31/19 36/3 38/7 43/25 44/4 46/15 48/2 48/20 59/5 87/22 121/7 127/20</p> <p><b>I thought: what [1]</b> 38/1</p> <p><b>I told [2]</b> 31/16 38/22</p> <p><b>I took [2]</b> 40/20 75/5</p> <p><b>I tried [1]</b> 48/8</p> <p><b>I understand [2]</b> 5/10 97/3</p> <p><b>I understand it [1]</b> 76/19</p>	<p><b>I used [5]</b> 14/6 109/2 109/25 109/25 119/23</p> <p><b>I want [4]</b> 35/21 100/21 109/4 135/15</p> <p><b>I wanted [2]</b> 57/9 118/3</p> <p><b>I was [75]</b> 2/9 2/12 3/4 3/6 3/9 3/10 8/18 10/14 11/9 12/5 13/10 17/9 17/9 17/16 31/13 32/4 33/1 33/15 37/2 37/25 38/3 38/18 38/18 38/24 41/12 41/16 41/16 42/14 43/25 45/20 45/22 45/24 46/5 46/8 46/10 48/9 48/11 48/19 52/24 58/13 58/21 61/13 61/19 70/20 88/1 91/25 91/25 98/16 105/1 105/2 108/11 109/1 109/1 109/3 109/6 109/21 110/2 110/3 110/3 113/8 115/21 117/6 119/9 119/21 119/23 120/7 121/1 126/6 126/6 126/7 127/2 127/2 127/8 132/2 135/22</p> <p><b>I wasn't [1]</b> 119/22</p> <p><b>I went [16]</b> 2/8 3/7 20/8 30/11 32/21 38/10 40/6 43/3 45/13 51/9 54/6 70/14 98/6 117/2 127/16 127/17</p> <p><b>I were [1]</b> 43/2</p> <p><b>I won't [1]</b> 58/7</p> <p><b>I wondered [1]</b> 63/15</p> <p><b>I worked [1]</b> 120/2</p> <p><b>I would [22]</b> 3/21 7/4 8/9 9/8 9/10 9/16 9/17 9/18 12/2 14/8 14/18 22/16 25/22 28/2 59/11 61/24 62/14 62/22 64/7 87/3 96/12 130/6</p> <p><b>I wrote [1]</b> 49/2</p> <p><b>I'd [30]</b> 5/25 8/16 9/5 9/17 28/19 31/13 31/20 32/2 32/22 40/14 41/22 42/11 42/25 48/21 48/22 57/14 57/18 59/23 62/10 62/25 63/5 70/17 108/8 108/18 116/11 117/4 119/21 121/13 126/11 134/22</p> <p><b>I'll [12]</b> 21/19 30/23 55/3 87/5 91/24 95/4 98/10 104/1 129/25 134/12 135/4 135/6</p>	<p><b>I'm [67]</b> 1/12 11/1 12/16 15/6 17/3 17/13 17/19 24/14 24/15 25/6 26/20 28/20 35/9 39/22 40/11 44/10 44/11 44/23 47/2 48/12 50/1 53/6 53/22 54/13 54/20 54/22 55/5 55/12 59/6 65/10 68/10 69/6 70/15 71/5 72/11 74/18 77/13 78/20 79/1 86/2 88/8 93/12 93/13 107/9 109/4 109/12 109/13 110/23 110/24 113/1 116/23 118/14 121/2 122/5 123/7 123/11 126/23 130/15 130/15 130/19 130/25 132/6 132/13 133/17 135/1 135/16 135/23</p> <p><b>I've [64]</b> 4/12 9/7 10/17 10/25 12/6 13/12 13/15 17/2 19/2 22/5 26/12 27/25 37/6 37/8 37/11 39/13 44/13 44/17 45/2 50/11 51/13 52/25 58/16 62/4 62/4 72/6 75/14 82/12 88/2 90/2 92/4 99/20 105/2 107/9 109/20 116/2 116/2 116/18 118/6 119/9 123/10 125/23 125/24 125/24 126/19 126/20 127/13 127/14 127/15 127/16 129/1 129/4 129/19 131/18 132/13 132/14 132/14 132/16 132/17 134/4 134/19 135/12 135/20 135/23</p> <p><b>ice [1]</b> 128/18</p> <p><b>idea [4]</b> 10/7 78/22 78/23 123/10</p> <p><b>identified [3]</b> 6/19 64/10 85/9</p> <p><b>if [142]</b></p> <p><b>ii [2]</b> 103/22 104/11</p> <p><b>iii [11]</b> 30/4 30/5 77/15 78/1 78/14 78/25 86/9 87/10 88/21 89/6 103/24</p> <p><b>ill [2]</b> 125/4 127/10</p> <p><b>imagine [2]</b> 21/7 58/15</p> <p><b>immunoassay [1]</b> 25/15</p> <p><b>implication [1]</b> 76/3</p> <p><b>implications [1]</b> 19/24</p> <p><b>important [2]</b> 135/25 136/5</p>	<p><b>impressed [1]</b> 70/21</p> <p><b>improved [1]</b> 43/9</p> <p><b>incident [1]</b> 58/5</p> <p><b>inclined [1]</b> 75/24</p> <p><b>include [1]</b> 35/5</p> <p><b>included [1]</b> 35/11</p> <p><b>including [2]</b> 49/3 61/7</p> <p><b>increase [2]</b> 52/21 101/11</p> <p><b>incredible [2]</b> 22/10 22/10</p> <p><b>indeed [4]</b> 27/17 64/3 115/6 115/10</p> <p><b>independent [1]</b> 61/25</p> <p><b>independently [1]</b> 61/12</p> <p><b>indicate [1]</b> 22/2</p> <p><b>indicated [1]</b> 135/12</p> <p><b>indication [3]</b> 21/2 21/10 105/14</p> <p><b>infected [13]</b> 19/11 28/5 28/8 29/5 30/9 49/20 62/15 85/17 116/19 116/24 122/11 123/6 123/13</p> <p><b>infection [14]</b> 4/20 34/9 34/17 35/13 38/6 39/21 41/10 41/11 41/24 43/15 119/1 120/15 122/1 125/13</p> <p><b>infections [5]</b> 29/7 37/21 42/9 85/23 86/1</p> <p><b>infinite [1]</b> 63/7</p> <p><b>Infirmity [1]</b> 14/7</p> <p><b>inform [2]</b> 13/19 13/19</p> <p><b>information [19]</b> 5/16 6/4 6/7 24/1 26/1 26/2 29/4 29/9 54/21 72/4 72/13 75/21 77/1 78/3 82/25 84/11 93/7 105/2 114/20</p> <p><b>informed [6]</b> 29/12 29/16 29/25 32/17 33/15 72/14</p> <p><b>informing [1]</b> 75/13</p> <p><b>infused [1]</b> 61/10</p> <p><b>infusing [1]</b> 61/9</p> <p><b>infusion [2]</b> 7/18 7/25</p> <p><b>inguinal [1]</b> 114/16</p> <p><b>inhibitors [1]</b> 23/4</p> <p><b>initial [2]</b> 47/13 91/2</p> <p><b>inject [1]</b> 105/3</p> <p><b>injecting [1]</b> 61/16</p> <p><b>injections [3]</b> 17/22 125/16 126/7</p> <p><b>injury [1]</b> 59/7</p> <p><b>Inquiry [8]</b> 37/1 51/22 56/18 60/19 63/6 95/8 95/21 134/23</p> <p><b>insignificant [1]</b> 25/25</p>	<p><b>instant [1]</b> 66/17</p> <p><b>instead [1]</b> 16/17</p> <p><b>institutional [1]</b> 57/24</p> <p><b>intended [1]</b> 60/1</p> <p><b>intentional [1]</b> 34/17</p> <p><b>Inter [2]</b> 101/6 101/7</p> <p><b>interaction [2]</b> 47/11 68/7</p> <p><b>interferon [3]</b> 42/17 43/6 125/15</p> <p><b>Interhem [7]</b> 80/13 101/12 104/5 105/24 106/21 106/21 106/21</p> <p><b>interview [1]</b> 50/19</p> <p><b>interviewed [1]</b> 42/2</p> <p><b>interviews [1]</b> 52/12</p> <p><b>intimately [1]</b> 23/23</p> <p><b>into [21]</b> 3/6 8/6 8/12 9/8 13/22 21/11 25/4 45/20 46/18 57/6 70/17 73/19 73/20 84/9 87/24 111/1 111/14 119/23 121/5 125/18 132/23</p> <p><b>invasive [1]</b> 76/16</p> <p><b>investigations [5]</b> 76/16 82/20 83/6 114/13 114/25</p> <p><b>invite [1]</b> 121/4</p> <p><b>invited [2]</b> 53/16 123/9</p> <p><b>involve [1]</b> 103/18</p> <p><b>involved [8]</b> 34/23 49/24 51/2 51/7 76/20 100/19 127/16 128/11</p> <p><b>involvement [2]</b> 11/11 49/18</p> <p><b>inward [1]</b> 130/4</p> <p><b>irritating [1]</b> 91/6</p> <p><b>isn't [2]</b> 18/10 65/1</p> <p><b>isolating [1]</b> 45/20</p> <p><b>issue [4]</b> 25/10 75/24 76/6 120/15</p> <p><b>issues [2]</b> 58/2 60/21</p> <p><b>it'll [3]</b> 64/14 91/5 91/5</p> <p><b>it's [98]</b> 4/23 4/23 4/24 6/14 11/1 11/6 11/8 11/10 11/16 15/21 15/25 18/8 18/10 21/13 22/10 22/22 22/23 24/19 25/8 25/25 28/14 28/25 34/2 43/6 43/20 43/21 44/16 45/5 45/12 46/20 48/14 51/12 51/19 51/20 51/20 52/5 52/20 53/13 53/21 58/23 59/10 59/16 60/2 61/2 64/11 65/1 66/10 69/10 71/2 72/24 73/6 73/9 73/14 74/25 75/1 75/2 76/25</p>
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<p><b>I</b></p> <p>it's... [41] 77/11 77/12 78/7 79/8 80/4 81/21 83/13 84/12 84/21 86/6 86/6 90/4 92/11 92/25 93/18 95/9 99/11 99/14 99/18 100/11 101/1 101/12 102/4 107/18 108/12 113/4 113/15 113/16 116/17 122/19 123/8 126/16 126/22 129/2 130/16 131/9 132/19 133/4 135/1 135/9 135/14</p> <p>itself [2] 7/3 55/1</p>	<p>86/19 87/6 87/19 91/23 92/5 93/4 93/12 94/3 94/6 95/2 95/22 95/25 137/5</p> <p>join [1] 53/17</p> <p>joined [6] 3/1 4/5 57/19 62/2 69/1 79/3</p> <p>joint [1] 73/20</p> <p>joints [6] 19/10 20/4 20/25 32/5 47/18 99/13</p> <p>joked [1] 5/5</p> <p>journalist [1] 50/18</p> <p>journalists [1] 50/16</p> <p>journey [1] 62/13</p> <p>JPEA0000001 [4]</p> <p>86/5 86/17 87/6 88/16</p> <p>JPEA0000004 [1]</p>	<p>78/19</p> <p>kindly [1] 17/22</p> <p>Kingston [5] 2/7 16/1 23/21 27/3 27/15</p> <p>Kingston General [1] 27/15</p> <p>Kingston Hospital [1] 27/3</p> <p>Kirk [9] 6/20 6/22 11/6 15/24 16/20 18/12 19/8 19/20 25/8</p> <p>kitchen [1] 121/12</p> <p>knee [10] 3/7 3/9 30/18 39/7 39/16 39/25 70/17 103/4 105/15 120/6</p> <p>knees [3] 39/6 107/18 107/19</p> <p>knew [23] 15/5 24/25 34/3 34/9 37/22 50/3 58/2 66/8 74/7 81/8 91/18 94/13 94/15 94/18 109/6 114/1 114/3 114/4 117/25 118/1 126/8 127/9 133/9</p> <p>knock [1] 108/6</p> <p>know [151]</p> <p>knowing [2] 37/12 122/10</p> <p>knowledge [2] 24/2 76/22</p> <p>known [6] 32/11 33/16 46/21 109/1 113/7 117/19</p> <p>knows [3] 41/20 43/14 132/20</p> <p>Koate [8] 71/11 71/12 71/13 71/14 71/17 71/17 71/21 82/8</p> <p>Kryobulin [16] 11/22 12/9 14/5 15/21 16/7 16/18 17/1 17/10 17/13 17/16 17/20 21/21 21/24 25/17 71/21 101/13</p>	<p>55/20 94/8 132/8 137/4 137/7 137/10</p> <p>language [1] 77/16</p> <p>large [3] 22/14 23/2 112/16</p> <p>largely [2] 2/7 118/25</p> <p>last [21] 3/14 12/7 17/3 25/12 29/3 44/22 45/12 46/13 52/24 62/8 62/24 71/1 74/1 75/7 75/10 85/1 88/16 91/6 94/1 105/11 128/24</p> <p>lasting [1] 27/13</p> <p>lasts [1] 42/22</p> <p>late [6] 6/25 62/11 64/8 66/4 72/22 74/5</p> <p>lately [1] 43/17</p> <p>later [16] 30/13 30/16 31/6 35/10 39/25 40/13 43/10 73/13 78/8 87/20 87/22 91/16 103/23 103/25 117/9 121/9</p> <p>latest [3] 27/13 44/1 103/16</p> <p>laugh [2] 131/15 131/16</p> <p>laughing [1] 59/9</p> <p>Laughs [2] 13/1 63/14</p> <p>laying [1] 99/13</p> <p>leading [1] 39/2</p> <p>leading to [1] 39/2</p> <p>leaflet [1] 6/3</p> <p>learn [2] 33/1 63/3</p> <p>learned [1] 94/10</p> <p>learning [1] 33/2</p> <p>learnt [4] 30/9 33/12 34/22 85/17</p> <p>least [4] 31/3 32/15 101/17 103/15</p> <p>leave [4] 40/17 118/17 130/6 134/13</p> <p>leaves [3] 133/14 133/24 134/6</p> <p>leaving [2] 77/23 134/4</p> <p>led [2] 44/14 46/19</p> <p>Lee [1] 136/10</p> <p>Lee Stay [1] 136/10</p> <p>Leeds [1] 51/14</p> <p>left [30] 3/7 10/5 20/10 22/19 26/25 27/6 31/17 34/8 39/7 39/25 53/22 55/6 62/16 62/20 74/10 78/21 79/13 82/23 84/9 85/11 86/10 89/11 103/12 112/13 112/14 114/18 115/13 115/19 121/12 133/19</p> <p>left-hand [5] 22/19</p>	<p>74/10 79/13 86/10 103/12</p> <p>leg [2] 39/8 39/22</p> <p>legal [3] 4/23 33/19 33/21</p> <p>legally [1] 34/8</p> <p>legs [1] 33/4</p> <p>Leigh [50] 65/11 65/15 66/25 67/22 67/23 67/23 67/25 68/15 68/25 69/10 69/20 70/3 70/7 70/14 70/15 70/23 70/25 71/19 71/24 72/25 73/23 74/6 74/10 75/2 75/3 75/17 76/6 77/23 78/1 78/8 78/16 78/21 78/23 81/9 81/14 89/13 89/22 90/6 90/6 90/6 90/7 90/14 90/22 90/22 91/8 91/16 91/17 91/20 92/23 94/10</p> <p>Leigh's [7] 71/8 73/18 75/1 76/20 77/2 78/4 92/1</p> <p>lesions [1] 91/20</p> <p>less [3] 10/18 33/25 75/8</p> <p>lessons [1] 47/24</p> <p>let [7] 4/9 11/14 13/7 32/20 69/15 83/2 114/22</p> <p>let's [2] 32/14 115/25</p> <p>letter [47] 11/3 12/4 12/6 12/11 12/14 12/17 13/11 13/13 13/15 14/2 14/23 15/24 19/8 23/20 25/8 26/9 26/13 28/12 28/22 28/25 30/21 33/7 40/18 40/20 69/8 69/18 73/13 73/14 74/1 74/22 76/24 82/15 86/18 86/21 86/23 86/25 87/7 87/9 88/18 102/2 102/4 102/20 114/10 114/12 123/10 123/10 123/11</p> <p>letters [5] 74/19 77/9 87/23 89/1 110/14</p> <p>leukaemia [1] 31/22</p> <p>level [1] 23/5</p> <p>Lewisham [1] 54/7</p> <p>life [16] 8/5 10/8 42/1 45/9 46/23 46/24 62/1 62/4 113/5 121/2 124/20 124/24 127/11 132/13 132/14 132/18</p> <p>lifespan [1] 62/17</p> <p>lifestyle [1] 31/2</p> <p>lifetime [1] 94/24</p>	<p>like [79] 1/3 1/18 3/20 6/11 13/3 15/15 20/10 26/19 27/22 31/22 32/1 33/14 35/14 39/20 41/13 43/10 45/9 45/17 47/16 49/7 50/10 50/21 51/20 54/7 55/19 57/12 57/14 57/20 58/2 58/9 58/18 59/16 59/18 59/23 62/10 62/14 62/22 62/25 63/5 64/7 64/18 65/3 69/16 72/15 84/21 84/23 86/10 88/12 89/21 91/2 91/7 91/23 92/11 92/16 95/2 96/12 99/10 102/20 105/19 107/6 107/8 107/10 111/8 116/24 119/7 120/5 120/25 122/2 122/13 127/7 128/2 128/15 130/22 134/2 134/3 134/7 134/10 134/12 134/22</p> <p>likely [1] 42/20</p> <p>limit [1] 22/11</p> <p>limited [1] 19/12</p> <p>limiting [2] 11/22 32/4</p> <p>line [6] 85/1 87/4 95/14 112/1 115/11 121/9</p> <p>lines [2] 63/23 84/23</p> <p>lip [1] 3/12</p> <p>list [1] 21/18</p> <p>listen [1] 135/16</p> <p>listened [1] 135/24</p> <p>listening [7] 116/22 127/21 128/4 134/17 134/23 135/5 135/14</p> <p>Lister [32] 21/17 21/17 21/18 21/20 21/20 21/21 21/21 66/8 66/9 66/10 66/19 70/4 71/16 71/17 71/20 72/10 74/8 79/16 79/17 79/21 80/4 80/17 81/22 81/25 102/13 106/13 106/21 106/22 106/22 106/22 106/22 106/22</p> <p>litigation [3] 34/24 36/24 51/11</p> <p>little [24] 7/20 9/16 14/18 18/21 26/20 35/12 35/13 40/2 44/4 45/11 47/2 67/6 68/2 73/16 74/18 78/11 99/22 112/11 113/8 121/22 123/15 128/12 131/12 131/12</p> <p>live [2] 112/25 113/2</p>
<p><b>J</b></p> <p>jobs [1] 126/21</p> <p>Jackie [2] 46/10 62/23</p> <p>Jan [6] 120/22 120/24 121/2 123/8 123/16 127/3</p> <p>January [5] 22/22 77/16 88/22 106/11 106/12</p> <p>January 1979 and [1] 22/22</p> <p>January 1983 [1] 106/11</p> <p>January 1984 [1] 77/16</p> <p>Jason [34] 65/11 65/15 66/25 67/22 67/22 67/24 68/1 68/1 78/19 79/2 79/3 79/8 79/17 80/8 80/16 81/19 82/4 82/7 82/10 82/16 85/9 85/11 86/22 87/1 87/3 87/10 87/17 88/21 89/6 89/13 90/7 90/18 90/21 91/10</p> <p>Jason's [4] 79/9 79/25 83/10 91/12</p> <p>jaundice [6] 25/21 81/8 81/12 94/11 94/12 94/16</p> <p>jeered [1] 50/7</p> <p>job [11] 17/22 20/24 28/3 33/1 39/5 89/22 109/20 124/23 132/17 132/17 135/21</p> <p>jobs [1] 127/11</p> <p>Joe [1] 128/4</p> <p>John [31] 64/11 65/1 65/7 65/8 65/10 69/7 71/3 71/18 72/11 74/20 76/24 77/13 78/11 82/15 83/5 83/15 84/4 85/16</p>	<p>93/17</p> <p>JPEA0000005 [1]</p> <p>93/24</p> <p>July [14] 29/10 29/14 29/21 30/5 33/9 36/13 82/15 82/19 83/13 83/21 84/21 85/7 90/17 101/15</p> <p>July '83 [1] 82/19</p> <p>July '84 [1] 83/21</p> <p>July '86 and [1] 30/5</p> <p>July '91 [1] 90/17</p> <p>July 1990 [2] 29/14 36/13</p> <p>June [14] 1/1 8/17 24/22 25/18 28/22 28/25 67/6 67/7 88/2 90/3 104/11 104/11 114/11 114/24</p> <p>June 1983 [2] 114/11 114/24</p> <p>junior [1] 3/4</p> <p>just [167]</p> <p>just have [1] 62/10</p> <p>justice [3] 60/7 60/24 60/24</p>	<p><b>L</b></p> <p>label [2] 4/19 27/19</p> <p>labelled [1] 58/8</p> <p>Laboratory [1] 77/4</p> <p>lad [1] 78/19</p> <p>lads [6] 91/19 92/17 96/7 108/3 111/9 127/21</p> <p>lady [3] 45/1 48/11 48/16</p> <p>laid [3] 45/23 130/4 130/4</p> <p>Lake [2] 51/10 53/18</p> <p>Land [1] 32/24</p> <p>LANGSTAFF [6]</p>	<p>78/19</p> <p>kindly [1] 17/22</p> <p>Kingston [5] 2/7 16/1 23/21 27/3 27/15</p> <p>Kingston General [1] 27/15</p> <p>Kingston Hospital [1] 27/3</p> <p>Kirk [9] 6/20 6/22 11/6 15/24 16/20 18/12 19/8 19/20 25/8</p> <p>kitchen [1] 121/12</p> <p>knee [10] 3/7 3/9 30/18 39/7 39/16 39/25 70/17 103/4 105/15 120/6</p> <p>knees [3] 39/6 107/18 107/19</p> <p>knew [23] 15/5 24/25 34/3 34/9 37/22 50/3 58/2 66/8 74/7 81/8 91/18 94/13 94/15 94/18 109/6 114/1 114/3 114/4 117/25 118/1 126/8 127/9 133/9</p> <p>knock [1] 108/6</p> <p>know [151]</p> <p>knowing [2] 37/12 122/10</p> <p>knowledge [2] 24/2 76/22</p> <p>known [6] 32/11 33/16 46/21 109/1 113/7 117/19</p> <p>knows [3] 41/20 43/14 132/20</p> <p>Koate [8] 71/11 71/12 71/13 71/14 71/17 71/17 71/21 82/8</p> <p>Kryobulin [16] 11/22 12/9 14/5 15/21 16/7 16/18 17/1 17/10 17/13 17/16 17/20 21/21 21/24 25/17 71/21 101/13</p>	<p>74/10 79/13 86/10 103/12</p> <p>leg [2] 39/8 39/22</p> <p>legal [3] 4/23 33/19 33/21</p> <p>legally [1] 34/8</p> <p>legs [1] 33/4</p> <p>Leigh [50] 65/11 65/15 66/25 67/22 67/23 67/23 67/25 68/15 68/25 69/10 69/20 70/3 70/7 70/14 70/15 70/23 70/25 71/19 71/24 72/25 73/23 74/6 74/10 75/2 75/3 75/17 76/6 77/23 78/1 78/8 78/16 78/21 78/23 81/9 81/14 89/13 89/22 90/6 90/6 90/6 90/7 90/14 90/22 90/22 91/8 91/16 91/17 91/20 92/23 94/10</p> <p>Leigh's [7] 71/8 73/18 75/1 76/20 77/2 78/4 92/1</p> <p>lesions [1] 91/20</p> <p>less [3] 10/18 33/25 75/8</p> <p>lessons [1] 47/24</p> <p>let [7] 4/9 11/14 13/7 32/20 69/15 83/2 114/22</p> <p>let's [2] 32/14 115/25</p> <p>letter [47] 11/3 12/4 12/6 12/11 12/14 12/17 13/11 13/13 13/15 14/2 14/23 15/24 19/8 23/20 25/8 26/9 26/13 28/12 28/22 28/25 30/21 33/7 40/18 40/20 69/8 69/18 73/13 73/14 74/1 74/22 76/24 82/15 86/18 86/21 86/23 86/25 87/7 87/9 88/18 102/2 102/4 102/20 114/10 114/12 123/10 123/10 123/11</p> <p>letters [5] 74/19 77/9 87/23 89/1 110/14</p> <p>leukaemia [1] 31/22</p> <p>level [1] 23/5</p> <p>Lewisham [1] 54/7</p> <p>life [16] 8/5 10/8 42/1 45/9 46/23 46/24 62/1 62/4 113/5 121/2 124/20 124/24 127/11 132/13 132/14 132/18</p> <p>lifespan [1] 62/17</p> <p>lifestyle [1] 31/2</p> <p>lifetime [1] 94/24</p>	<p><b>K</b></p> <p>keen [1] 107/1</p> <p>keep [11] 13/8 18/18 20/24 37/2 49/21 66/11 75/10 75/22 90/5 92/10 132/16</p> <p>kept [4] 4/13 30/20 91/10 130/6</p> <p>Kerry [2] 120/23 127/3</p> <p>kick [1] 127/19</p> <p>kicked [2] 27/8 113/10</p> <p>killed [1] 59/25</p> <p>killing [1] 50/25</p> <p>kilograms [1] 9/11</p> <p>kind [4] 4/3 5/13 16/6</p>

<p><b>L</b></p> <p><b>lived</b> [3] 62/4 62/5 62/17</p> <p><b>liver</b> [19] 34/5 36/10 43/16 43/22 56/21 74/17 75/4 75/9 75/11 75/20 75/22 76/4 76/13 76/15 76/17 76/18 76/21 130/14 130/24</p> <p><b>liver's</b> [1] 109/9</p> <p><b>lives</b> [9] 34/19 34/19 46/14 46/25 50/9 50/24 60/2 60/4 61/4</p> <p><b>living</b> [3] 31/1 31/2 135/17</p> <p><b>load</b> [2] 41/20 43/19</p> <p><b>loads</b> [3] 98/25 99/1 134/12</p> <p><b>local</b> [10] 4/11 15/14 46/6 46/7 53/15 62/3 67/8 89/14 97/22 98/7</p> <p><b>lock</b> [1] 46/12</p> <p><b>lock-up</b> [1] 46/12</p> <p><b>locked</b> [1] 122/14</p> <p><b>London</b> [6] 51/13 52/6 52/11 52/16 131/12 131/13</p> <p><b>long</b> [20] 5/18 8/8 20/14 38/13 40/3 43/14 47/21 52/5 62/4 92/9 95/9 99/11 105/15 107/17 112/9 116/17 126/1 126/1 131/3 134/24</p> <p><b>longer</b> [3] 27/13 32/3 55/8</p> <p><b>look</b> [47] 3/24 9/10 10/21 12/17 15/20 19/14 21/13 22/10 22/17 23/19 23/21 24/19 25/9 28/12 28/17 31/15 40/8 42/7 55/4 60/14 60/18 61/6 67/10 67/12 68/22 69/17 70/24 72/16 73/12 73/17 74/1 74/9 74/16 78/10 79/1 79/6 79/13 79/23 81/10 86/5 100/21 101/3 104/3 104/5 108/18 110/8 132/6</p> <p><b>looked</b> [11] 5/4 13/2 61/11 63/1 63/9 86/19 90/10 90/11 90/14 93/22 128/9</p> <p><b>looked at</b> [3] 86/19 90/10 90/14</p> <p><b>looking</b> [8] 40/15 53/23 62/25 83/21 105/19 112/5 119/9</p>	<p>119/19</p> <p><b>looks</b> [7] 16/20 84/21 84/23 86/10 102/20 105/19 130/22</p> <p><b>Lord</b> [5] 4/11 61/5 62/15 69/13 102/8</p> <p><b>Lorraine</b> [2] 115/16 115/17</p> <p><b>Lorraine's</b> [1] 116/9</p> <p><b>lorry</b> [1] 125/1</p> <p><b>lose</b> [4] 21/19 39/22 62/7 135/4</p> <p><b>losing</b> [2] 127/10 133/2</p> <p><b>loss</b> [3] 62/8 64/1 126/7</p> <p><b>lost</b> [6] 32/5 46/24 46/25 98/6 126/14 126/19</p> <p><b>lot</b> [24] 6/15 11/13 13/16 31/14 38/8 39/14 54/9 59/12 67/24 67/25 68/16 95/18 96/7 96/8 98/12 98/12 98/13 107/24 108/16 112/25 113/18 123/23 129/23 135/20</p> <p><b>lots</b> [3] 92/9 132/14 132/15</p> <p><b>love</b> [7] 62/14 117/23 132/17 132/18 132/18 135/5 135/21</p> <p><b>loved</b> [4] 61/19 119/25 120/23 120/24</p> <p><b>lovely</b> [2] 8/10 46/10</p> <p><b>low</b> [3] 31/25 38/20 130/5</p> <p><b>luck</b> [1] 44/9</p> <p><b>lucky</b> [2] 43/12 119/9</p> <p><b>lump</b> [3] 39/15 129/19 131/6</p> <p><b>lumps</b> [1] 109/10</p> <p><b>lunch</b> [3] 64/8 64/16 96/19</p> <p><b>luncheon</b> [1] 96/25</p> <p><b>lunchtime</b> [1] 64/6</p> <p><b>lungs</b> [2] 41/10 91/24</p> <p><b>lymph</b> [6] 82/22 82/24 83/16 114/15 114/17 114/18</p> <p><b>lymph nodes</b> [3] 82/22 82/24 83/16</p> <p><b>Lymphadenopathy</b> [1] 84/22</p> <p><b>Lymphadenopathy/Al DS</b> [1] 84/22</p> <p><b>lymphatic</b> [1] 43/23</p> <p><b>lymphedema</b> [2] 43/18 44/15</p>	<p>47/5 47/12 127/4</p> <p><b>machine</b> [1] 112/8</p> <p><b>made</b> [12] 17/14 41/24 47/14 49/10 49/12 50/2 60/14 67/24 67/25 73/23 87/12 90/3</p> <p><b>Mail</b> [1] 60/8</p> <p><b>main</b> [1] 8/3</p> <p><b>mainly</b> [2] 65/22 84/9</p> <p><b>major</b> [2] 41/12 107/10</p> <p><b>majority</b> [1] 87/14</p> <p><b>make</b> [7] 7/12 23/3 60/12 64/1 90/24 103/4 113/5</p> <p><b>makes</b> [1] 135/18</p> <p><b>making</b> [2] 16/7 77/21</p> <p><b>man</b> [2] 31/21 50/11</p> <p><b>manage</b> [1] 102/11</p> <p><b>managed</b> [3] 8/23 61/21 134/18</p> <p><b>Manchester</b> [1] 51/13</p> <p><b>manifestations</b> [1] 56/22</p> <p><b>many</b> [25] 9/11 15/18 15/18 19/2 27/24 27/24 27/25 41/20 46/25 48/25 57/15 60/10 60/21 60/21 60/23 62/2 63/8 63/18 69/24 107/15 108/6 108/6 119/21 119/21 134/4</p> <p><b>marble</b> [2] 131/21 131/23</p> <p><b>March</b> [9] 19/9 44/22 76/25 77/25 81/19 82/4 88/19 89/7 110/9</p> <p><b>March 1983</b> [1] 82/4</p> <p><b>March 1985</b> [2] 88/19 89/7</p> <p><b>marginally</b> [2] 75/25 76/13</p> <p><b>market</b> [1] 80/22</p> <p><b>marks</b> [1] 20/10</p> <p><b>marriage</b> [1] 121/15</p> <p><b>married</b> [6] 91/8 93/20 117/5 118/19 119/9 132/19</p> <p><b>marry</b> [1] 118/20</p> <p><b>Mary</b> [4] 1/20 1/22 65/6 97/4</p> <p><b>massive</b> [2] 58/6 59/10</p> <p><b>master</b> [1] 13/23</p> <p><b>masters</b> [1] 57/24</p> <p><b>mate</b> [2] 118/17 132/21</p> <p><b>material</b> [10] 11/23 21/14 25/14 25/17 69/16 69/24 79/15</p>	<p>79/24 104/7 105/19</p> <p><b>Materials</b> [1] 81/22</p> <p><b>mates</b> [1] 125/5</p> <p><b>matter</b> [7] 12/2 24/17 37/12 109/16 123/16 131/2 131/12</p> <p><b>Matthews</b> [4] 65/22 66/20 82/16 91/3</p> <p><b>may</b> [17] 21/15 26/9 26/9 51/23 53/7 55/22 64/15 85/11 88/14 101/11 101/13 101/14 102/2 103/11 115/4 129/12 130/2</p> <p><b>May 1980</b> [1] 21/15</p> <p><b>May 1981</b> [1] 101/11</p> <p><b>May 1982</b> [1] 103/11</p> <p><b>May 2017</b> [1] 129/12</p> <p><b>maybe</b> [5] 12/5 17/18 109/22 122/2 135/2</p> <p><b>Mayor</b> [5] 4/11 61/5 62/15 69/13 102/8</p> <p><b>McHardy</b> [2] 6/20 6/22</p> <p><b>me</b> [116] 1/6 1/8 1/25 7/17 8/8 8/11 10/21 11/14 13/4 14/14 14/15 17/5 17/11 17/12 18/5 19/4 21/25 25/23 26/12 26/14 26/23 27/20 28/16 30/22 31/6 31/9 31/12 31/12 31/16 31/17 32/3 32/8 32/20 32/25 33/3 34/5 34/12 36/25 37/23 38/11 40/2 40/8 40/11 40/14 40/18 41/7 41/9 41/15 41/25 42/1 42/8 43/8 43/11 43/20 44/22 45/7 46/13 46/19 48/5 48/16 49/2 54/1 54/7 54/10 55/6 55/16 58/17 58/25 59/3 62/13 62/24 62/25 63/1 63/2 63/3 69/15 87/4 88/2 90/3 93/14 95/16 98/7 99/17 100/9 108/9 109/21 111/21 111/21 112/10 115/25 116/10 117/2 117/4 117/5 118/11 118/17 120/24 121/11 121/13 122/2 122/4 122/15 122/22 123/8 124/24 124/25 126/9 126/16 127/23 128/8 129/4 132/16 133/23 134/14 134/20 135/3</p> <p><b>meal</b> [1] 5/9</p> <p><b>mean</b> [61] 4/22 7/17 9/22 10/2 10/5 10/10 10/12 10/20 12/10</p>	<p>12/23 13/2 13/18 14/6 14/14 15/2 15/3 20/1 20/22 23/1 23/15 23/15 27/25 31/12 32/8 34/11 34/16 35/7 38/7 41/7 41/25 46/21 47/17 51/12 52/6 55/1 57/15 58/7 58/19 58/19 58/21 59/8 59/10 59/13 59/23 64/8 66/14 67/21 70/13 76/14 77/10 80/19 87/13 88/14 89/20 90/9 90/20 91/1 91/1 92/17 112/24 128/24</p> <p><b>means</b> [3] 24/3 87/11 87/18</p> <p><b>meant</b> [1] 45/5</p> <p><b>media</b> [2] 50/25 62/7</p> <p><b>medic</b> [1] 94/15</p> <p><b>medical</b> [21] 3/22 5/3 26/7 29/8 29/14 33/10 34/25 36/13 40/19 45/18 60/13 61/18 68/4 68/18 72/13 83/10 84/5 84/17 93/6 94/14 135/20</p> <p><b>medicine</b> [1] 94/15</p> <p><b>meet</b> [3] 115/17 115/24 118/15</p> <p><b>meeting</b> [6] 15/8 51/10 113/19 116/16 116/18 121/2</p> <p><b>meetings</b> [1] 51/4</p> <p><b>memories</b> [2] 4/13 19/2</p> <p><b>memory</b> [1] 133/24</p> <p><b>men</b> [1] 62/16</p> <p><b>mention</b> [4] 3/15 36/13 36/14 120/17</p> <p><b>mentioned</b> [15] 7/23 11/10 20/2 23/16 23/17 24/4 34/4 48/9 53/15 87/2 88/12 92/12 103/5 124/14 131/9</p> <p><b>mentioning</b> [1] 26/13</p> <p><b>merged</b> [1] 7/1</p> <p><b>mess</b> [2] 112/8 119/24</p> <p><b>message</b> [1] 52/8</p> <p><b>messed</b> [1] 51/23</p> <p><b>messing</b> [1] 108/17</p> <p><b>met</b> [11] 52/17 98/9 98/12 115/15 115/20 117/9 117/25 120/17 120/22 121/2 121/11</p> <p><b>microphones</b> [1] 99/22</p> <p><b>mid</b> [1] 27/9</p> <p><b>mid-eighties</b> [1] 27/9</p>	<p><b>middle</b> [5] 5/20 19/16 49/4 53/24 111/14</p> <p><b>might</b> [17] 12/10 18/8 25/9 34/11 38/17 42/24 56/16 57/1 64/6 64/8 67/4 93/1 113/20 116/8 120/18 124/5 135/2</p> <p><b>mild</b> [7] 5/14 5/14 6/7 14/25 56/5 56/5 81/15</p> <p><b>miles</b> [2] 4/12 67/5</p> <p><b>military</b> [1] 57/25</p> <p><b>Milton</b> [2] 51/16 51/18</p> <p><b>mimic</b> [1] 42/23</p> <p><b>mind</b> [4] 32/14 54/25 61/22 63/16</p> <p><b>mine</b> [1] 62/21</p> <p><b>minimising</b> [1] 20/6</p> <p><b>minister</b> [3] 51/25 52/14 95/13</p> <p><b>ministerial</b> [1] 15/12</p> <p><b>minority</b> [1] 51/24</p> <p><b>minute</b> [6] 91/23 91/24 92/5 99/15 121/11 134/14</p> <p><b>minutes</b> [6] 4/1 23/6 103/23 133/13 133/18 134/7</p> <p><b>miserable</b> [1] 132/24</p> <p><b>miss</b> [1] 95/5</p> <p><b>missed</b> [5] 3/8 3/14 98/25 98/25 99/1</p> <p><b>mistake</b> [1] 77/17</p> <p><b>mixed</b> [1] 4/6</p> <p><b>mm</b> [12] 70/2 71/23 79/5 80/2 81/23 83/4 88/24 89/2 100/6 121/25 123/4 129/13</p> <p><b>mm-hm</b> [5] 79/5 100/6 121/25 123/4 129/13</p> <p><b>moaned</b> [1] 59/3</p> <p><b>mobile</b> [2] 40/3 117/14</p> <p><b>mode</b> [1] 132/24</p> <p><b>Mollie</b> [1] 62/11</p> <p><b>moment</b> [6] 44/11 54/17 54/18 55/12 93/12 99/17</p> <p><b>Monday</b> [1] 46/9</p> <p><b>money</b> [5] 31/7 48/22 49/1 92/15 92/25</p> <p><b>monitor</b> [1] 130/24</p> <p><b>monitored</b> [1] 43/16</p> <p><b>Montgomery</b> [3] 30/19 42/21 43/5</p> <p><b>month</b> [6] 40/7 44/13 47/16 82/2 105/22 106/4</p> <p><b>months</b> [12] 3/15 23/24 31/14 39/25 44/1 88/19 90/12 91/16 106/10 109/13</p>
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<p><b>M</b></p> <p><b>months...</b> [2] 125/4 126/10</p> <p><b>moody</b> [2] 125/24 129/18</p> <p><b>moping</b> [1] 127/24</p> <p><b>more</b> [34] 4/1 4/24 13/22 22/11 30/17 33/25 35/15 39/11 44/10 47/8 47/21 51/2 58/19 61/11 63/7 64/14 67/12 67/24 75/8 76/17 87/18 91/17 91/25 92/23 94/24 98/18 104/1 105/5 107/24 108/10 108/16 108/20 108/21 126/21</p> <p><b>morning</b> [7] 1/25 9/20 72/7 77/13 86/19 111/7 123/9</p> <p><b>most</b> [12] 3/14 3/14 13/2 25/22 31/25 39/13 55/3 67/16 67/16 68/13 91/19 102/11</p> <p><b>Mostly</b> [1] 13/1</p> <p><b>Motability</b> [2] 47/25 48/10</p> <p><b>mother</b> [4] 12/12 48/18 66/4 69/25</p> <p><b>mother's</b> [1] 72/22</p> <p><b>mould</b> [1] 130/18</p> <p><b>mound</b> [1] 29/5</p> <p><b>mouth</b> [3] 37/21 38/7 38/12</p> <p><b>move</b> [4] 6/10 19/7 38/22 41/17</p> <p><b>moved</b> [5] 7/2 91/10 113/5 113/9 133/7</p> <p><b>MP</b> [3] 15/9 15/14 46/6</p> <p><b>MPs</b> [1] 51/4</p> <p><b>Mr</b> [8] 55/13 64/11 64/11 64/12 93/14 123/12 133/16 136/10</p> <p><b>Mr and</b> [1] 133/16</p> <p><b>Mr BC</b> [1] 136/10</p> <p><b>Mr Bennett</b> [1] 123/12</p> <p><b>Mr Gary</b> [2] 64/11 64/12</p> <p><b>Mr John Peach</b> [1] 64/11</p> <p><b>Mr Snowden</b> [2] 55/13 93/14</p> <p><b>Mrs</b> [1] 133/17</p> <p><b>Mrs Bennett</b> [1] 133/17</p> <p><b>Ms</b> [7] 1/19 1/24 65/9 97/7 137/3 137/6 137/9</p>	<p><b>MS FRASER BUTLIN</b> [2] 97/7 137/9</p> <p><b>Ms Richards</b> [5] 1/19 1/24 65/9 137/3 137/6</p> <p><b>much</b> [25] 2/1 7/6 7/22 10/19 18/6 24/5 37/10 40/17 57/8 61/14 62/5 62/12 62/20 63/10 64/3 64/18 68/6 94/20 95/1 96/17 110/16 122/25 134/9 135/12 136/2</p> <p><b>multiple</b> [2] 22/3 77/9</p> <p><b>mum</b> [27] 26/5 32/8 38/3 38/5 48/16 54/7 58/22 62/23 73/7 100/12 112/7 113/3 113/15 115/21 115/23 115/23 115/24 116/2 116/9 117/4 117/5 119/10 120/23 122/4 122/21 131/23 133/20</p> <p><b>must</b> [6] 17/14 59/12 61/4 77/7 87/23 96/2</p> <p><b>my</b> [157]</p> <p><b>myself</b> [4] 9/10 40/6 61/8 127/19</p> <p><b>N</b></p> <p><b>name</b> [20] 11/7 11/7 24/16 27/12 29/20 58/7 68/13 75/1 75/18 103/12 104/4 104/9 111/10 111/11 111/12 120/17 120/19 128/2 134/24 135/1</p> <p><b>names</b> [1] 68/8</p> <p><b>naming</b> [1] 54/22</p> <p><b>natural</b> [3] 61/2 62/17 96/9</p> <p><b>naughty</b> [4] 109/1 109/2 110/2 110/3</p> <p><b>nearest</b> [1] 67/4</p> <p><b>nebuliser</b> [1] 92/10</p> <p><b>nebulisers</b> [1] 92/8</p> <p><b>necessary</b> [1] 20/8</p> <p><b>need</b> [13] 2/25 9/1 28/19 64/14 64/19 99/5 107/17 111/23 117/20 117/21 118/8 126/21 131/13</p> <p><b>needed</b> [14] 3/23 22/8 22/9 22/14 30/16 31/16 36/23 37/1 58/15 92/24 103/1 109/6 127/12 127/12</p> <p><b>needle</b> [2] 8/5 8/12</p> <p><b>needles</b> [2] 107/6 107/8</p> <p><b>needs</b> [1] 43/24</p> <p><b>negative</b> [3] 22/21 22/23 30/15</p>	<p><b>nervous</b> [1] 135/22</p> <p><b>never</b> [38] 3/6 10/17 13/6 13/12 13/15 15/3 20/21 23/13 23/16 24/3 24/4 26/8 26/22 27/20 27/21 35/19 52/19 56/12 57/18 58/8 61/23 63/16 72/7 72/12 78/12 84/19 85/22 89/7 93/6 95/15 107/4 109/3 109/3 117/5 117/5 124/9 127/16 129/20</p> <p><b>new</b> [7] 7/18 14/12 33/1 48/24 49/5 100/10 128/1</p> <p><b>news</b> [3] 116/19 123/12 126/21</p> <p><b>newspaper</b> [1] 131/17</p> <p><b>next</b> [22] 9/19 9/20 13/8 13/24 15/20 28/24 30/22 43/3 47/2 48/10 53/9 53/10 59/1 59/9 64/6 64/12 72/16 81/18 82/6 97/2 110/14 132/19</p> <p><b>NHS</b> [9] 37/3 66/8 69/20 70/4 70/23 71/17 80/17 102/10 102/13</p> <p><b>nice</b> [6] 45/1 47/14 47/18 53/19 69/21 121/7</p> <p><b>NICHOLAS</b> [5] 1/23 16/10 16/17 18/13 137/2</p> <p><b>Nick</b> [28] 1/3 1/4 1/22 1/25 2/2 10/22 11/3 14/20 21/16 22/18 24/5 30/1 36/9 40/14 44/19 46/14 47/2 49/11 52/24 54/16 54/20 55/9 55/12 55/18 55/22 57/9 57/12 63/11</p> <p><b>Nick's</b> [3] 53/8 55/25 56/23</p> <p><b>night</b> [10] 37/20 37/23 37/24 38/3 38/5 46/1 118/16 118/18 128/24 133/8</p> <p><b>nightmare</b> [1] 8/7</p> <p><b>nights</b> [1] 120/2</p> <p><b>nine</b> [1] 97/20</p> <p><b>nineteen</b> [1] 130/8</p> <p><b>nineteen years</b> [1] 130/8</p> <p><b>no</b> [161]</p> <p><b>nobody</b> [8] 8/20 34/1 43/14 50/2 92/23 117/16 124/9 124/10</p> <p><b>node</b> [1] 114/19</p>	<p><b>nodes</b> [5] 82/22 82/24 83/15 83/16 114/17</p> <p><b>non</b> [14] 5/14 6/6 15/5 15/5 15/7 15/7 34/17 56/10 56/10 56/18 56/18 56/24 56/24 60/16</p> <p><b>non-A</b> [3] 15/5 15/7 56/24</p> <p><b>non-A, non-B</b> [2] 56/10 56/18</p> <p><b>non-B</b> [3] 15/5 15/7 56/24</p> <p><b>non-consensual</b> [1] 60/16</p> <p><b>non-fatal</b> [2] 5/14 6/6</p> <p><b>non-intentional</b> [1] 34/17</p> <p><b>none</b> [11] 7/24 11/12 28/21 60/12 61/18 63/18 76/19 82/21 83/19 113/23 114/14</p> <p><b>normal</b> [1] 67/2</p> <p><b>normally</b> [1] 130/3</p> <p><b>Northampton</b> [1] 67/9</p> <p><b>not</b> [97] 5/12 9/13 13/23 15/6 15/12 16/10 16/14 17/13 24/14 25/25 26/9 26/23 28/7 29/12 29/16 30/20 31/17 33/15 33/21 34/19 36/17 37/4 37/12 39/22 47/9 49/24 51/18 54/22 56/4 59/22 60/20 66/23 67/7 67/20 68/5 68/21 68/21 72/9 72/17 72/18 73/5 73/5 73/6 73/11 73/25 74/15 76/8 76/8 76/12 76/17 76/22 77/15 78/5 78/13 80/17 81/3 83/8 84/1 84/19 86/6 86/8 86/12 87/13 88/14 89/3 89/4 90/7 93/1 93/11 97/24 101/12 104/16 105/13 109/4 109/4 110/20 110/23 110/24 112/9 112/13 112/25 122/5 123/7 123/25 124/10 124/17 125/5 126/1 126/1 126/18 126/22 126/24 127/15 128/12 130/15 130/16 132/25</p> <p><b>note</b> [5] 90/2 90/3 101/14 105/24 106/6</p> <p><b>notes</b> [12] 28/16 29/11 29/14 33/10 35/4 36/13 36/20 36/22 36/23 83/11</p>	<p>90/5 114/15</p> <p><b>nothing</b> [28] 4/24 5/15 12/9 12/17 12/20 13/4 14/25 15/5 29/16 32/1 34/9 48/8 56/22 57/3 58/11 58/21 59/8 59/10 62/13 66/15 81/13 82/11 82/12 117/18 117/18 117/18 122/21 132/1</p> <p><b>notice</b> [2] 4/23 105/16</p> <p><b>notified</b> [1] 58/17</p> <p><b>November</b> [7] 79/18 79/20 79/25 80/7 84/6 86/24 105/18</p> <p><b>November 1982</b> [1] 105/18</p> <p><b>now</b> [43] 1/3 2/11 3/1 20/7 24/3 27/12 27/13 28/5 30/1 34/14 37/1 42/21 44/13 44/14 62/3 64/5 66/24 68/8 69/14 69/24 79/1 80/6 86/22 94/22 100/1 106/23 107/9 109/11 111/18 111/25 112/5 116/10 121/3 122/8 122/13 123/12 123/25 128/24 130/14 130/24 132/15 132/18 134/20</p> <p><b>nowhere</b> [3] 133/13 133/14 134/6</p> <p><b>number</b> [11] 18/15 25/18 51/13 84/9 87/16 89/1 112/3 112/13 112/16 112/16 136/1</p> <p><b>numbers</b> [3] 110/16 111/24 111/25</p> <p><b>nurse</b> [11] 6/4 6/13 8/10 8/22 8/25 9/7 9/18 56/1 61/5 103/7 126/15</p> <p><b>nurses</b> [3] 4/21 63/1 113/18</p> <p><b>nursing</b> [4] 68/4 68/18 101/2 101/2</p>	<p><b>occasionally</b> [2] 23/25 81/14</p> <p><b>occasions</b> [4] 18/15 18/23 18/25 81/25</p> <p><b>October</b> [3] 18/12 101/8 101/10</p> <p><b>October 1975</b> [1] 18/12</p> <p><b>October 1980</b> [1] 101/8</p> <p><b>odd</b> [1] 104/23</p> <p><b>off</b> [11] 18/5 27/8 38/18 40/10 59/9 90/16 97/13 101/4 102/10 130/17 135/4</p> <p><b>offered</b> [2] 44/19 61/23</p> <p><b>offhand</b> [1] 2/22</p> <p><b>office</b> [4] 46/7 52/15 92/19 99/12</p> <p><b>officer</b> [1] 40/7</p> <p><b>official</b> [1] 40/13</p> <p><b>officials</b> [1] 46/7</p> <p><b>officially</b> [1] 37/2</p> <p><b>often</b> [3] 4/3 67/2 76/17</p> <p><b>oh</b> [33] 15/11 18/3 35/5 36/5 37/2 41/19 43/20 46/15 48/16 53/3 54/24 58/9 63/14 66/14 68/8 70/15 77/10 77/23 98/22 99/11 111/12 113/7 113/16 116/17 118/6 118/18 118/24 119/2 122/19 126/20 126/20 128/14 128/23</p> <p><b>okay</b> [7] 4/18 15/13 26/18 68/24 100/24 126/6 132/13</p> <p><b>old</b> [3] 29/8 91/14 121/9</p> <p><b>older</b> [3] 54/1 54/8 67/6</p> <p><b>once</b> [12] 1/20 10/2 10/3 23/9 44/17 52/6 58/13 91/1 91/4 94/24 100/4 119/5</p> <p><b>one</b> [91] 4/21 8/1 8/3 8/9 8/13 9/13 10/12 10/15 13/13 15/17 16/13 20/9 22/11 24/6 25/6 26/8 28/22 28/23 34/1 38/15 38/17 38/24 39/11 41/11 43/20 45/4 45/5 46/1 48/5 48/17 50/8 50/11 51/24 52/4 53/10 53/22 53/24 54/3 55/3 55/5 55/6 55/22 56/1 56/4 56/5 56/8 58/7 61/5 62/20 64/8 67/3</p>
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<p><b>O</b></p> <p><b>one...</b> [40] 71/15 72/9 73/12 80/20 80/23 80/24 84/19 86/7 88/16 90/15 90/15 92/12 92/21 94/1 94/9 94/13 103/12 104/1 105/23 109/5 109/8 109/23 109/25 111/7 111/13 113/15 113/15 113/22 121/8 127/25 128/7 128/13 129/6 129/8 131/2 131/3 132/9 133/13 133/18 134/7</p> <p><b>ones</b> [1] 41/12</p> <p><b>ongoing</b> [1] 56/21</p> <p><b>online</b> [1] 62/6</p> <p><b>only</b> [30] 2/21 3/21 5/8 11/21 20/1 22/23 36/19 41/4 41/23 42/22 44/1 51/22 53/22 55/5 56/7 56/19 57/23 57/25 60/20 61/2 62/20 69/20 70/3 72/9 87/15 98/10 106/12 107/19 109/21 132/22</p> <p><b>Ontario</b> [1] 53/18</p> <p><b>onto</b> [1] 99/3</p> <p><b>ooh</b> [1] 127/8</p> <p><b>open</b> [3] 13/18 26/21 70/19</p> <p><b>opened</b> [3] 32/24 98/17 131/20</p> <p><b>operate</b> [1] 16/6</p> <p><b>operation</b> [3] 3/12 40/1 63/4</p> <p><b>operations</b> [1] 107/10</p> <p><b>opportunities</b> [1] 57/18</p> <p><b>opportunity</b> [1] 75/5</p> <p><b>opposed</b> [1] 14/5</p> <p><b>opposite</b> [1] 3/5</p> <p><b>or</b> [93] 2/13 2/17 2/24 4/9 6/13 6/24 7/10 7/10 9/20 9/25 10/4 11/7 12/8 17/9 19/23 20/6 22/10 23/10 24/2 24/9 24/10 26/9 26/13 27/14 27/16 29/12 29/16 29/17 30/13 32/19 33/25 38/2 42/10 44/19 45/3 45/4 47/3 47/10 51/13 51/14 52/10 56/2 58/2 61/18 61/23 64/16 66/16 66/20 66/20 66/21 68/4 68/12 68/12 69/3 70/17 70/17 70/18 72/15</p> <p>73/4 74/5 74/13 74/14 75/8 75/12 76/7 76/7 76/20 77/19 78/6 78/7 80/6 87/13 87/17 88/12 88/13 89/4 89/4 93/6 93/10 94/12 99/4 100/7 100/9 100/12 102/18 103/3 109/10 109/25 110/25 112/13 122/6 122/20 129/20</p> <p><b>order</b> [6] 8/19 71/2 79/12 81/20 92/15 96/10</p> <p><b>ordinary</b> [1] 26/18</p> <p><b>ordination</b> [1] 8/4</p> <p><b>organised</b> [1] 20/20</p> <p><b>orthopaedic</b> [1] 33/4</p> <p><b>orthopedic</b> [1] 31/10</p> <p><b>other</b> [41] 5/6 6/2 6/7 8/7 9/23 10/12 10/20 16/23 21/23 22/1 22/1 22/12 27/14 27/24 32/21 33/14 38/25 47/22 51/25 52/4 56/4 56/16 57/3 60/10 61/18 62/13 74/5 76/15 80/17 85/2 96/1 97/22 98/9 105/12 108/6 111/2 113/22 117/25 122/23 124/5 132/22</p> <p><b>other's</b> [1] 108/24</p> <p><b>others</b> [5] 11/14 61/3 111/16 118/15 136/6</p> <p><b>otherwise</b> [2] 21/19 39/19</p> <p><b>ought</b> [2] 42/7 42/10</p> <p><b>our</b> [33] 3/5 4/7 11/11 15/9 20/1 20/24 34/7 34/7 34/19 34/19 46/14 48/17 50/24 52/10 57/24 60/7 60/8 60/9 60/18 61/2 61/12 62/23 64/9 75/21 97/2 103/4 111/8 111/8 111/9 118/12 120/25 124/25 134/3</p> <p><b>ours</b> [1] 108/8</p> <p><b>ourselves</b> [2] 10/9 61/11</p> <p><b>out</b> [71] 10/12 11/14 13/14 13/21 24/16 27/23 28/11 32/5 33/17 34/12 35/14 40/18 41/6 45/15 48/1 48/15 50/13 50/19 52/22 52/23 54/6 54/9 54/10 55/25 60/15 60/24 62/19 66/15 68/15 70/15 70/20 78/8 87/1 89/19 94/11 95/4 95/11 109/2</p>	<p>109/2 111/24 112/9 113/2 113/10 115/23 117/3 117/21 117/22 118/11 118/13 118/15 120/22 123/14 123/17 126/19 127/18 127/18 128/2 128/3 128/3 128/16 129/19 130/8 130/17 131/25 132/3 133/13 133/14 134/1 134/25 135/14 135/16</p> <p><b>outbreak</b> [4] 5/1 5/24 14/21 23/15</p> <p><b>Outrageous</b> [2] 50/19 51/19</p> <p><b>outside</b> [6] 44/15 50/3 50/13 52/15 121/14 134/20</p> <p><b>outsider</b> [1] 127/13</p> <p><b>over</b> [30] 5/21 6/10 7/23 13/8 14/10 16/8 22/12 22/13 31/8 32/13 35/23 38/15 43/5 44/20 45/18 50/4 50/9 51/17 63/9 79/14 85/3 100/8 100/19 101/8 102/7 104/9 109/8 118/9 121/10 126/6</p> <p><b>overall</b> [1] 39/2</p> <p><b>overspeaking</b> [1] 54/14</p> <p><b>Owen's</b> [1] 95/11</p> <p><b>own</b> [15] 4/7 6/2 8/12 8/13 10/17 11/1 31/20 50/12 58/10 62/2 95/9 107/11 123/1 123/1 125/13</p> <p><b>Oxford</b> [23] 2/8 3/10 3/16 11/19 19/1 65/17 66/21 67/5 69/10 73/15 74/23 75/3 75/12 76/10 76/25 78/1 82/17 85/19 86/8 88/3 88/5 88/20 89/5</p> <p><b>oxygen</b> [2] 45/23 91/25</p>	<p><b>P</b></p> <p><b>paediatric</b> [1] 14/9</p> <p><b>page</b> [41] 24/19 28/24 33/7 53/9 71/1 71/2 71/5 71/6 71/13 71/16 71/16 73/16 74/21 75/15 76/10 77/22 79/12 79/14 79/19 79/23 80/4 80/6 80/11 81/24 82/1 82/6 82/18 83/12 84/2 84/20 101/9 101/10 104/6 104/9 105/11 105/20 106/3 106/3 106/12</p> <p>106/19 115/9</p> <p><b>page</b> 10 [1] 79/12</p> <p><b>page</b> 2 [1] 80/11</p> <p><b>page</b> 3 [1] 106/3</p> <p><b>page</b> 4 [1] 83/12</p> <p><b>page</b> 5 [1] 80/6</p> <p><b>page</b> 6 [4] 71/16 80/4 82/1 84/2</p> <p><b>page</b> 7 [2] 71/2 79/23</p> <p><b>page</b> 9 [1] 79/19</p> <p><b>pages</b> [1] 71/18</p> <p><b>paid</b> [2] 48/4 49/4</p> <p><b>pain</b> [3] 10/19 31/14 44/17</p> <p><b>painful</b> [3] 39/8 39/12 44/17</p> <p><b>pains</b> [1] 109/11</p> <p><b>painted</b> [1] 24/11</p> <p><b>paints</b> [1] 55/1</p> <p><b>palate</b> [1] 63/4</p> <p><b>pallet</b> [1] 3/12</p> <p><b>palpable</b> [3] 82/23 114/16 114/18</p> <p><b>pandemic</b> [1] 45/17</p> <p><b>paper</b> [5] 103/6 111/23 131/24 134/25 135/2</p> <p><b>papers</b> [2] 89/19 92/19</p> <p><b>paperwork</b> [1] 70/19</p> <p><b>paragraph</b> [9] 19/9 19/14 19/15 23/22 33/8 73/17 74/1 75/7 75/10</p> <p><b>parcel</b> [2] 51/20 51/21</p> <p><b>parcelled</b> [1] 18/5</p> <p><b>Pardon</b> [2] 89/25 94/4</p> <p><b>parent</b> [2] 26/10 96/10</p> <p><b>parent/guardian</b> [1] 26/10</p> <p><b>parental</b> [2] 11/11 60/17</p> <p><b>parents</b> [27] 2/23 3/20 12/3 13/6 13/20 14/4 15/25 16/24 19/23 24/2 24/10 24/10 26/3 26/13 31/13 58/17 58/18 62/11 80/19 99/2 100/8 101/23 104/14 104/22 110/21 112/2 115/2</p> <p><b>Parliament</b> [1] 95/16</p> <p><b>part</b> [9] 13/2 19/5 23/3 27/16 37/3 72/25 75/7 106/11 129/25</p> <p><b>parted</b> [1] 113/12</p> <p><b>participating</b> [1] 17/7</p> <p><b>particular</b> [3] 8/9 120/11 120/15</p> <p><b>particularly</b> [15] 3/19 31/21 32/12 45/13 49/9 53/23 55/4 58/21</p>	<p>62/24 63/21 64/2 68/5 76/14 97/24 135/11</p> <p><b>partly</b> [1] 46/19</p> <p><b>partner</b> [2] 122/20 124/10</p> <p><b>partners</b> [2] 34/17 34/20</p> <p><b>parts</b> [1] 109/9</p> <p><b>party</b> [2] 123/9 123/14</p> <p><b>pass</b> [2] 51/20 51/21</p> <p><b>passed</b> [4] 133/18 133/18 134/7 134/7</p> <p><b>passing</b> [1] 127/10</p> <p><b>past</b> [8] 16/9 23/24 59/20 64/14 64/22 108/7 133/13 134/15</p> <p><b>patient</b> [4] 16/23 24/10 25/16 25/19</p> <p><b>patients</b> [6] 25/13 61/10 74/3 76/16 77/18 102/10</p> <p><b>pause</b> [1] 54/16</p> <p><b>pay</b> [3] 8/22 48/4 61/4</p> <p><b>payment</b> [4] 33/18 33/19 91/2 131/6</p> <p><b>payments</b> [1] 47/15</p> <p><b>payout</b> [1] 131/12</p> <p><b>Peach</b> [5] 64/11 65/8 65/11 72/25 137/5</p> <p><b>pen</b> [1] 111/23</p> <p><b>penny</b> [1] 49/13</p> <p><b>people</b> [25] 1/18 41/12 45/2 47/23 49/15 50/4 50/13 50/23 54/3 54/21 55/8 62/6 63/8 87/14 92/24 95/17 98/9 98/12 121/2 123/15 127/8 127/9 127/14 134/16 136/1</p> <p><b>people's</b> [1] 64/6</p> <p><b>per</b> [4] 34/15 57/22 123/7 130/16</p> <p><b>perfectly</b> [1] 90/12</p> <p><b>perhaps</b> [2] 16/18 63/19</p> <p><b>period</b> [5] 19/12 31/3 49/13 93/5 102/8</p> <p><b>periods</b> [3] 20/8 20/15 22/1</p> <p><b>permission</b> [1] 111/25</p> <p><b>persistently</b> [1] 75/4</p> <p><b>person</b> [3] 8/9 34/1 121/10</p> <p><b>personal</b> [2] 57/21 121/15</p> <p><b>personally</b> [2] 14/12 122/2</p> <p><b>pharmaceutical</b> [1] 34/24</p> <p><b>Philip</b> [2] 46/10 62/23</p> <p><b>phone</b> [3] 48/15 59/5</p>	<p>126/15</p> <p><b>phones</b> [1] 117/14</p> <p><b>photo</b> [8] 53/1 53/2 53/5 53/12 53/13 53/20 54/23 94/1</p> <p><b>photos</b> [4] 55/3 93/12 93/16 93/23</p> <p><b>physical</b> [4] 35/22 37/15 40/25 120/5</p> <p><b>physically</b> [2] 117/21 126/6</p> <p><b>physio</b> [1] 40/3</p> <p><b>physiotherapy</b> [1] 105/16</p> <p><b>pick</b> [3] 59/5 118/3 135/19</p> <p><b>picked</b> [2] 99/22 118/3</p> <p><b>picture</b> [7] 1/16 24/5 24/11 32/12 52/9 55/1 90/11</p> <p><b>piece</b> [1] 25/25</p> <p><b>pieces</b> [6] 117/24 119/25 124/22 128/23 130/15 135/6</p> <p><b>place</b> [4] 61/12 71/7 98/5 127/1</p> <p><b>placed</b> [1] 26/10</p> <p><b>places</b> [1] 22/16</p> <p><b>plague</b> [1] 91/19</p> <p><b>plainly</b> [1] 42/5</p> <p><b>plasma</b> [3] 2/11 2/18 2/20</p> <p><b>plaster</b> [1] 3/11</p> <p><b>plates</b> [1] 5/18</p> <p><b>playing</b> [2] 34/18 34/18</p> <p><b>pleasant</b> [2] 49/8 49/9</p> <p><b>please</b> [41] 1/22 21/3 26/12 49/2 65/5 65/7 69/5 71/1 71/16 72/16 72/20 73/13 73/16 74/21 75/16 76/23 79/6 80/11 82/1 83/12 84/2 84/20 86/17 87/3 93/24 94/1 97/4 100/25 101/9 102/1 104/3 105/10 105/20 106/3 106/12 106/20 110/6 112/3 114/10 129/4 130/1</p> <p><b>plus</b> [2] 59/25 105/16</p> <p><b>pm</b> [5] 64/25 96/24 97/1 101/13 136/15</p> <p><b>pneumocystis</b> [2] 41/9 92/6</p> <p><b>pneumonia</b> [2] 92/6 92/8</p> <p><b>poignant</b> [2] 53/23 55/3</p> <p><b>point</b> [15] 7/15 12/23 38/15 39/7 40/22 42/8</p>
---	--	---	---	---

<p><b>P</b></p> <p><b>point... [9]</b> 46/20 62/3 66/1 66/24 78/22 86/12 117/9 126/5 127/1</p> <p><b>police [1]</b> 50/12</p> <p><b>polite [1]</b> 113/21</p> <p><b>political [1]</b> 52/1</p> <p><b>poorly [3]</b> 13/5 18/25 40/5</p> <p><b>pop [1]</b> 36/23</p> <p><b>POS [1]</b> 110/11</p> <p><b>position [2]</b> 47/1 84/13</p> <p><b>positive [35]</b> 22/23 25/15 29/10 29/13 29/18 29/21 29/23 30/25 32/4 33/8 33/15 34/3 34/23 35/4 36/15 36/18 45/21 46/16 57/15 62/3 74/12 77/6 78/2 78/9 78/14 78/17 78/25 87/10 87/14 88/4 88/23 89/6 110/12 116/12 121/24</p> <p><b>positivity [1]</b> 30/6</p> <p><b>possibility [2]</b> 76/21 85/8</p> <p><b>possible [4]</b> 9/15 16/17 19/20 64/7</p> <p><b>possibly [2]</b> 28/9 77/8</p> <p><b>post [1]</b> 23/5</p> <p><b>post-level [1]</b> 23/5</p> <p><b>poster [1]</b> 52/11</p> <p><b>potential [1]</b> 19/24</p> <p><b>potentially [3]</b> 34/9 54/20 56/20</p> <p><b>power [1]</b> 46/2</p> <p><b>powerful [2]</b> 53/13 53/21</p> <p><b>pre [1]</b> 23/4</p> <p><b>preferably [1]</b> 103/20</p> <p><b>pregnant [1]</b> 118/23</p> <p><b>prep [1]</b> 99/5</p> <p><b>prepare [2]</b> 10/8 28/16</p> <p><b>preparing [1]</b> 72/18</p> <p><b>present [1]</b> 134/15</p> <p><b>presentation [1]</b> 136/12</p> <p><b>press [3]</b> 32/9 50/20 52/12</p> <p><b>pressure [1]</b> 8/16</p> <p><b>presumably [1]</b> 111/4</p> <p><b>pretty [5]</b> 7/18 13/3 46/16 46/20 94/14</p> <p><b>previously [2]</b> 41/7 60/16</p> <p><b>Prime [2]</b> 51/25 52/14</p> <p><b>priority [1]</b> 46/8</p> <p><b>private [1]</b> 112/1</p> <p><b>probably [30]</b> 3/14</p>	<p>4/15 17/3 22/15 28/2 28/7 36/21 41/11 44/8 55/2 55/11 64/16 75/4 91/5 91/5 94/25 99/15 99/19 107/18 107/19 116/11 119/17 119/19 119/22 122/2 122/8 129/18 129/18 134/12 134/13</p> <p><b>problem [9]</b> 3/6 8/4 23/13 23/14 27/21 45/11 102/9 129/2 129/3</p> <p><b>problems [6]</b> 10/6 11/17 30/17 87/16 127/20 127/20</p> <p><b>proceeded [1]</b> 7/25</p> <p><b>process [2]</b> 38/13 102/25</p> <p><b>produced [1]</b> 43/23</p> <p><b>product [29]</b> 4/19 6/2 6/14 9/3 9/12 9/13 16/10 16/14 22/3 22/6 22/11 66/9 66/19 70/5 70/8 71/17 71/20 79/18 79/21 80/17 80/20 80/21 81/12 81/21 82/5 101/15 102/17 106/1 106/17</p> <p><b>products [11]</b> 21/2 27/5 80/24 82/9 95/18 101/4 101/17 101/21 101/24 108/13 108/24</p> <p><b>professional [2]</b> 113/21 113/24</p> <p><b>profusely [1]</b> 3/13</p> <p><b>programme [1]</b> 7/18</p> <p><b>progress [1]</b> 93/7</p> <p><b>prolonged [1]</b> 20/8</p> <p><b>promise [1]</b> 15/12</p> <p><b>promised [1]</b> 15/10</p> <p><b>promotion [1]</b> 32/23</p> <p><b>proper [1]</b> 115/19</p> <p><b>proph [2]</b> 112/18 112/19</p> <p><b>prophylactic [4]</b> 20/11 20/13 104/18 104/20</p> <p><b>prophylactically [3]</b> 19/17 19/25 73/24</p> <p><b>prophylaxis [25]</b> 17/18 19/12 19/21 20/5 20/15 21/10 73/21 84/10 104/18 104/25 105/1 105/4 105/15 105/25 106/6 106/14 106/20 106/24 106/25 107/5 107/9 107/11 108/10 108/20 108/21</p> <p><b>protect [3]</b> 25/20 31/12 32/8</p>	<p><b>protection [1]</b> 41/9</p> <p><b>proteins [2]</b> 23/24 43/22</p> <p><b>protested [1]</b> 52/15</p> <p><b>proved [1]</b> 25/14</p> <p><b>psychological [3]</b> 44/20 61/24 109/25</p> <p><b>pull [1]</b> 135/18</p> <p><b>punched [1]</b> 58/14</p> <p><b>punish [1]</b> 59/7</p> <p><b>punished [1]</b> 59/21</p> <p><b>pupil [4]</b> 32/10 58/12 69/13 98/20</p> <p><b>pupils [1]</b> 57/1</p> <p><b>purely [3]</b> 4/5 4/6 20/5</p> <p><b>purer [1]</b> 6/15</p> <p><b>purport [1]</b> 15/25</p> <p><b>purposes [1]</b> 4/23</p> <p><b>pushed [1]</b> 134/20</p> <p><b>put [30]</b> 4/9 8/12 38/5 38/12 39/17 43/11 48/15 48/21 51/5 53/6 55/7 58/24 61/22 66/16 90/2 90/3 90/4 90/4 90/5 90/17 93/12 104/20 104/25 105/25 108/9 109/5 109/8 112/19 130/18 132/23</p> <p><b>putting [2]</b> 35/1 99/16</p> <p><b>puzzling [1]</b> 77/12</p> <p><b>pyhsiotherapist [1]</b> 63/2</p>	<p><b>quarters [1]</b> 39/12</p> <p><b>queries [1]</b> 12/1</p> <p><b>query [1]</b> 35/2</p> <p><b>question [4]</b> 36/6 55/22 94/9 121/11</p> <p><b>questions [23]</b> 1/20 1/24 26/12 51/5 55/18 55/20 60/20 65/9 65/10 94/3 94/5 94/8 97/7 115/22 132/5 132/8 132/9 137/3 137/4 137/6 137/7 137/9 137/10</p> <p><b>quiet [4]</b> 23/16 126/17 132/11 132/23</p> <p><b>quite [28]</b> 12/10 13/10 13/17 15/6 18/1 28/9 30/20 36/18 38/12 38/14 40/1 47/21 54/8 67/2 67/23 70/21 88/11 89/22 92/9 98/10 110/24 112/12 120/7 125/23 126/25 129/22 133/10 135/23</p> <p><b>quote [1]</b> 49/5</p>	<p><b>R</b></p> <p><b>rabies [1]</b> 38/8</p>	<p><b>rack [1]</b> 17/2</p> <p><b>radio [1]</b> 25/15</p> <p><b>radio-immunoassay [1]</b> 25/15</p> <p><b>raise [4]</b> 22/8 23/8 30/19 73/21</p> <p><b>raised [5]</b> 9/12 23/24 23/25 60/22 76/7</p> <p><b>ran [2]</b> 58/8 58/9</p> <p><b>rang [5]</b> 13/6 18/2 35/2 36/24 37/1</p> <p><b>range [4]</b> 6/19 21/2 110/14 110/15</p> <p><b>ransacked [1]</b> 121/12</p> <p><b>Raper [13]</b> 16/1 16/5 16/20 17/14 18/2 18/2 18/12 19/8 23/21 23/22 25/8 27/14 42/2</p> <p><b>rash [1]</b> 129/20</p> <p><b>rather [2]</b> 19/25 49/4</p> <p><b>ratty [1]</b> 48/13</p> <p><b>re [1]</b> 114/17</p> <p><b>re-examined [1]</b> 114/17</p> <p><b>reacted [1]</b> 16/15</p> <p><b>reaction [5]</b> 16/11 17/1 116/25 122/10 130/7</p> <p><b>reactions [3]</b> 2/12 6/11 16/9</p> <p><b>read [8]</b> 4/18 11/1 11/14 74/18 81/24 95/4 101/11 129/25</p> <p><b>reading [3]</b> 6/2 63/22 116/22</p> <p><b>ready [2]</b> 69/14 102/5</p> <p><b>real [1]</b> 7/22</p> <p><b>realise [2]</b> 80/22 105/1</p> <p><b>realised [2]</b> 55/5 103/1</p> <p><b>really [50]</b> 4/22 8/24 11/12 15/13 15/16 20/24 23/17 26/19 31/11 31/19 32/3 37/12 40/6 42/7 43/2 43/2 45/5 47/18 49/8 52/19 52/20 55/25 58/2 60/18 68/19 68/21 68/21 72/15 90/22 90/22 92/24 93/22 99/7 100/14 100/14 104/24 105/9 116/23 118/22 120/6 121/1 122/24 123/11 126/17 126/18 127/16 130/4 130/5 130/25 133/17</p> <p><b>reason [5]</b> 3/3 22/7 24/22 31/5 98/6</p> <p><b>reasons [2]</b> 2/9 8/2</p> <p><b>rebuild [1]</b> 46/14</p>	<p><b>recall [26]</b> 7/5 7/24 16/25 19/22 20/14 22/24 23/10 25/4 65/20 66/8 66/20 67/17 68/3 70/8 72/12 73/25 75/12 84/17 88/7 100/18 101/20 102/13 102/16 102/25 107/23 129/14</p> <p><b>recalls [2]</b> 65/23 129/21</p> <p><b>receipts [1]</b> 48/2</p> <p><b>receive [5]</b> 11/21 16/17 92/15 106/25 131/4</p> <p><b>received [20]</b> 2/5 12/3 15/11 21/2 22/3 22/5 25/16 47/5 67/13 69/20 70/4 72/12 84/17 88/1 93/6 100/2 101/4 101/18 105/22 107/23</p> <p><b>receiving [10]</b> 4/2 19/24 49/16 65/23 66/18 100/5 102/13 104/18 106/1 108/15</p> <p><b>recent [2]</b> 51/2 86/25</p> <p><b>recently [5]</b> 44/21 53/2 75/3 104/25 116/21</p> <p><b>reckon [1]</b> 133/1</p> <p><b>recognise [1]</b> 72/9</p> <p><b>recognised [1]</b> 15/7</p> <p><b>recollection [19]</b> 5/23 9/25 12/6 14/20 22/4 23/9 26/13 30/8 33/12 56/1 57/11 70/5 85/15 85/16 86/11 87/19 87/24 108/1 123/5</p> <p><b>recollections [2]</b> 4/2 6/18</p> <p><b>recombinant [1]</b> 27/12</p> <p><b>recommend [1]</b> 34/12</p> <p><b>recommendation [1]</b> 19/11</p> <p><b>record [6]</b> 21/4 36/12 40/17 57/1 74/10 77/25</p> <p><b>recorded [5]</b> 22/21 22/22 56/17 71/11 83/16</p> <p><b>records [30]</b> 3/25 10/22 11/8 18/19 21/16 21/23 22/1 22/18 23/19 24/21 25/1 29/8 29/22 34/25 56/20 56/23 68/22 70/25 71/3 73/12 75/2 75/21 77/19 79/1 79/9 81/19 86/8 86/8 100/21 101/3</p>	<p><b>red [2]</b> 5/20 38/23</p> <p><b>redacted [15]</b> 5/3 10/15 45/14 45/22 46/11 46/12 53/24 54/1 54/12 73/2 75/1 75/18 102/5 113/15 120/18</p> <p><b>redecorating [1]</b> 48/25</p> <p><b>reducing [1]</b> 20/2</p> <p><b>refer [1]</b> 18/8</p> <p><b>reference [15]</b> 10/25 14/22 21/6 22/20 30/4 33/8 70/7 74/2 74/11 77/20 79/15 79/24 80/12 84/22 110/14</p> <p><b>references [1]</b> 20/12</p> <p><b>referred [2]</b> 66/12 120/8</p> <p><b>referring [1]</b> 18/7</p> <p><b>refers [2]</b> 19/10 56/23</p> <p><b>reflects [1]</b> 89/4</p> <p><b>reformed [1]</b> 51/18</p> <p><b>reformist [1]</b> 51/24</p> <p><b>regarding [1]</b> 33/22</p> <p><b>regards [2]</b> 13/3 59/23</p> <p><b>regime [1]</b> 57/20</p> <p><b>registered [1]</b> 69/12</p> <p><b>Registry [1]</b> 32/24</p> <p><b>regret [2]</b> 116/3 134/13</p> <p><b>regular [2]</b> 111/8 113/18</p> <p><b>regularly [2]</b> 37/24 67/15</p> <p><b>regulation [1]</b> 95/18</p> <p><b>relate [2]</b> 56/13 56/18</p> <p><b>related [9]</b> 57/7 82/19 83/1 83/6 87/1 105/13 114/13 114/21 114/24</p> <p><b>relating [3]</b> 56/20 79/2 86/25</p> <p><b>relation [15]</b> 3/25 15/21 21/4 24/20 25/10 34/21 36/6 36/8 77/18 84/13 86/22 88/20 89/3 105/23 106/5</p> <p><b>relationship [5]</b> 116/1 116/5 119/13 120/25 121/10</p> <p><b>relationships [1]</b> 121/15</p> <p><b>relaxed [1]</b> 135/23</p> <p><b>relayed [1]</b> 6/5</p> <p><b>relented [1]</b> 107/19</p> <p><b>relevant [2]</b> 34/14 58/4</p> <p><b>reliant [1]</b> 46/21</p> <p><b>relieved [1]</b> 61/20</p> <p><b>reluctant [1]</b> 61/15</p> <p><b>remain [3]</b> 37/18 74/8</p>
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<b>R</b>	107/16	<b>Rizza [14]</b> 3/16 65/22 66/20 69/9 69/17 69/19 70/3 70/23 86/21 86/24 87/8 87/25 88/6 88/18 <b>Rizza's [1]</b> 87/5 <b>RLIT0000664 [1]</b> 53/7 <b>road [4]</b> 133/7 133/11 134/2 134/3 <b>role [1]</b> 118/2 <b>room [20]</b> 1/12 1/15 1/19 9/8 40/2 45/21 48/25 56/7 98/23 99/8 99/14 108/7 108/16 111/14 111/16 122/3 128/16 131/21 132/12 133/17 <b>Rosemary [1]</b> 11/18 <b>rough [2]</b> 42/3 42/25 <b>roughly [1]</b> 99/20 <b>roulette [1]</b> 34/19 <b>round [9]</b> 5/11 33/5 50/16 52/11 63/13 67/5 115/24 117/20 124/17 <b>routine [2]</b> 16/8 49/9 <b>row [3]</b> 59/21 104/4 110/13 <b>Royal [2]</b> 3/11 14/7 <b>rude [1]</b> 48/17 <b>run [9]</b> 21/14 21/15 60/24 109/2 109/2 128/25 129/1 129/3 129/5 <b>rung [5]</b> 30/14 37/6 48/16 48/18 126/16 <b>running [1]</b> 55/11 <b>rush [1]</b> 64/20	42/2 42/6 42/24 43/5 43/10 43/20 44/2 44/6 44/7 44/23 44/24 45/1 45/2 45/5 45/7 45/8 45/25 46/2 46/13 48/13 48/14 48/16 48/16 48/18 49/2 51/16 58/10 58/11 59/8 59/13 59/22 63/23 67/6 69/11 83/22 83/25 88/2 88/4 88/25 89/16 92/6 92/20 92/25 94/16 95/25 98/17 99/8 110/25 111/14 111/22 111/23 116/17 116/18 116/23 116/23 117/19 118/14 118/22 119/6 122/23 124/6 124/13 124/20 126/16 126/17 126/18 126/18 126/20 128/11 128/12 130/5 130/6 130/21 131/23 135/3 136/3 <b>SAINSBURY [3]</b> 1/23 18/17 137/2 <b>sake [1]</b> 76/9 <b>same [25]</b> 8/13 10/15 14/15 19/1 24/13 48/7 49/15 52/3 57/2 79/19 79/24 80/12 81/22 82/2 85/18 85/19 90/21 92/18 104/7 105/20 108/4 116/11 131/10 133/25 136/2 <b>sample [6]</b> 17/24 18/4 21/16 22/18 23/5 23/6 <b>samples [2]</b> 25/3 25/23 <b>sat [11]</b> 19/5 26/22 40/18 43/2 92/19 111/18 118/11 128/2 128/3 132/10 135/17 <b>saw [12]</b> 3/21 13/24 14/17 25/1 32/10 34/25 35/1 43/4 54/3 59/9 72/7 133/6 <b>say [45]</b> 7/4 9/7 10/4 10/10 24/13 26/4 31/19 35/4 41/14 42/6 48/13 49/11 51/7 57/13 57/14 59/6 59/16 59/23 67/22 70/12 70/15 81/10 87/22 88/14 92/18 93/11 96/12 104/24 107/12 108/8 108/9 109/11 111/10 111/10 115/25 117/4 120/24 125/1 129/16 129/19 131/7 133/5 134/11 134/12 134/22	<b>saying [16]</b> 9/17 12/8 21/24 37/25 39/14 49/4 56/2 56/2 70/3 76/11 88/20 102/3 105/3 107/4 123/15 134/13 <b>says [19]</b> 11/15 12/18 16/4 19/15 25/11 26/10 29/1 69/19 72/19 75/2 75/7 75/19 76/25 83/15 83/17 84/14 85/1 103/13 106/23 <b>scales [1]</b> 9/9 <b>scan [1]</b> 44/1 <b>scandal [2]</b> 60/3 60/22 <b>scared [1]</b> 38/3 <b>scenario [1]</b> 95/10 <b>schemes [3]</b> 47/4 47/9 51/18 <b>school [39]</b> 3/4 3/9 4/6 5/3 7/3 8/17 9/4 10/8 12/23 12/24 12/25 12/25 13/19 14/19 20/17 26/1 26/7 36/24 37/5 48/19 53/14 54/2 58/23 60/6 60/13 62/16 62/20 67/2 67/3 67/17 70/12 96/7 97/14 97/16 98/7 98/23 98/25 98/25 108/4 <b>schooling [2]</b> 97/13 99/6 <b>schools [2]</b> 6/25 97/22 <b>scores [1]</b> 44/2 <b>scrape [1]</b> 130/17 <b>scratch [2]</b> 52/22 52/22 <b>scrawled [1]</b> 50/9 <b>screen [3]</b> 53/6 69/5 100/23 <b>screwed [1]</b> 135/2 <b>searching [1]</b> 51/16 <b>second [15]</b> 3/12 19/14 32/18 73/17 75/15 84/21 93/20 104/4 104/9 106/11 115/9 115/11 120/8 120/12 120/19 <b>see [98]</b> 1/6 1/25 3/18 5/17 9/18 11/3 11/9 12/23 13/11 15/20 18/3 19/9 21/1 21/3 21/13 21/16 21/24 22/12 22/20 23/22 24/19 27/23 30/4 30/22 32/21 33/7 40/9 41/2 42/10 53/21 55/3 55/13 64/17 65/20	68/11 68/14 69/18 69/20 70/3 70/7 70/22 71/8 71/11 71/16 74/2 74/9 74/22 75/16 76/10 77/8 77/10 77/22 79/7 79/13 79/15 79/17 79/23 80/11 81/21 82/2 82/19 83/15 83/20 84/4 86/6 86/7 88/5 88/17 88/25 91/3 92/11 93/21 94/20 101/1 101/3 101/10 101/14 103/12 104/4 104/5 105/18 105/20 105/22 106/20 107/12 109/21 110/7 110/11 110/13 110/15 114/12 115/21 117/3 117/5 117/16 129/16 131/13 133/21 <b>seeing [5]</b> 25/4 28/20 66/12 84/19 112/21 <b>seem [4]</b> 12/8 17/15 101/2 102/11 <b>seemed [2]</b> 4/18 23/16 <b>seems [6]</b> 44/13 96/9 101/5 101/11 106/6 125/15 <b>seen [17]</b> 10/4 13/12 13/15 56/19 57/3 72/6 72/17 72/18 75/3 75/14 82/13 105/2 105/12 116/2 116/2 124/5 129/1 <b>selected [1]</b> 11/21 <b>self [11]</b> 7/18 9/1 9/22 10/18 15/10 46/21 61/10 69/15 102/6 102/6 102/21 <b>self-administered [1]</b> 102/6 <b>self-infused [1]</b> 61/10 <b>self-infusion [1]</b> 7/18 <b>self-reliant [1]</b> 46/21 <b>self-sufficiency [1]</b> 15/10 <b>self-therapy [2]</b> 102/6 102/21 <b>self-treat [1]</b> 9/1 <b>self-treating [1]</b> 9/22 <b>send [3]</b> 41/23 59/18 112/3 <b>sensationalism [1]</b> 50/20 <b>sense [3]</b> 77/21 96/2 108/15 <b>sensible [1]</b> 69/25 <b>sent [16]</b> 12/5 12/10 12/14 13/12 14/10 17/16 17/19 17/25
	<b>responsible [1]</b> 95/17 <b>rest [5]</b> 20/3 20/3 59/4 61/22 112/15 <b>restricted [1]</b> 16/19 <b>restrictions [1]</b> 1/17 <b>result [12]</b> 28/5 28/9 29/10 29/12 29/17 29/19 29/21 30/5 32/18 33/6 34/23 78/2 <b>results [12]</b> 13/17 23/10 23/11 29/25 30/4 77/4 83/3 86/15 87/2 87/9 87/20 114/23 <b>resume [1]</b> 96/20 <b>retired [1]</b> 51/17 <b>retirement [3]</b> 40/19 58/1 61/14 <b>retrospective [2]</b> 77/20 89/5 <b>retroviral [1]</b> 41/5 <b>return [2]</b> 33/19 72/20 <b>returned [1]</b> 97/20 <b>reunited [1]</b> 45/22 <b>revealed [2]</b> 82/23 114/16 <b>reverse [2]</b> 71/2 79/12 <b>reviewed [1]</b> 29/9 <b>ribavirin [1]</b> 42/17 <b>Richards [5]</b> 1/19 1/24 65/9 137/3 137/6 <b>ridiculous [3]</b> 42/5 48/14 48/20 <b>right [48]</b> 3/3 3/5 6/23 14/20 14/23 27/1 28/25 31/24 32/19 37/6 39/8 39/11 40/12 44/14 49/17 51/15 54/2 58/14 59/22 65/19 66/7 68/25 71/7 71/10 72/11 73/19 78/24 82/3 84/3 84/5 84/16 85/6 85/12 85/13 87/23 89/15 91/24 96/6 100/2 105/15 108/12 113/9 120/6 120/17 123/24 126/18 128/17 130/20 <b>right-hand [2]</b> 84/3 84/5 <b>rightly [1]</b> 18/1 <b>rights [2]</b> 34/7 34/8 <b>ring [5]</b> 17/5 17/6 25/2 25/5 112/1 <b>ringing [1]</b> 117/15 <b>risk [7]</b> 14/24 20/22 24/23 81/8 83/25 86/9 119/1 <b>risks [7]</b> 6/8 27/17 66/21 72/4 81/4 93/10 100/18	<b>S</b> <b>sad [1]</b> 64/1 <b>saddened [1]</b> 61/13 <b>safe [1]</b> 112/12 <b>safety [1]</b> 7/23 <b>said [137]</b> 4/19 4/21 4/21 4/22 5/9 5/11 6/12 6/13 12/13 12/15 13/7 15/9 15/11 15/12 17/4 18/3 20/21 22/5 23/13 26/5 27/20 27/21 30/14 30/23 31/1 31/14 31/20 32/14 32/16 33/20 34/6 34/12 34/21 35/2 35/3 35/5 35/23 36/8 37/5 37/5 37/7 37/8 37/9 38/11 39/12 39/21 39/23 40/1 40/8 40/8 40/11 40/11 40/14 40/15 40/17 40/22 41/15 41/15 41/18 41/19 41/23			

<b>S</b>	119/16 120/23 120/24 121/11 126/20 130/9 130/9 132/20 <b>she'd</b> [2] 51/24 73/4 <b>She's</b> [3] 73/2 94/14 132/21 <b>sheets</b> [1] 38/4 <b>shell</b> [2] 49/23 50/2 <b>sheltering</b> [1] 44/8 <b>shielded</b> [1] 44/6 <b>shielding</b> [1] 46/19 <b>Shields</b> [1] 43/4 <b>shocked</b> [1] 55/6 <b>shoes</b> [1] 44/16 <b>shook</b> [1] 39/24 <b>shop</b> [1] 50/17 <b>short</b> [2] 49/4 64/24 <b>Shortly</b> [1] 124/11 <b>shot</b> [1] 130/15 <b>shotty</b> [1] 114/16 <b>should</b> [14] 11/24 25/21 31/15 45/25 46/23 49/5 53/9 95/17 96/10 102/9 103/15 104/7 110/15 130/6 <b>shoulder</b> [2] 118/9 135/4 <b>shouldn't</b> [4] 21/24 46/22 46/23 58/17 <b>show</b> [4] 69/6 76/17 87/10 99/19 <b>showing</b> [1] 24/22 <b>shown</b> [2] 63/8 72/7 <b>shows</b> [3] 34/4 71/19 89/5 <b>shuffle</b> [2] 99/21 107/7 <b>shut</b> [2] 122/24 122/25 <b>shuttered</b> [1] 49/25 <b>sic</b> [1] 4/12 <b>sick</b> [9] 4/7 4/7 4/14 40/16 98/23 99/2 99/5 103/4 108/16 <b>side</b> [15] 22/19 39/15 42/20 52/8 79/13 90/14 90/21 103/12 109/5 109/8 125/20 125/22 129/14 129/17 133/17 <b>sign</b> [6] 33/25 34/1 92/13 92/21 92/22 131/24 <b>signature</b> [2] 72/23 73/3 <b>signed</b> [5] 34/2 34/7 73/2 93/2 132/3 <b>significance</b> [3] 23/11 36/15 75/25 <b>significant</b> [1] 76/1 <b>signs</b> [2] 25/21 83/21 <b>silly</b> [1] 42/21	<b>similar</b> [5] 21/23 24/9 29/23 56/17 57/4 <b>simply</b> [1] 80/17 <b>since</b> [9] 19/16 39/7 62/23 75/5 113/7 116/2 116/3 121/19 134/4 <b>since 2010</b> [1] 121/19 <b>single</b> [2] 90/15 90/15 <b>singled</b> [1] 60/15 <b>sir</b> [27] 36/2 55/18 55/20 56/19 58/10 63/5 64/5 77/8 77/12 85/4 85/6 94/7 94/8 96/19 96/22 111/23 115/12 124/14 132/5 132/8 132/13 134/22 135/7 136/9 137/4 137/7 137/10 <b>Sir Brian</b> [8] 55/18 63/5 94/7 124/14 132/5 132/13 134/22 135/7 <b>sit</b> [1] 8/11 <b>site</b> [3] 3/23 7/9 37/7 <b>sitting</b> [1] 100/12 <b>six</b> [7] 2/13 2/13 3/11 31/14 52/18 109/12 113/8 <b>six months</b> [1] 31/14 <b>six years</b> [1] 52/18 <b>sixth</b> [1] 77/23 <b>skin</b> [2] 91/20 94/11 <b>Sky</b> [1] 60/9 <b>sledge</b> [1] 59/17 <b>sleep</b> [2] 113/12 113/12 <b>sliding</b> [1] 131/22 <b>slight</b> [1] 59/19 <b>slightly</b> [6] 57/4 83/14 99/14 99/21 113/2 122/3 <b>sling</b> [1] 54/4 <b>slip</b> [1] 9/17 <b>slot</b> [1] 98/6 <b>slow</b> [1] 132/11 <b>slowly</b> [2] 121/2 127/9 <b>small</b> [4] 8/5 76/1 82/23 87/16 <b>smirk</b> [1] 13/24 <b>Snowden</b> [2] 55/13 93/14 <b>so</b> [174] <b>social</b> [1] 62/7 <b>society</b> [1] 51/1 <b>socks</b> [1] 44/16 <b>solely</b> [1] 2/18 <b>solicitors</b> [1] 92/19 <b>solution</b> [1] 51/16 <b>some</b> [58] 5/10 12/12 13/17 17/4 17/16 18/16 18/21 28/13	32/11 37/6 38/11 41/9 48/24 49/8 50/17 61/13 65/10 68/22 70/24 74/18 75/8 76/17 78/10 79/1 81/19 83/10 84/11 84/24 85/8 87/11 88/19 90/5 92/15 93/12 95/8 95/14 96/3 97/22 100/21 101/3 101/17 105/2 107/10 116/18 117/9 117/19 117/24 120/12 123/12 124/5 125/24 127/21 127/21 133/21 134/13 134/17 134/18 134/19 <b>somebody</b> [12] 10/6 13/12 61/25 92/11 95/14 108/8 108/18 118/1 121/11 128/1 129/4 135/3 <b>somebody's</b> [1] 121/4 <b>someone</b> [1] 10/18 <b>something</b> [29] 1/17 7/11 14/25 17/8 24/25 35/14 45/4 47/15 52/10 53/1 64/18 67/7 74/13 80/12 81/15 81/16 81/16 84/5 104/2 104/21 106/25 107/1 107/5 114/4 116/24 117/10 118/8 127/12 129/16 <b>sometime</b> [1] 73/9 <b>sometimes</b> [4] 20/10 49/9 68/11 108/24 <b>son</b> [7] 11/21 26/10 48/17 59/6 83/5 124/16 125/6 <b>son's</b> [1] 119/10 <b>sons</b> [4] 53/16 65/11 85/25 96/14 <b>sons'</b> [1] 85/23 <b>sores</b> [2] 32/13 38/15 <b>sorry</b> [25] 1/12 11/1 19/14 21/18 28/20 35/21 36/4 42/22 50/1 51/14 54/13 54/15 58/12 59/6 63/14 68/10 71/6 72/18 77/24 85/4 92/3 116/23 120/18 123/11 133/18 <b>sort</b> [11] 13/15 20/21 26/22 27/8 27/23 28/3 37/3 38/8 49/21 66/17 113/25 <b>sorts</b> [1] 136/3 <b>Soubry</b> [1] 51/17 <b>sought</b> [1] 62/2 <b>soul</b> [1] 132/21 <b>Soumik</b> [28] 10/24	21/19 24/17 25/6 26/24 28/14 35/22 53/7 69/5 71/1 71/6 71/16 74/21 75/16 76/23 79/11 79/19 80/11 82/1 82/14 83/12 84/3 84/20 93/17 94/1 100/25 105/20 106/3 <b>sound</b> [2] 126/17 127/9 <b>sounds</b> [3] 6/22 85/13 93/4 <b>source</b> [1] 11/24 <b>Southampton</b> [1] 113/2 <b>speak</b> [1] 48/12 <b>speaking</b> [5] 12/11 26/14 48/12 76/12 121/13 <b>speaks</b> [1] 55/1 <b>special</b> [1] 61/12 <b>specialist</b> [2] 41/2 42/10 <b>speech</b> [1] 63/3 <b>spent</b> [5] 3/8 43/18 53/19 92/9 121/7 <b>splints</b> [1] 20/3 <b>split</b> [1] 13/18 <b>spoke</b> [8] 18/2 42/23 44/5 54/3 76/20 88/6 115/25 124/9 <b>spoken</b> [5] 37/8 41/22 48/19 86/3 128/24 <b>spot</b> [2] 5/20 134/5 <b>squeeze</b> [1] 64/13 <b>stable</b> [1] 45/25 <b>stacked</b> [1] 112/12 <b>staff</b> [8] 5/19 27/14 60/13 68/4 68/6 68/7 68/19 135/20 <b>staff'</b> [1] 48/17 <b>stage</b> [5] 36/14 85/7 104/10 104/11 116/25 <b>stage I</b> [1] 104/10 <b>stages</b> [2] 103/19 104/8 <b>stained</b> [1] 60/5 <b>stamp</b> [1] 24/23 <b>stand</b> [1] 125/2 <b>standing</b> [1] 126/15 <b>start</b> [10] 30/3 40/15 64/15 65/17 68/25 91/5 96/16 101/4 102/10 103/20 <b>started</b> [26] 4/16 7/17 12/12 14/13 14/14 32/23 37/22 38/2 43/4 43/8 45/16 46/9 46/12 47/16 47/24 50/4 51/7 51/9 51/11 55/7 73/21 90/8 90/16 100/4	126/11 135/10 <b>starting</b> [3] 33/2 116/21 120/22 <b>state</b> [1] 119/23 <b>stated</b> [1] 123/11 <b>statement</b> [37] 5/23 6/21 22/5 28/13 32/16 33/16 34/22 35/24 37/17 39/1 40/22 47/5 47/8 49/11 49/18 51/3 65/23 66/12 73/7 85/15 87/19 89/10 90/23 92/12 104/17 107/23 111/1 119/18 120/11 122/23 124/7 125/7 126/25 129/21 129/25 130/2 130/21 <b>stating</b> [1] 29/11 <b>status</b> [1] 32/17 <b>stay</b> [2] 99/5 136/10 <b>stickers</b> [2] 119/2 119/4 <b>sticks</b> [1] 123/18 <b>stigmata</b> [6] 76/15 82/21 83/18 83/19 85/2 114/14 <b>stigmatised</b> [1] 89/20 <b>still</b> [24] 21/25 33/3 36/25 48/10 66/10 82/10 91/10 99/18 106/13 107/10 118/14 121/3 125/2 125/24 126/23 127/15 128/25 129/1 129/3 129/18 129/18 133/21 135/1 135/1 <b>stomach</b> [1] 125/18 <b>stood</b> [4] 5/9 111/22 122/16 123/14 <b>stop</b> [5] 54/18 54/19 106/23 112/3 126/21 <b>stopped</b> [3] 52/12 66/16 92/4 <b>stopping</b> [1] 20/6 <b>stories</b> [3] 50/4 50/11 127/22 <b>story</b> [6] 59/24 60/8 60/10 62/20 63/19 92/18 <b>straight</b> [3] 25/4 46/18 118/4 <b>Straightaway</b> [1] 46/4 <b>strange</b> [2] 8/21 44/5 <b>strangely</b> [1] 41/16 <b>street</b> [1] 50/8 <b>strength</b> [1] 32/1 <b>stress</b> [3] 44/8 124/9 133/6 <b>stroke</b> [2] 41/16 124/3 <b>strong</b> [2] 39/9 110/1 <b>struggle</b> [1] 31/17 <b>students</b> [1] 59/25
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<p><b>S</b></p> <p><b>Study</b> [2] 16/7 17/8</p> <p><b>stuff</b> [5] 6/14 13/3 26/23 27/13 66/15</p> <p><b>stupid</b> [2] 109/19 109/19</p> <p><b>subject</b> [1] 11/20</p> <p><b>subsequent</b> [1] 28/8</p> <p><b>successful</b> [3] 19/18 98/1 130/10</p> <p><b>such</b> [1] 10/18</p> <p><b>suddenly</b> [5] 30/21 32/25 41/14 46/1 55/5</p> <p><b>Sue</b> [1] 67/8</p> <p><b>suffering</b> [1] 57/1</p> <p><b>sufficiency</b> [1] 15/10</p> <p><b>sufficiently</b> [1] 59/7</p> <p><b>suggest</b> [3] 20/13 42/9 87/16</p> <p><b>suggested</b> [1] 67/9</p> <p><b>suggestive</b> [1] 76/17</p> <p><b>suggests</b> [2] 36/12 106/7</p> <p><b>sum</b> [1] 131/6</p> <p><b>summary</b> [1] 51/6</p> <p><b>summer</b> [4] 18/13 26/25 73/20 78/21</p> <p><b>summer's</b> [1] 118/12</p> <p><b>Sunday</b> [3] 53/2 60/8 60/9</p> <p><b>superficial</b> [2] 82/22 114/15</p> <p><b>supervisor</b> [1] 37/8</p> <p><b>supper</b> [1] 59/19</p> <p><b>supplied</b> [2] 69/22 70/23</p> <p><b>supply</b> [2] 17/12 22/14</p> <p><b>support</b> [12] 3/22 44/20 45/14 47/3 49/16 61/24 62/2 62/5 62/8 62/14 62/23 134/19</p> <p><b>supportive</b> [1] 60/14</p> <p><b>suppose</b> [3] 116/9 120/1 127/11</p> <p><b>supposed</b> [5] 44/12 50/24 54/5 63/9 132/18</p> <p><b>supposedly</b> [1] 41/8</p> <p><b>sure</b> [27] 10/23 14/3 15/6 17/3 17/19 23/3 24/14 30/2 32/16 40/12 69/25 75/8 77/13 78/20 86/2 88/8 99/24 100/22 107/8 110/23 110/24 114/9 121/23 122/5 123/7 130/15 130/16</p> <p><b>Surely</b> [1] 34/13</p> <p><b>surface</b> [1] 110/10</p>	<p><b>surnames</b> [1] 57/23</p> <p><b>surprised</b> [5] 11/9 13/11 26/20 43/13 43/25</p> <p><b>survey</b> [2] 11/19 12/1</p> <p><b>survive</b> [1] 46/23</p> <p><b>survived</b> [1] 60/7</p> <p><b>Susan</b> [1] 72/24</p> <p><b>suspect</b> [3] 22/6 39/18 64/15</p> <p><b>swallowing</b> [1] 84/25</p> <p><b>swapped</b> [1] 44/17</p> <p><b>sweat</b> [1] 1/22</p> <p><b>sweat</b> [1] 38/8</p> <p><b>sweats</b> [3] 37/20 37/23 37/25</p> <p><b>sweets</b> [1] 50/17</p> <p><b>switch</b> [1] 74/6</p> <p><b>swollen</b> [1] 105/15</p> <p><b>sworn</b> [4] 65/8 97/6 137/5 137/8</p> <p><b>symptoms</b> [6] 25/21 40/5 47/20 56/17 85/8 91/5</p> <p><b>system</b> [1] 43/23</p> <p><b>systematic</b> [1] 57/1</p> <p><b>T</b></p> <p><b>table</b> [4] 21/14 99/16 110/7 111/9</p> <p><b>tables</b> [2] 99/15 111/8</p> <p><b>tablet</b> [3] 38/13 41/8 41/13</p> <p><b>tablets</b> [2] 129/22 130/5</p> <p><b>tackle</b> [1] 58/2</p> <p><b>tackling</b> [1] 59/22</p> <p><b>Tainted</b> [1] 51/8</p> <p><b>take</b> [30] 4/10 4/22 17/13 18/21 23/5 26/24 30/1 30/23 33/21 35/17 35/21 55/9 64/5 64/18 65/6 68/15 70/14 75/24 81/20 85/14 89/9 90/9 91/25 92/5 97/5 103/6 103/8 130/17 134/5 134/5</p> <p><b>taken</b> [6] 17/25 36/15 38/18 45/19 53/14 53/20</p> <p><b>takes</b> [2] 25/7 136/3</p> <p><b>taking</b> [9] 9/24 40/15 41/13 43/1 43/5 72/25 74/3 88/13 110/4</p> <p><b>talk</b> [11] 9/2 61/25 62/6 63/3 69/7 113/17 117/4 121/22 122/13 122/15 122/21</p> <p><b>talked</b> [10] 37/15 44/25 47/8 49/18 50/1 58/20 58/20 89/17</p>	<p>92/15 104/17</p> <p><b>talking</b> [14] 1/15 1/19 12/14 38/1 57/5 61/1 68/3 77/14 86/21 87/25 108/18 121/8 122/23 126/11</p> <p><b>talks</b> [2] 73/17 84/8</p> <p><b>task</b> [1] 135/10</p> <p><b>taught</b> [1] 59/10</p> <p><b>teacher</b> [1] 68/12</p> <p><b>teaching</b> [3] 7/19 68/6 68/7</p> <p><b>team</b> [7] 60/19 61/19 63/6 134/23 134/24 135/7 135/20</p> <p><b>tears</b> [1] 43/3</p> <p><b>teeth</b> [1] 63/4</p> <p><b>tell</b> [32] 7/12 11/12 27/15 31/6 38/3 40/14 49/2 52/25 58/22 81/4 92/17 98/4 98/20 99/9 103/2 108/2 111/6 111/18 115/18 117/10 118/8 118/10 119/20 120/16 122/6 122/20 122/21 123/21 126/5 127/6 129/4 131/8</p> <p><b>telling</b> [6] 13/23 23/22 40/17 66/21 78/1 128/8</p> <p><b>tells</b> [2] 77/22 107/23</p> <p><b>telly</b> [2] 32/12 116/22</p> <p><b>ten</b> [5] 23/24 35/15 39/8 136/13 136/14</p> <p><b>ten o'clock</b> [2] 136/13 136/14</p> <p><b>ten years</b> [1] 35/15</p> <p><b>tended</b> [4] 4/10 31/23 32/3 57/25</p> <p><b>term</b> [18] 5/25 13/22 14/21 23/2 23/9 26/6 43/14 59/1 59/4 71/9 73/18 77/3 79/9 79/10 83/2 84/15 105/15 114/22</p> <p><b>terminology</b> [1] 77/9</p> <p><b>terms</b> [15] 2/5 9/3 9/21 14/22 23/18 33/6 37/15 42/16 68/13 68/18 92/16 97/13 106/23 121/15 131/2</p> <p><b>Terrence</b> [1] 44/23</p> <p><b>terrible</b> [3] 39/10 61/16 62/12</p> <p><b>terrorist</b> [1] 45/3</p> <p><b>test</b> [23] 29/10 29/14 29/17 29/18 29/19 29/21 29/22 29/25 30/5 30/7 30/12 30/15 30/25 32/18 33/6 33/8 56/9 56/10 77/11 78/2 86/15 87/2 119/7</p>	<p><b>tested</b> [8] 30/25 38/19 45/21 78/1 78/14 78/17 88/4 88/21</p> <p><b>testing</b> [7] 22/21 22/25 25/16 57/6 77/15 77/20 89/5</p> <p><b>tests</b> [26] 23/2 23/11 25/24 29/24 36/15 43/20 44/4 44/10 56/21 74/12 74/18 75/5 75/6 75/20 75/23 76/13 83/1 83/2 83/6 86/22 87/1 87/9 114/21 119/5 119/8 126/8</p> <p><b>text</b> [1] 25/9</p> <p><b>Thames</b> [1] 18/24</p> <p><b>than</b> [24] 6/2 13/10 13/23 14/14 19/25 32/19 35/15 54/1 62/13 63/7 64/14 67/23 67/24 76/17 78/8 87/21 87/22 94/24 100/11 105/6 107/24 108/11 122/4 122/23</p> <p><b>thank</b> [42] 2/1 26/24 36/7 37/9 37/14 55/9 57/8 62/10 62/25 63/5 63/10 63/11 63/21 64/3 64/4 83/14 86/25 87/9 89/9 94/20 95/1 95/6 95/8 95/21 95/22 95/24 95/25 96/15 96/16 96/18 99/25 102/4 105/21 115/12 134/9 134/22 135/7 135/7 135/9 135/24 136/6 136/8</p> <p><b>thankfully</b> [1] 2/25</p> <p><b>thanking</b> [1] 62/22</p> <p><b>thanks</b> [2] 8/25 40/17</p> <p><b>that</b> [487]</p> <p><b>that I</b> [6] 3/21 3/22 42/2 59/7 62/5 107/4</p> <p><b>that I needed</b> [2] 22/9 31/16</p> <p><b>that is</b> [1] 55/2</p> <p><b>that's</b> [71] 1/5 1/19 2/4 3/3 3/23 5/11 5/16 6/12 8/4 8/14 10/18 15/23 18/6 22/9 22/16 23/9 25/16 27/1 28/23 31/13 31/15 31/20 36/21 37/3 39/14 42/22 42/25 43/7 44/4 44/13 46/19 46/24 46/25 51/11 53/11 55/6 57/9 59/10 65/3 65/19 70/4 71/17 72/22 77/2 77/24 78/24 80/8 82/3 82/12</p>	<p>83/16 84/16 89/15 92/7 93/2 93/20 99/17 99/19 103/7 105/8 109/4 112/14 116/4 118/11 119/18 120/21 120/25 121/20 125/25 132/4 135/21 136/5</p> <p><b>their</b> [27] 5/18 5/19 9/24 18/18 46/25 50/5 50/6 50/7 52/23 53/17 56/21 60/2 60/24 61/3 62/17 62/23 67/13 67/17 86/1 90/25 93/7 93/7 93/8 94/23 107/16 127/21 127/22</p> <p><b>their concentrate</b> [1] 9/24</p> <p><b>theirs</b> [1] 62/21</p> <p><b>them</b> [60] 7/12 12/8 13/23 23/4 24/16 25/3 28/17 29/9 30/19 31/14 36/25 37/1 37/7 37/9 37/11 38/4 38/18 38/22 39/10 46/9 47/11 50/18 53/17 53/20 61/4 65/23 67/4 67/13 67/15 68/13 68/14 68/15 68/19 69/8 81/2 81/20 86/1 88/5 88/7 89/16 89/24 90/1 90/2 90/3 90/4 92/20 93/23 95/8 96/8 109/23 113/5 117/11 117/14 117/23 117/24 118/3 121/10 128/22 134/6 136/2</p> <p><b>then</b> [150]</p> <p><b>therapist</b> [1] 63/3</p> <p><b>therapy</b> [7] 48/6 48/7 69/15 69/23 102/6 102/21 109/12</p> <p><b>there</b> [147]</p> <p><b>There'd</b> [1] 86/18</p> <p><b>there's</b> [22] 5/15 12/17 12/20 20/22 21/6 24/14 24/21 27/21 36/14 44/6 74/2 74/11 83/12 84/11 84/22 86/9 93/14 100/10 104/23 118/8 127/23 131/12</p> <p><b>thereabouts</b> [1] 64/16</p> <p><b>therefore</b> [2] 19/16 61/13</p> <p><b>Theresa</b> [1] 51/23</p> <p><b>Theresa May</b> [1] 51/23</p> <p><b>these</b> [25] 1/14 23/11 29/7 29/25 30/1 45/12 51/18 64/1 70/24 75/6 75/18 76/12 79/9 81/18 82/13 83/1</p>	<p>83/10 84/17 87/22 95/5 96/7 111/24 114/21 128/13 134/14</p> <p><b>they</b> [166]</p> <p><b>they'd</b> [14] 7/12 37/23 41/7 47/14 80/21 86/3 91/2 91/4 91/7 92/7 92/13 94/23 94/24 94/25</p> <p><b>they'll</b> [2] 92/18 100/23</p> <p><b>they're</b> [12] 15/12 23/7 31/24 40/15 44/14 44/24 57/5 79/11 88/15 131/1 132/5 132/15</p> <p><b>they've</b> [4] 108/9 128/13 129/1 130/21</p> <p><b>thing</b> [18] 12/24 32/22 34/5 36/10 37/3 38/9 39/13 46/13 47/17 51/15 52/20 52/24 95/15 121/20 131/3 132/22 133/2 136/2</p> <p><b>things</b> [24] 1/14 8/3 13/21 20/18 31/22 44/22 45/12 47/24 49/21 50/10 50/21 55/25 57/15 57/18 58/18 59/18 59/18 59/22 64/1 90/24 92/12 124/24 132/14 134/13</p> <p><b>think</b> [169]</p> <p><b>thinking</b> [5] 18/6 20/23 35/9 66/7 69/1</p> <p><b>third</b> [5] 23/21 33/8 64/9 74/21 83/13</p> <p><b>this</b> [174]</p> <p><b>thorough</b> [1] 43/11</p> <p><b>those</b> [15] 4/14 16/15 27/8 28/11 60/4 60/6 60/20 66/18 68/3 77/21 94/3 94/5 127/6 127/7 129/21</p> <p><b>though</b> [4] 16/20 68/8 93/5 133/4</p> <p><b>thought</b> [32] 4/24 5/7 5/22 8/21 10/17 12/7 12/9 17/11 26/21 30/15 31/18 31/19 32/17 36/3 38/7 41/15 43/25 44/4 45/15 46/15 47/23 48/2 48/20 58/17 59/5 63/19 80/19 87/21 87/22 121/17 127/20 134/24</p> <p><b>thought:</b> [1] 38/1</p> <p><b>thoughts</b> [2] 95/9 117/1</p> <p><b>thousand</b> [1] 55/2</p>
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<p><b>T</b></p> <p><b>thousands [1]</b> 41/21</p> <p><b>three [17]</b> 6/24 10/16 16/11 38/2 39/12 74/19 78/7 81/25 90/11 93/16 103/19 112/13 118/12 128/20 133/13 133/18 134/7</p> <p><b>three years [2]</b> 16/11 78/7</p> <p><b>three-quarters [1]</b> 39/12</p> <p><b>thrive [1]</b> 46/24</p> <p><b>throat [1]</b> 37/21</p> <p><b>through [28]</b> 7/7 8/24 9/2 17/17 28/17 30/9 39/14 40/24 44/7 45/7 45/9 46/14 52/16 54/2 58/12 58/14 62/5 71/4 71/18 95/7 95/15 101/3 117/24 118/1 119/16 127/14 132/7 134/21</p> <p><b>throughout [4]</b> 8/5 19/21 93/5 106/4</p> <p><b>thrush [3]</b> 38/7 38/11 84/24</p> <p><b>ticking [1]</b> 50/21</p> <p><b>time [112]</b> 2/15 5/9 5/18 7/18 8/8 8/11 8/11 8/13 10/1 10/11 12/25 13/20 14/11 14/15 14/17 15/8 17/14 17/15 18/6 19/19 20/1 20/3 20/7 20/24 22/1 22/14 27/17 28/4 28/8 30/3 30/18 31/4 31/25 33/23 40/3 40/4 40/11 40/23 41/5 41/19 42/3 42/6 42/12 43/1 45/12 47/6 47/6 47/22 47/22 49/15 50/15 50/21 52/3 56/9 56/11 58/23 60/24 62/16 64/19 66/1 66/24 67/8 67/17 71/20 71/20 72/6 73/14 74/5 75/14 77/6 78/6 81/20 82/12 85/18 85/19 86/12 87/11 88/22 92/9 92/10 92/22 93/3 95/8 95/9 98/24 99/11 103/18 105/21 106/1 106/20 107/17 109/3 109/13 111/2 111/17 112/7 112/10 115/15 116/17 118/4 118/18 119/20 120/5 120/23 125/4 128/19 129/10 131/4 132/4 133/25</p>	<p>134/4 134/24</p> <p><b>timeline [1]</b> 114/8</p> <p><b>times [14]</b> 38/2 48/23 51/13 53/2 61/21 70/13 107/15 108/6 108/6 108/10 109/15 117/8 119/21 119/21</p> <p><b>tiny [1]</b> 114/18</p> <p><b>tired [2]</b> 43/1 125/23</p> <p><b>to [701]</b></p> <p><b>today [7]</b> 63/24 72/19 85/16 99/19 113/16 129/3 131/9</p> <p><b>together [8]</b> 8/14 46/14 54/2 90/11 98/14 108/5 121/18 125/4</p> <p><b>toilet [2]</b> 112/12 128/6</p> <p><b>told [63]</b> 3/17 5/12 8/18 9/12 9/18 13/1 15/3 17/10 23/10 24/4 29/7 31/9 31/15 31/16 33/25 34/15 35/16 35/20 36/9 37/2 38/22 42/7 42/19 51/3 59/4 63/22 71/24 72/2 78/12 78/16 80/16 80/23 81/1 83/5 85/7 85/22 86/1 87/20 88/10 88/13 89/6 89/7 89/9 89/10 90/23 91/4 91/21 92/7 94/17 94/21 101/23 110/18 110/21 116/12 116/15 117/10 121/11 122/1 122/7 123/5 125/23 125/24 126/2</p> <p><b>tomorrow [2]</b> 136/9 136/13</p> <p><b>Tone [4]</b> 112/17 112/19 126/7 126/12</p> <p><b>tongue [1]</b> 37/21</p> <p><b>tony [24]</b> 97/10 98/14 107/21 109/17 113/8 113/16 121/22 121/24 123/3 123/19 123/21 124/1 124/11 124/13 124/18 125/12 126/9 126/14 131/4 132/2 133/4 133/18 133/23 133/23</p> <p><b>Tony's [4]</b> 122/10 125/8 126/1 126/24</p> <p><b>too [5]</b> 46/25 47/25 60/23 68/17 90/18</p> <p><b>took [18]</b> 8/8 17/21 17/22 18/4 25/3 25/3 35/17 40/2 40/20 40/20 40/20 45/18 51/17 67/10 75/5 90/15 98/7 112/14</p> <p><b>top [7]</b> 24/19 71/6</p>	<p>86/10 101/10 109/12 109/13 110/7</p> <p><b>total [3]</b> 3/8 23/24 35/14</p> <p><b>touched [1]</b> 121/13</p> <p><b>tough [4]</b> 46/20 46/21 52/21 89/22</p> <p><b>tourniquet [1]</b> 8/12</p> <p><b>towards [6]</b> 48/11 82/18 110/11 117/17 124/10 135/13</p> <p><b>Tower [1]</b> 52/2</p> <p><b>trace [1]</b> 11/24</p> <p><b>track [1]</b> 21/19</p> <p><b>traction [2]</b> 3/10 3/11</p> <p><b>tragedy [5]</b> 60/2 60/2 61/2 63/20 63/20</p> <p><b>train [2]</b> 69/16 131/19</p> <p><b>trained [8]</b> 10/3 10/11 17/21 69/22 70/7 94/15 102/5 102/20</p> <p><b>training [5]</b> 8/1 61/10 69/14 70/1 70/12</p> <p><b>transcript [2]</b> 54/19 55/10</p> <p><b>transferring [1]</b> 16/16</p> <p><b>transfused [6]</b> 101/5 101/7 101/12 101/13 101/14 101/16</p> <p><b>transfusing [1]</b> 11/22</p> <p><b>transfusion [3]</b> 4/8 103/16 105/12</p> <p><b>transfusions [1]</b> 77/3</p> <p><b>transmission [1]</b> 34/16</p> <p><b>transpired [1]</b> 5/6</p> <p><b>trauma [1]</b> 44/25</p> <p><b>traumatised [1]</b> 45/10</p> <p><b>travel [1]</b> 89/21</p> <p><b>travelled [1]</b> 62/12</p> <p><b>treat [3]</b> 8/19 9/1 69/22</p> <p><b>treated [22]</b> 2/17 4/4 6/9 6/18 19/17 25/13 27/5 27/10 71/19 71/20 71/25 73/24 74/3 74/6 79/17 79/25 80/9 80/16 81/1 89/24 90/1 118/25</p> <p><b>treating [3]</b> 7/15 9/22 107/14</p> <p><b>treatment [70]</b> 2/5 2/18 3/25 4/2 4/3 9/2 9/17 11/11 12/15 14/13 16/8 18/14 19/24 20/11 20/14 26/17 28/7 28/8 28/10 30/10 30/17 31/10 33/4 38/23 41/5 42/4 42/10 42/13 42/13 42/16 42/17 42/20 50/24 54/5 57/17 66/2</p>	<p>66/5 66/18 66/22 67/12 70/25 79/20 81/7 81/19 84/13 88/14 89/21 93/8 98/23 99/8 99/14 102/7 102/10 103/1 103/7 104/18 104/20 107/24 108/7 108/16 109/18 122/17 123/19 123/22 125/12 125/21 126/2 129/10 129/15 130/10</p> <p><b>treatments [2]</b> 43/12 71/4</p> <p><b>trees [1]</b> 134/6</p> <p><b>TREL000071 [1]</b> 10/25</p> <p><b>TREL0000074 [6]</b> 11/2 15/22 18/9 19/7 23/19 25/7</p> <p><b>TREL0000110 [6]</b> 100/25 102/1 104/3 105/10 110/6 114/10</p> <p><b>TREL0000221 [4]</b> 21/3 22/17 24/17 55/24</p> <p><b>TREL0000239 [4]</b> 79/6 81/18 82/14 83/9</p> <p><b>TREL0000241 [3]</b> 73/13 74/16 76/23</p> <p><b>TREL0000242 [5]</b> 69/6 69/18 70/24 72/16 74/9</p> <p><b>Treloar [18]</b> 3/17 4/11 12/14 20/15 32/10 36/20 36/22 36/23 50/15 52/8 57/14 60/15 61/6 61/20 62/15 63/2 69/13 102/9</p> <p><b>Treloar's [82]</b> 2/6 2/16 3/1 3/8 3/25 4/2 4/14 6/8 6/19 10/22 11/8 22/2 22/18 23/19 24/6 24/21 26/3 26/25 27/6 28/7 28/10 32/2 36/16 56/23 59/24 61/19 63/19 66/25 67/1 67/9 67/14 67/15 68/22 69/1 69/9 70/13 72/13 73/14 73/23 74/24 74/25 75/10 75/12 76/6 76/24 77/25 78/3 78/12 78/17 78/21 79/3 80/23 81/4 82/16 83/7 83/11 85/7 85/9 85/22 86/1 86/8 88/20 89/6 93/4 93/6 97/16 98/3 98/5 98/8 98/17 98/21 98/23 100/4 100/15 100/16 100/21 102/18 102/23 102/25</p>	<p>107/16 107/21 110/4</p> <p><b>Treloars [2]</b> 24/13 100/1</p> <p><b>trespass [1]</b> 64/6</p> <p><b>tret [5]</b> 4/12 7/13 14/8 38/24 50/25</p> <p><b>trial [15]</b> 17/10 26/11 72/25 103/11 103/13 103/14 103/16 103/18 103/19 103/21 103/22 103/24 104/8 104/12 104/15</p> <p><b>trials [1]</b> 60/16</p> <p><b>tribute [2]</b> 61/4 96/13</p> <p><b>tried [4]</b> 48/8 51/5 90/23 122/16</p> <p><b>trip [4]</b> 8/17 20/17 53/14 67/5</p> <p><b>trouble [3]</b> 13/22 19/10 31/8</p> <p><b>Truly [1]</b> 76/12</p> <p><b>trust [7]</b> 31/8 44/24 47/4 47/6 47/9 47/12 127/4</p> <p><b>trusts [1]</b> 51/4</p> <p><b>truth [5]</b> 60/7 60/19 95/20 109/1 112/9</p> <p><b>Truthfully [1]</b> 110/23</p> <p><b>try [6]</b> 20/24 22/11 25/6 32/14 43/10 100/11</p> <p><b>trying [8]</b> 10/7 17/2 18/10 22/7 31/12 31/12 33/1 59/15</p> <p><b>tubes [1]</b> 133/21</p> <p><b>Tuesday [1]</b> 1/1</p> <p><b>tune [1]</b> 112/22</p> <p><b>turn [7]</b> 30/1 55/13 83/9 102/1 105/10 106/3 110/5</p> <p><b>turned [8]</b> 10/13 35/14 42/11 47/19 69/4 111/24 115/23 132/13</p> <p><b>twelve [1]</b> 25/13</p> <p><b>twice [3]</b> 42/18 119/5 119/10</p> <p><b>twist [1]</b> 8/6</p> <p><b>twizzling [1]</b> 19/5</p> <p><b>two [36]</b> 2/23 2/24 5/12 6/6 6/25 12/8 16/22 18/13 19/19 25/22 27/8 29/23 30/16 38/2 38/24 39/16 39/20 41/7 42/14 45/19 45/24 53/16 55/25 56/3 77/21 78/7 96/14 96/21 96/23 106/10 112/17 121/10 128/25 129/3 129/5 132/9</p> <p><b>Two o'clock [1]</b> 96/23</p> <p><b>two weeks [1]</b> 38/24</p>	<p><b>two years [5]</b> 30/16 39/16 39/20 41/7 42/14</p> <p><b>type [6]</b> 5/14 5/14 11/23 13/13 16/11 22/6</p> <p><b>typed [1]</b> 40/18</p> <p><b>types [4]</b> 5/12 6/6 22/3 56/4</p> <p><b>typical [1]</b> 131/16</p> <hr/> <p><b>U</b></p> <p><b>ultimately [1]</b> 119/13</p> <p><b>um [1]</b> 4/5</p> <p><b>unchanged [1]</b> 74/8</p> <p><b>unclear [1]</b> 31/25</p> <p><b>unconditional [1]</b> 62/13</p> <p><b>uncover [1]</b> 60/19</p> <p><b>undated [1]</b> 86/21</p> <p><b>under [5]</b> 1/16 8/16 27/2 65/17 104/10</p> <p><b>underneath [1]</b> 121/8</p> <p><b>understand [10]</b> 5/10 6/25 32/7 57/10 76/19 78/11 78/23 85/16 86/11 97/3</p> <p><b>understanding [3]</b> 72/11 116/5 124/3</p> <p><b>understood [3]</b> 14/4 14/23 81/15</p> <p><b>undertaken [4]</b> 82/25 83/6 114/20 114/25</p> <p><b>underwent [2]</b> 42/17 123/19</p> <p><b>unfortunately [2]</b> 16/8 58/25</p> <p><b>union [1]</b> 40/13</p> <p><b>unit [2]</b> 22/8 81/22</p> <p><b>unit-wise [1]</b> 22/8</p> <p><b>units [6]</b> 9/15 19/17 79/14 79/16 79/24 82/7</p> <p><b>unknowingly [1]</b> 62/17</p> <p><b>unless [2]</b> 12/5 129/16</p> <p><b>unpleasant [1]</b> 38/14</p> <p><b>unsuccessful [1]</b> 126/3</p> <p><b>untested [1]</b> 60/16</p> <p><b>until [14]</b> 3/24 14/6 25/1 27/8 33/16 40/22 72/18 99/17 100/1 104/25 105/16 113/9 129/11 136/16</p> <p><b>unwell [1]</b> 63/24</p> <p><b>up [83]</b> 2/22 4/7 5/3 5/9 7/7 7/11 7/12 9/6 9/10 10/3 10/13 10/14 13/6 14/6 14/7 14/7 17/21 18/2 18/5 20/18</p>
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<p><b>U</b></p> <p><b>up...</b> [63] 27/8 27/24 32/24 33/2 35/2 36/24 37/1 38/5 39/4 39/19 40/7 40/13 40/22 45/23 46/12 47/12 47/14 48/16 48/18 51/9 51/23 51/23 53/6 55/10 59/5 69/5 83/14 93/13 94/21 94/25 98/8 98/14 99/6 99/9 99/22 100/12 100/23 103/3 107/21 108/5 108/7 110/2 112/8 112/19 113/9 113/20 116/21 117/15 118/3 118/3 119/22 120/3 122/5 123/15 124/7 128/15 131/13 131/19 133/6 133/15 134/7 135/2 135/19 <b>upon</b> [1] 2/7 <b>upper</b> [1] 63/4 <b>upset</b> [2] 32/9 54/4 <b>upsetting</b> [1] 32/22 <b>upstairs</b> [1] 117/16 <b>urgent</b> [1] 44/11 <b>us</b> [103] 3/17 4/10 7/19 8/20 8/22 9/2 9/14 10/8 10/8 10/11 10/13 10/16 13/3 18/21 21/1 22/13 25/7 26/21 26/23 28/13 31/1 33/18 35/12 47/14 50/2 50/21 50/25 51/3 51/24 52/1 52/25 53/17 55/9 57/23 59/18 60/6 60/12 60/14 61/9 61/10 61/16 61/18 63/9 63/18 63/18 63/22 63/22 67/5 68/17 69/16 77/14 77/22 78/19 89/9 89/10 90/11 90/23 91/4 93/16 98/4 98/11 98/20 98/24 99/9 100/11 103/2 107/5 107/23 108/2 108/3 111/6 111/17 112/17 113/7 113/10 115/18 115/21 118/10 118/12 119/7 119/20 120/16 123/21 126/5 127/6 127/15 127/15 127/21 128/25 131/8 131/19 131/22 131/24 133/9 133/10 133/12 134/2 134/18 134/18 134/25 135/18 135/20 135/25 <b>use</b> [12] 9/12 9/14</p>	<p>9/16 12/8 15/21 20/2 20/4 27/18 55/7 72/5 109/5 112/1 <b>used</b> [29] 14/6 18/20 18/23 20/3 20/4 57/23 58/6 65/20 66/11 67/14 68/17 77/9 77/16 89/22 101/15 103/3 103/5 103/6 104/24 109/2 109/2 109/21 109/25 109/25 112/25 113/1 113/17 117/4 119/23 <b>useful</b> [1] 61/25 <b>using</b> [2] 59/16 108/24 <b>usually</b> [1] 111/8</p> <p><b>V</b></p> <p><b>vague</b> [2] 48/3 99/14 <b>Vaguely</b> [1] 104/23 <b>value</b> [1] 56/17 <b>vandalised</b> [1] 50/5 <b>various</b> [4] 56/21 81/24 82/9 83/16 <b>vary</b> [1] 9/15 <b>vast</b> [1] 87/14 <b>vein</b> [1] 8/7 <b>Verde</b> [2] 45/13 62/25 <b>very</b> [82] 2/1 2/9 8/1 8/2 8/23 10/13 13/5 13/5 16/22 17/22 20/8 20/20 24/5 26/21 27/13 28/3 31/25 32/8 32/8 35/12 35/13 37/4 37/10 38/12 38/20 38/22 39/6 39/9 40/2 40/2 40/17 41/10 41/16 41/16 41/17 44/16 44/24 45/1 45/9 48/12 48/17 52/5 53/13 53/13 53/21 57/8 57/11 57/20 57/21 59/2 63/10 64/1 64/1 64/3 64/22 67/25 69/25 74/1 75/22 77/12 87/15 91/11 91/20 94/20 95/1 96/17 97/18 102/11 104/6 109/1 110/3 119/9 121/3 122/12 125/22 127/25 128/22 132/17 134/9 136/1 136/2 136/13 <b>view</b> [1] 11/17 <b>VIII</b> [29] 4/16 8/20 11/23 15/18 19/3 23/6 25/17 27/10 32/1 32/4 58/7 58/15 59/11 59/13 60/1 60/17 61/11 61/17 74/3 74/4 88/13 100/5 100/15</p>	<p>103/16 103/21 103/22 103/24 105/23 113/20 <b>village</b> [1] 50/17 <b>violent</b> [1] 119/22 <b>viral</b> [2] 4/20 41/20 <b>virtually</b> [3] 91/21 119/3 127/22 <b>virus</b> [3] 43/9 87/1 87/12 <b>viruses</b> [1] 33/22 <b>visit</b> [2] 61/21 67/15 <b>visited</b> [1] 68/20 <b>visits</b> [2] 61/15 68/3 <b>voice</b> [1] 132/10</p> <p><b>W</b></p> <p><b>wait</b> [1] 55/12 <b>waited</b> [2] 60/23 130/8 <b>waiting</b> [3] 14/11 44/10 44/11 <b>waiver</b> [2] 33/20 92/13 <b>wake</b> [2] 103/3 110/2 <b>walk</b> [8] 7/7 44/15 45/23 99/1 108/7 117/21 130/8 131/25 <b>walked</b> [6] 52/12 52/16 58/11 111/17 111/20 111/21 <b>walking</b> [3] 63/2 119/3 127/23 <b>wall</b> [1] 9/11 <b>Wallingford</b> [1] 18/24 <b>walnut</b> [1] 59/17 <b>want</b> [36] 8/22 13/21 23/8 30/1 35/21 38/4 42/4 51/15 52/25 55/10 58/24 59/18 90/9 91/18 91/20 95/6 100/11 100/21 104/25 105/3 107/4 107/9 109/4 109/14 117/3 117/3 117/16 117/18 118/2 120/15 121/22 127/8 131/3 132/22 132/23 135/15 <b>wanted</b> [9] 10/8 32/7 50/13 52/19 57/9 86/23 95/20 106/25 118/3 <b>wants</b> [1] 93/14 <b>ward</b> [1] 14/9 <b>warmth</b> [1] 57/24 <b>warning</b> [2] 4/18 4/19 <b>wary</b> [1] 18/1 <b>was</b> [524] <b>wasn't</b> [12] 9/6 13/9 23/14 47/25 49/8 49/9 50/19 57/21 97/18 97/19 119/22 135/10 <b>Wassef</b> [8] 6/20 6/23 7/20 23/20 23/22</p>	<p>88/19 111/13 114/11 <b>Wassef's</b> [1] 99/11 <b>watch</b> [1] 75/22 <b>watched</b> [1] 49/15 <b>watching</b> [1] 1/18 <b>way</b> [15] 3/21 54/2 57/2 71/4 71/15 95/14 103/4 107/11 113/2 116/4 119/6 123/15 125/25 128/4 128/18 <b>ways</b> [4] 32/6 62/2 77/21 136/3 <b>we</b> [409] <b>we'd</b> [10] 4/12 7/11 15/10 43/10 47/12 88/4 121/3 123/14 131/19 133/11 <b>we'll</b> [17] 3/24 30/3 46/13 46/14 55/9 64/15 64/17 64/18 67/12 69/7 73/12 78/10 83/14 96/19 99/15 105/10 131/14 <b>we're</b> [14] 13/7 26/5 46/21 47/1 51/15 58/12 68/22 68/25 80/6 106/4 118/15 121/3 128/5 128/9 <b>we've</b> [33] 5/11 9/23 18/7 21/14 22/19 24/15 24/22 46/24 49/12 49/15 52/21 52/22 53/6 56/19 57/3 67/7 71/3 73/2 79/20 82/6 82/15 86/9 93/16 93/23 101/1 104/10 105/11 119/2 128/24 128/24 131/11 131/11 133/19 <b>weak</b> [1] 41/17 <b>wear</b> [1] 44/16 <b>wedding</b> [2] 91/9 93/21 <b>week</b> [7] 30/13 40/13 44/18 54/1 103/20 119/5 119/5 <b>weekend</b> [5] 53/15 53/19 68/3 127/18 127/25 <b>weekends</b> [7] 67/16 67/16 68/11 127/4 127/6 127/7 128/20 <b>weekly</b> [1] 40/10 <b>weeks</b> [7] 3/10 3/11 3/13 16/9 38/24 85/3 85/5 <b>weigh</b> [1] 70/20 <b>weighed</b> [1] 9/9 <b>weight</b> [2] 40/9 61/16 <b>weird</b> [2] 125/3 125/3 <b>welfare</b> [1] 40/7 <b>well</b> [74] 1/14 4/5 4/13</p>	<p>7/4 7/6 13/3 15/12 17/10 20/5 20/20 22/4 24/12 27/7 30/11 31/15 31/23 32/14 33/1 33/14 35/3 37/6 39/22 39/23 40/11 41/23 42/5 42/6 42/21 43/17 43/25 44/6 44/23 44/24 47/12 51/19 59/5 63/11 64/20 64/22 67/2 70/12 71/19 73/12 75/20 77/8 77/18 78/18 81/10 81/16 88/4 88/11 88/11 90/12 90/20 91/3 91/7 92/17 93/21 93/22 94/14 96/21 102/7 102/11 105/12 109/19 117/19 120/7 121/1 121/5 132/9 133/10 135/16 135/25 136/13 <b>well-known</b> [1] 117/19 <b>went</b> [68] 2/6 2/8 2/16 2/22 3/7 3/18 5/3 10/16 13/10 13/14 19/1 20/8 20/17 30/11 30/23 31/5 32/21 38/10 40/6 40/18 43/3 43/11 45/13 46/16 47/22 48/15 51/9 52/13 53/14 54/2 54/6 58/9 59/9 66/24 67/1 67/9 67/10 68/11 70/14 88/5 91/3 92/18 95/15 97/13 97/22 98/6 98/8 98/14 100/1 100/15 100/16 102/8 112/10 115/24 117/2 118/9 118/9 119/16 122/4 122/25 123/8 123/14 124/22 127/16 127/17 131/19 132/3 134/6 <b>were</b> [193] <b>weren't</b> [9] 4/6 12/22 15/16 32/16 72/14 78/20 86/2 94/17 118/1 <b>what</b> [96] 4/1 4/3 4/22 5/5 9/2 9/5 9/17 14/18 15/9 22/8 22/16 23/10 24/3 27/5 27/11 28/4 29/24 30/11 30/25 31/13 31/19 33/16 33/24 34/11 34/18 38/1 39/4 39/16 42/19 43/14 45/15 46/19 46/24 47/10 48/3 48/7 48/18 48/23 49/3 50/14 52/18 53/22</p>	<p>59/23 60/19 63/23 67/17 68/6 68/16 70/11 70/17 71/3 73/4 76/12 77/10 87/18 88/9 92/7 93/2 94/14 94/16 98/20 99/8 99/9 101/1 101/11 102/25 103/2 107/3 107/16 108/1 108/8 108/12 108/19 109/25 111/6 112/5 112/14 112/24 115/18 116/25 116/25 117/13 117/14 119/25 120/5 120/16 122/10 123/21 125/20 127/6 127/23 129/14 131/7 131/8 133/1 134/12 <b>what's</b> [11] 5/7 30/8 33/12 36/19 40/9 108/1 109/16 116/20 123/5 123/16 130/14 <b>whatever</b> [3] 26/11 98/6 109/11 <b>whatsoever</b> [3] 70/1 72/13 93/10 <b>wheelchairs</b> [1] 113/11 <b>when</b> [104] 2/2 2/9 2/13 2/13 2/22 3/15 4/5 5/9 6/1 6/10 7/21 7/21 9/1 11/22 12/12 13/14 14/13 15/7 16/21 18/10 20/17 25/3 26/5 28/17 30/8 31/16 32/16 32/20 34/23 36/23 36/25 37/22 38/19 41/14 44/5 45/5 45/22 46/12 47/12 47/16 48/15 49/20 51/8 51/11 51/17 55/6 57/19 61/1 61/9 61/10 61/10 62/1 63/22 63/24 63/24 65/21 66/9 66/14 66/18 67/6 68/11 68/20 69/22 70/13 72/14 73/10 81/25 83/3 89/19 90/3 90/5 90/11 91/17 91/21 92/1 93/20 94/9 95/12 98/8 100/4 100/14 102/18 103/1 103/1 104/20 105/24 108/23 109/9 110/24 110/25 113/8 113/14 114/17 114/23 115/19 118/23 125/12 126/14 131/1 133/9 133/16 134/13 135/10 135/22 <b>where</b> [23] 4/3 4/9 7/15 17/16 28/20 31/4 33/17 37/12 42/8</p>
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<p><b>W</b></p> <p><b>where... [14]</b> 52/14 54/5 59/15 62/4 99/2 99/18 110/9 111/18 113/1 118/4 118/5 119/23 120/12 123/10</p> <p><b>Where's [1]</b> 117/15</p> <p><b>whether [13]</b> 2/17 12/3 16/16 19/22 24/15 26/2 27/16 29/12 29/16 57/1 84/17 89/4 104/21</p> <p><b>which [64]</b> 2/25 3/4 3/13 4/11 6/12 9/16 9/19 9/21 12/18 12/20 18/18 19/18 20/3 21/1 21/6 22/2 24/14 25/14 29/5 29/6 29/20 32/24 33/20 36/14 38/24 39/7 39/9 39/16 41/10 41/10 44/1 46/12 48/19 53/2 56/16 56/17 56/18 57/18 60/1 63/7 63/18 64/8 65/20 66/1 66/24 67/5 69/16 69/19 70/20 71/22 72/17 82/4 87/11 94/22 97/24 101/21 103/19 105/23 106/1 106/11 111/18 113/14 113/15 116/9</p> <p><b>while [4]</b> 18/17 43/1 78/11 129/21</p> <p><b>whilst [3]</b> 20/15 31/11 49/15</p> <p><b>who [46]</b> 1/19 10/18 16/10 16/15 24/12 33/14 37/8 43/4 45/14 46/7 50/4 50/23 52/10 53/16 53/17 54/8 55/8 55/13 59/6 59/25 60/4 60/6 60/13 61/3 61/6 61/20 62/12 62/15 62/16 62/19 63/1 63/2 63/3 63/8 64/10 69/8 69/12 74/3 87/14 94/11 103/13 107/14 111/20 111/21 117/20 117/23</p> <p><b>whoever [1]</b> 6/13</p> <p><b>whole [8]</b> 10/7 12/17 21/18 94/23 95/10 95/15 105/20 105/22</p> <p><b>whose [1]</b> 76/5</p> <p><b>why [17]</b> 22/9 32/7 36/21 39/19 40/6 42/6 51/18 57/10 59/5 81/10 88/25 117/2 118/7 126/23 129/3 129/4 136/5</p> <p><b>widowed [1]</b> 54/7</p>	<p><b>wife [13]</b> 46/10 66/4 66/21 71/24 72/12 72/22 74/14 76/7 76/20 93/20 94/14 120/8 120/12</p> <p><b>wife's [1]</b> 120/19</p> <p><b>will [24]</b> 1/20 6/11 11/23 24/13 25/20 40/12 59/7 63/18 65/6 77/14 77/23 83/2 92/17 99/3 99/4 103/18 103/19 103/20 114/22 126/12 126/13 133/23 136/9 136/12</p> <p><b>window [1]</b> 60/5</p> <p><b>windows [2]</b> 49/5 50/7</p> <p><b>Windsor [1]</b> 54/10</p> <p><b>wing [1]</b> 70/18</p> <p><b>winner [1]</b> 33/5</p> <p><b>wise [1]</b> 22/8</p> <p><b>wish [2]</b> 55/16 60/12</p> <p><b>with [206]</b></p> <p><b>with it [4]</b> 12/6 38/5 42/15 122/11</p> <p><b>within [9]</b> 7/3 25/12 32/23 35/6 44/12 49/21 60/2 60/5 63/20</p> <p><b>without [10]</b> 26/15 26/15 45/9 49/16 50/18 52/4 60/17 60/18 66/14 87/17</p> <p><b>WITN [1]</b> 28/18</p> <p><b>WITN1800002 [1]</b> 28/14</p> <p><b>WITN1800002 [1]</b> 28/20</p> <p><b>witness [7]</b> 28/13 64/7 64/9 85/15 89/10 97/2 136/10</p> <p><b>witnessed [1]</b> 58/5</p> <p><b>witnesses [4]</b> 9/23 95/7 96/1 105/12</p> <p><b>Witney [1]</b> 52/14</p> <p><b>woman [1]</b> 50/8</p> <p><b>Won [1]</b> 61/12</p> <p><b>won't [6]</b> 6/14 58/7 64/13 64/20 71/18 131/25</p> <p><b>wonder [2]</b> 2/15 16/16</p> <p><b>wondered [1]</b> 63/15</p> <p><b>word [4]</b> 104/5 108/22 109/4 110/11</p> <p><b>wording [2]</b> 77/12 88/25</p> <p><b>words [2]</b> 55/2 57/14</p> <p><b>work [9]</b> 28/3 30/14 31/3 31/17 32/24 40/6 40/21 61/8 63/6</p> <p><b>worked [3]</b> 120/2 124/23 124/25</p> <p><b>worker [1]</b> 45/14</p> <p><b>working [6]</b> 26/18</p>	<p>44/23 89/11 123/24 126/9 126/22</p> <p><b>works [1]</b> 122/19</p> <p><b>world [4]</b> 45/18 58/24 89/17 132/20</p> <p><b>worried [5]</b> 5/10 14/25 116/6 116/7 116/9</p> <p><b>worry [5]</b> 5/12 5/15 46/13 56/2 68/9</p> <p><b>worrying [1]</b> 38/5</p> <p><b>wise [40]</b> 32/5 40/5 92/8 130/19</p> <p><b>worst [1]</b> 133/2</p> <p><b>worth [1]</b> 15/13</p> <p><b>would [100]</b> 1/22 3/21 4/3 4/7 4/8 4/9 7/4 8/9 8/11 8/11 9/2 9/6 9/8 9/9 9/10 9/14 9/16 9/17 9/18 9/21 10/3 10/6 12/2 13/13 14/4 14/8 14/12 14/16 14/18 14/24 16/17 18/21 20/4 22/14 22/16 23/5 25/22 26/16 26/17 27/22 28/2 30/12 30/19 31/8 32/2 34/1 35/12 35/16 35/17 37/18 39/19 41/9 48/3 48/10 55/16 55/19 56/20 57/12 58/6 59/11 59/18 61/24 62/14 62/22 63/19 63/25 64/7 66/4 68/11 69/16 69/21 70/11 70/15 77/21 78/18 81/14 86/4 86/7 87/3 87/3 91/23 92/8 92/23 94/13 94/21 94/25 96/12 97/4 97/4 99/6 108/5 108/5 108/7 113/1 119/7 122/14 122/14 130/6 134/12 134/16</p> <p><b>wouldn't [12]</b> 28/1 37/2 48/4 57/16 57/17 91/6 91/25 118/17 122/13 122/13 122/20 122/21</p> <p><b>wrapped [1]</b> 119/4</p> <p><b>write [2]</b> 30/19 111/24</p> <p><b>writing [3]</b> 16/20 16/22 76/10</p> <p><b>written [2]</b> 50/6 88/20</p> <p><b>wrong [8]</b> 10/25 40/9 47/23 89/4 114/5 114/6 117/6 121/1</p> <p><b>wrote [1]</b> 49/2</p> <p><b>Y</b></p> <p><b>yards [1]</b> 52/13</p> <p><b>yeah [150]</b></p> <p><b>year [24]</b> 3/9 3/14 6/1</p>	<p>32/22 44/6 44/7 44/23 45/12 48/5 48/6 57/22 62/8 62/24 77/17 83/21 98/7 98/14 102/7 117/2 117/7 117/17 117/17 132/19 132/19</p> <p><b>years [48]</b> 4/15 6/24 12/12 14/14 16/11 27/6 30/16 31/6 32/11 35/10 35/15 35/17 35/17 35/23 37/6 37/17 39/16 39/20 41/7 42/14 43/10 49/1 49/13 49/20 50/4 51/2 51/8 51/21 52/7 52/18 54/8 57/25 60/23 61/13 63/10 66/18 69/24 78/7 91/7 91/14 93/1 98/22 99/1 109/8 121/9 122/14 130/8 133/12</p> <p><b>yellow [6]</b> 5/4 5/4 81/11 81/14 94/11 119/2</p> <p><b>yes [101]</b> 1/5 1/7 1/10 2/4 2/8 3/3 7/4 7/8 7/17 9/5 11/5 15/2 15/2 15/2 15/23 16/3 21/8 21/12 24/8 28/6 28/15 33/11 36/2 39/3 41/3 41/6 42/18 43/17 49/14 50/2 53/3 53/5 53/11 53/13 56/15 57/8 64/13 65/5 65/12 65/14 65/14 65/25 66/3 66/6 66/6 66/10 68/8 68/13 69/2 70/6 70/10 70/10 85/6 85/18 89/12 90/2 91/1 92/14 94/19 95/1 96/22 97/9 97/12 97/17 97/21 97/23 98/16 98/19 98/24 107/22 107/25 109/14 109/21 111/3 111/23 115/10 116/23 118/21 118/21 119/19 119/19 120/10 121/20 121/21 121/21 124/12 127/11 128/18 128/21 128/23 129/7 129/9 130/9 130/11 130/23 130/23 130/23 130/25 131/7 131/10 135/14</p> <p><b>yesterday [7]</b> 1/17 24/12 53/23 64/10 103/5 135/15 135/22</p> <p><b>yet [3]</b> 39/23 51/19 122/17</p> <p><b>you [620]</b></p> <p><b>you were [1]</b> 7/15</p>	<p><b>you'd [25]</b> 1/3 6/24 7/9 7/9 9/3 10/2 10/3 14/23 37/15 41/15 63/15 65/3 67/3 68/14 68/14 72/7 72/17 87/20 95/2 98/3 101/21 106/1 112/16 125/12 134/10</p> <p><b>you'll [8]</b> 57/10 69/25 84/4 88/25 117/4 117/5 121/5 131/24</p> <p><b>you're [32]</b> 1/11 1/15 1/19 12/24 12/25 13/1 14/20 18/7 18/10 18/14 21/17 24/5 28/24 40/8 54/20 59/22 85/6 85/25 99/22 103/12 106/13 107/17 109/19 109/19 116/24 118/10 119/7 128/8 128/17 131/7 132/11 135/5</p> <p><b>you've [50]</b> 5/14 6/4 6/18 6/19 20/2 23/7 28/12 34/6 34/21 35/23 36/9 39/1 41/19 43/5 43/21 44/6 44/7 44/9 47/4 47/8 49/10 49/18 50/14 51/5 56/3 56/5 63/20 63/23 87/24 89/16 93/16 96/13 98/17 99/8 104/17 110/25 111/25 116/19 119/12 119/18 120/8 120/11 121/18 124/5 124/6 128/20 129/25 130/21 132/10 133/20</p> <p><b>young [11]</b> 2/10 8/3 52/9 62/16 100/14 100/14 107/20 108/3 113/17 131/18 131/22</p> <p><b>younger [6]</b> 14/14 97/10 98/22 99/1 122/4 132/3</p> <p><b>your [192]</b></p> <p><b>yours [1]</b> 53/4</p> <p><b>yourself [3]</b> 7/16 8/19 9/22</p> <p><b>Z</b></p> <p><b>zeros [1]</b> 28/20</p> <p><b>zone [1]</b> 135/16</p> <p><b>zoom [2]</b> 53/12 84/2</p>
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