

**Witness name: Charles Dowden**

**Statement No: WITN1867001**

**Exhibits: WITN1867002-05**

**Dated: 18 February 2019**

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN STATEMENT OF CHARLES DOWDEN**

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**I, Charles Dowden, will say as follows:-**

#### **Section 1: Introduction**

1. My name is Charles Dowden. My date of birth and address are known to the inquiry.
2. I have been a widower for ten years. I am making this statement as an affected person. My late wife, Gillian Dowden (d.o.b. GRO-C 1947), passed away on 1 June 2008 from a hepatocellular carcinoma caused by her underlying Hepatitis C ("HCV"). Gillian, known as "Gilly", was infected with HCV in May 1982 as a result of one or more blood transfusions that she was given while she was being treated in Southampton General Hospital following an accident.
2. I am now newly married. I am a director of a limited company that produces military recognition models. I am also a district councillor on North Dorset District Council and the Vice-Chairman of the North Dorset District Council Planning Committee.
3. I make this statement in response to the questions set out in a "Rule 9 Request" letter dated 13 November 2018 sent to me by the Inquiry care of my solicitors, Leigh Day. Those question headings are set out below, followed by

my responses to them. Save where I state otherwise, the facts and matters set out below are within my own knowledge and are true. Where I refer to matters that are not within my own knowledge, they are derived from the sources stated and are true to the best of my knowledge and belief.

4. I append some key supporting documents to this statement and I state their corresponding Exhibit Numbers in the body of this statement.

## **Section 2: How infected**

5. Gilly was infected with HCV before we met, although she explained to me in detail the exact events which led to her admission to Southampton General Hospital for treatment, during which she was given multiple blood transfusions and consequently contracted HCV.
6. Gilly was admitted to hospital on 15 May 1982 having fallen down some stairs at an event she had been attending. Gilly's then husband was a director of a company called GRO-C which ran hotels and bars throughout the south of England. That night she had been attending the grand opening event of the Railway Arms in Eastleigh, Hampshire. She had been in the toilets in the top right-hand corner of the building. I understand that these toilets fed off a T-shaped corridor and that the steps were indented into the floor of the corridor. Gilly came out of the toilets and missed her step and tumbled down the stairs. She completely shattered her femur.
7. She was admitted to the Accident and Emergency Department of Southampton General Hospital on 15 May 1982 and proceeded to have emergency surgery under the care of a consultant orthopaedic surgeon, Mr J A W Fitzgerald. Mr Fitzgerald's clinical notes, which are in Gilly's medical records, record that she sustained a long spiral sub trochanteric fracture to her left femur, and that this had been anatomically reduced and fixed with an inter fragmentary screw, pin and 12-hole plate.

8. I understand that Gilly had suffered a large amount of blood loss. As a result, she was given a blood transfusion on 15 May 1982. From Gilly's Blood Transfusion Record Card, which I exhibit to this statement as **WITN1867002**, it appears that Gilly may have been given more than one blood transfusion. The bag numbers for the transfusion on 15 May 1982 were as follows: 038207; 041137; 041142; 46859; 38241 and 39629. Gilly was in hospital for approximately six to eight weeks I believe. Gilly was given at least one more blood transfusion approximately a week later. Her blood transfusion record shows that Gilly had more transfusions between 21 to 22 May 1982. The bag numbers were as follows: 46179; 46559; 48004.
  
9. These blood transfusions are the only blood transfusions that Gilly ever had. When Gilly was eventually diagnosed with HCV in April 2003, her consultant gastroenterologist, Dr Chris Hovell, stated explicitly to us that his view was that Gilly's HCV was caused by the blood transfusions that she received in 1982. A letter dated 9 April 2003 sent to Gilly's then GP, diagnosing Gilly with HCV, states, "*Talking to her today there is no history of iv drugs but she did have a blood transfusion after a road traffic accident in 1982 and I suspect this is the likely source*" (**WITN1867003**). Another letter dated 24 October 2005 from Dr Hovell (**WITN1867004**) records that, "*she is thought to have gained [HCV] from a blood transfusion in the past*". I can confirm that the reference to Gilly having had a road traffic accident in 1982 is wrong and the circumstances of her accident are as stated above.
  
10. In terms of the information or advice about the risks of being exposed to infection that was provided to Gilly before she was given blood, I can confirm that no information or advice was given. It is possible that Gilly was not in a fit state to receive information or advice. We had discussions after her HCV diagnosis about what she would have done had she been given advice or information about the risks of being infected by the blood transfusion. We considered that, although she needed blood, and she needed it quickly, it should never be the responsibility of the end user of blood to be able to ascertain beyond any reasonable knowledge base what is dangerous and

what is not. Any relevant authority that knew risks existed should have screened the blood for infections. It is my view that the authorities knew that there was some kind of infection in the blood being used by the NHS, which was not Hepatitis A or Hepatitis B. However, nobody screened for it. I believe that is criminal. I cannot blame Gilly's doctor or nurses, nor Gilly as the end user. But somebody did know about the risks of HCV infection, or something like it, and a conscious decision was taken not to screen the blood for it until over 4000 people had been infected. This is absolutely not right.

11. By way of analogy, when I first started work as an engineer, PCB oils (polychlorinated biphenyls) were commonly used in the work environment. They are now known to cause a number of health effects and elicit a number of toxic responses in humans. However, we were not protected against them as nobody knew they were dangerous. By the 1990s, it was commonly known that they were dangerous. Those affected before that point in time could not sue anybody because nobody had known of the dangers. However, this was very much not the case with infected blood. Those in authority *did* know that there were risks and dangers associated with blood and blood products, and they were knowingly used in the NHS.
12. Gilly was infected only with HCV.
13. I now to turn to the circumstances in which Gilly discovered in April 2003 that she had HCV.
14. In 1999, Gilly was suspended from her work as a medical secretary at Southampton General Hospital. I cannot now remember the exact quoted reasons but, in essence, it had been assumed by her employers that she had been continually drunk at work. This was not the case.
15. In 2000 after Gilly was suspended from work, we moved from Hampshire to Dorset. It was our intention that Gilly would take a year off work to get our new house up and running, before starting to seek work at end of 2000. She also

needed to get over the shock of being suspended, as she never had been suspended or anything like it in the past.

16. It was during the summer of 2000 that things started to go awry. Gilly had not been right or focused for some time. For example, a couple of times she had got lost while walking around the village. This was particularly bizarre because Gilly was born only a mile away and it was pretty much her home village.
17. Over 2000, her behaviour got more and more bizarre. She also collapsed a couple of times. I recall that one time she got taken to hospital. Towards the end of 2000, Gilly was seen on a couple of occasions by Dr Philip Watts, who was our GP in the village at the time. Although by this point it had been presumed that Gilly was an alcoholic and this was the reason for her bizarre behaviour, Dr Watts looked through her medical records (which included blood alcohol test results) and considered that something was not right. He compared the number of incidences that her test results showed alcohol in her blood to the symptoms she was actually experiencing. He did not believe that Gilly was an alcoholic or that alcoholism was causing her symptoms, but that there was something else wrong with her. However, he said that he was not sure what was wrong and that he would like to conduct more tests.
18. At some point after this, Dr Watts was suspended. His surgery in the village was left unattended or closed and we transferred to the Stalbridge Surgery.
19. At some point between 2002 and April 2003, Gilly had a major collapse while I was at work and was admitted to hospital. Her GP, Dr Deborah Compertz at the Surgery in Stalbridge, diagnosed her with alcoholism. This was a conclusion drawn from Gilly's medical records and no actual diagnostic tests were carried out.
20. I went to visit Gilly in Dorset County Hospital where she had been admitted. While she was an inpatient, she was being treated as if her problem was alcoholism and was continually being moved from ward to ward. One evening,

I went to visit her in hospital and I realised that she had moved wards yet again. When I questioned this with a nurse, she responded to me, *“well, what do you expect from an alcoholic? It’s all self-inflicted”*.

21. The door then opened and in came Dr Christopher Hovell, a consultant gastroenterologist who eventually became Gilly’s treating clinician. In our discussions with him, he reaffirmed what Dr Watts had said – that there was no apparent reason for Gilly’s supposed alcoholism. I confirmed that this chimed with my own experience. Over the years that I had been told Gilly was an alcoholic, I had turned the house upside down looking for hidden alcohol, but never found anything. Furthermore, by this point, Gilly had been in hospital for 2-3 days and the nurse was saying that she was still showing signs of being drunk. This was impossible as there was no way Gilly could have had access to alcohol. I got Dr Hovell to promise to read Gilly’s notes, which he did.
22. The following morning, I phoned Dr Hovell, and he said that he agreed with me. He told me that there was one more test that he could carry out, a PCR test, to aid in a diagnosis.
23. He carried out that test and called me the following day to tell me that Gilly had HCV. At this point, everything began to make sense. There had been no explanation for Gilly’s presumed alcoholic symptoms, such as the fogginess, cirrhosis of the liver, reddening of palms and rosacea around the nose (see below for greater detail on Gilly’s symptoms in **“Section 5: Impact”**). This diagnosis was confirmed in a clinic on 8 April 2003 (**WITN1867003**).
24. In terms of the information that was provided about Gilly’s infection, Dr Hovell could not give us an awful lot of information at that stage in all fairness. He was, however, as honest as he possibly could be. He did not know much about HCV but he did give us some information about where we could research HCV, including a private medical website that he gave me a password to get into. Our experience was that there was not much information

anywhere at that time about HCV. There were about six pages of information from Southampton University Hospitals Trust but that was about it.

25. After this Gilly had a succession of tests. A CAT scan proved that she had cirrhosis and I believe that either that first or a second scan showed that she had tumours within her liver. Apart from that, after that point there seemed to be a lot of talk and not much else.
26. In terms of whether Gilly was given adequate information to understand and manage the infection, I would have to say no. This is because she had a burning desire to find out more about her condition and how it was going to affect her, but the information simply was not there. Further, there were no help groups or support groups at the time. As I stated above, Dr Hovell gave us a password for a private medical website but there was barely anything on that website either about HCV. It was almost like it did not exist. I do not mean to imply by the above that Dr Hovell could have done more; I expect he probably could not.
27. I consider that information should have been provided to Gilly earlier about her HCV. The relevant authorities knew that this virus, HCV, existed and had nearly 20 years to conduct more research and identify appropriate treatments but they did nothing. Instead, it was decided that *"they will all be dead by the time this comes out"*.
28. I also have no doubt that Gilly should have been diagnosed earlier and that her diagnosis of HCV was delayed specifically because she was misdiagnosed by multiple medical professionals as having alcoholism.
29. In particular, I believe that one of Gilly's GPs, Dr [GRO-D], who was based in Portswood, Southampton, is particularly to blame for this misdiagnosis and the delay in diagnosing Gilly's HCV. Gilly and I had met in May 1986 and moved in together in October 1986. Her GP at the time was Dr [GRO-D] At this point Gilly was concerned enough about her GP's fixation on

her supposed alcoholism to ask me to come along with her to an appointment. I recall that Dr [GRO-D]'s mother had been an alcoholic and had died from alcohol poisoning. Therefore, when Gilly presented with her symptoms – things like confusion, dizziness, an inability to concentrate, fatigue, rosacea around her nose and neck and reddening of the palms (classically symptoms of HCV as far as I am aware)– he immediately diagnosed her condition as alcoholism. It was as if from this point on a target had been set and after this everything had to point towards alcohol. It was always a question of how much she had been drinking, where she had been drinking, and so on. Dr [GRO-D] even convinced me that Gilly was an alcoholic, even though I had not seen it with my own eyes. My perspective was that the very worst of our drinking was that we had a few too many drinks at parties from time to time; in other words what would be considered a very normal level of drinking. I even had phone calls from Dr [GRO-D] asking me whether Gilly was drinking orange juice, warning me that alcoholics can be very crafty. This led me on occasion to turn the entire kitchen upside down to try and find something. Rarely I would find the odd tin or empty bottle but nothing that suggested Gilly was hiding alcohol. Yet Dr [GRO-D] told me that Gilly was likely outwitting me. I even found myself checking the rubbish for alcohol.

30. This occurred all the way through from November 1986 to when we moved away from Southampton in 2000.
31. After this point, it simply became easier to say to medical professionals that Gilly had now stopped drinking rather than protesting that she had never been an alcoholic in the first place. I believe that this explains how multiple references were thereafter made in Gilly's medical records to her drinking or being an alcoholic.
32. Dr [GRO-D] was so persistent in his line that Gilly was an alcoholic that he had reported it to her employers, Southampton General Hospital. She therefore started having random blood alcohol tests at work. However, apart from once



or twice when we had been out for drinks as a couple, these random tests never showed alcohol in Gilly's blood.

33. I have to express my shock and upset that, despite this, nobody ever thought to check for anything else or to work out what really was causing Gilly's symptoms. Instead, everyone carried on with a fixed notion that she was an alcoholic. I include in this group not only Dr [GRO-D] but Gilly's employers. She worked as a medical secretary at Southampton General Hospital. Whoever took the random blood tests and interpreted them must surely have looked at the tests and thought that something was odd given how infrequently they showed any alcohol in her blood.
34. I must say that overall Dr Hovell was brilliant in the way he managed Gilly's diagnosis of HCV. He went out of his way to warn us that treatment in other hospitals might be tricky because many people viewed HCV, along with HIV, as being highly contagious and that, as a result, Gilly might not get the treatment she deserved. We therefore stayed with the Dorset County Hospital.
35. After her diagnosis Dr Hovell did everything he could for us, filling out all possible forms and so on, including those for the Department for Work and Pensions ("DWP").

### **Section 3 – Other infections**

36. I do not believe that Gilly received any other infections as a result of being given infected blood.

### **Section 4 – Consent**

37. I believe that Gilly did not give her informed consent for the blood transfusion in 1982 that was the cause of her infection. She was not made aware at any point of the material risks of the transfusion or that the blood might be

infected, including with HCV. She certainly would have attached great significance to the risks if she had known of them, I believe. She was not informed at any point if there was any reasonable alternative course of treatment, if indeed there was one.

38. I do not know if Gilly was treated or tested for the purposes of research without her consent.

### **Section 5 – Impact**

39. I now turn to the impact that being infected with HCV had on Gilly, before discussing the impact that it had on me and our family life.
40. Realistically, Gilly's HCV symptoms started with confusion and dizziness. I can recall the sheer physical grind of it all on a daily basis. Gilly had a fairly stressful job as a medical secretary. I started to notice quickly after we had settled down together that in the evenings Gilly would come home and collapse, so exhausted that she would sleep for an hour or more. At weekends she was so tired that she would literally collapse. This continued from about 1987 to 1988 onwards. It did restrict us greatly in terms of what we could do in our private time.
41. After Gilly had been suspended from work in the late 1990s, her symptoms, changed. Her tiredness remained but she was increasingly dizzy and/or confused. She began to lose track of what she was doing halfway through an activity, and found it difficult to carry out and enjoy her hobbies. In the late 1990s I would occasionally catch her standing gazing out from the kitchen windows. Now I understand that this was likely because of the poisons building up in her blood as much as anything else. She did not have swelling or discomfort at that stage.
42. By the early 2000s, Gilly suffered from the overwhelming effect of having been suspended from her job for purported alcoholism. As I explained above,

by this point we had moved to Dorset and Gilly began to get lost while out walking and collapsing occasionally. I recall a couple of times she had to be rescued by neighbours and on several occasions she was brought back home. One specific incident I recall was when she had collapsed in the front garden and she had to be helped by our 90-year-old neighbour.

43. By 2003-2004, Gilly's condition was manifesting itself differently in terms of her mental and emotional symptoms, and she displayed a shortening of her temper. The exhaustion she had been experiencing for a long time simply got worse and worse. She also began to show some swelling around her tummy, which indicated that something was not right. She also started to experience acute itchiness.
44. As I explained above, Gilly's HCV was eventually diagnosed in April 2003. By the time her HCV was spotted, it was so late that her liver was badly cirrhotic and had started to mutate. I believe she had three hepatomas but we did not know that at the time (this was discovered only in 2005).
45. From the point of Gilly's diagnosis in April 2003 onwards her symptoms became a lot more noticeable. Her skin colour did not change that much but she had severe dental problems and weakening of her bones. Some of this was age-related but it was accelerated by her HCV. Gilly started to lose her teeth. This was a real blow to her pride as she was very proud of her appearance.
46. From around 2005, Gilly started to suffer from skin dryness and cracking. She also suffered from general discomfort when seated or standing.
47. As Gilly began to understand her disease more, after her diagnosis, she somewhat lost the aggression and temper that she had developed. This was probably because she was starting to manage her own symptoms and she would pre-emptively go and lie down when she felt tired or cross.

48. In December 2005, Gilly received her terminal diagnosis after an MRI located a tumour in her liver. Gilly remained remarkably calm when she received her diagnosis, despite everything she had been through. When we got the terminal diagnosis in Dr Hovell's office in Dorchester, Gilly asked him how long she had to live and he told her that she had one year. She responded, *"well, we'll see about that"*.
49. For that year after her terminal diagnosis Gilly's tummy became more uncomfortable but nothing really happened. She was determined to go on for two years. She began to get more tired. Looking back at photographs, I can really see that now. She did her absolute best, though, and it was only really in the last week of her life that there was a sudden plummet.
50. Gilly had oesophageal varices as a result of her HCV, which meant that she had veins running down her throat that were far more prominent than they should have been. In the last weekend of her life, one of them burst. That was really the end. I recall that Gilly's last day was beautifully sunny. Gilly's then GP, Dr Clayton, had been for a home visit. Suddenly, shortly after he left, Gilly began to cough up blood. I went to get a carrier bag to catch the blood as she could not move. I was up to my elbows in blood. We suddenly realised that the door was wide open and we could be seen from the street. We could not help but start laughing at what a sight we must look. I am unable to recall the sequence of events after this. Dr Clayton returned either that night or first thing in the morning and Gilly's morphine dosage was increased. Eventually, she was put on a line for direct morphine injection and she never really came round after that. Gilly died a day later.
51. I must add that Dr Clayton was generally brilliant at treating and caring for Gilly. He came up to visit whenever he was needed and gave us a resuscitation kit. He was very good at trying to find us help and assistance.
52. Gilly was not given any treatment for HCV or her consequent conditions. She was never offered treatment, despite discussion of her being offered

Interferon and Ribavirin therapy in the future. It appears from her medical records that potentially she was not considered a candidate for Interferon and Ribavirin therapy because it was considered that she was an alcoholic. There is a reference in a letter (**WITN1867005**) dated 14 July 2003 from Dr Hovell to her GP, Dr Compertz, stating:

*"I reviewed this lady in clinic today. She is somewhat improved however I gather she has still been drinking occasional alcohol. She was pretty evasive regarding the amount to me today.*

*I am going to organise a liver biopsy... I do not think at the moment she is a candidate for Interferon/Ribavirin therapy but obviously should she get her act together in the future then we could certainly consider it. However the success rate in established cirrhosis is probably only about 30%."*

53. By this time, despite the diagnosis, we were sick and tired of hearing about alcohol. We made a conscious decision to continue our lives as normally as possible and we could not believe that Gilly's treating clinicians were still talking about her being an alcoholic, which was not true.
54. I remember overhearing a conversation, I believe in the Dorset County Hospital, that the only real alternative treatment available to Gilly was a liver transplant, but she could not have that because she needed to knock the HCV, but she could not have treatments for that because her cirrhosis was too bad. It was a catch-22 situation and it felt like Gilly's HCV had been discovered at a point where it was simply too late for any effective treatment, or at least that was how it was presented to us. Another treatment that was offered and discussed was to use a type of radiotherapy to treat each of the hepatomas in turn. However, I recall the chances of survival were pretty grim; something like a 10-20% success rate, a 20% chance of no impact and a 60% chance of killing her. These were not good odds so we discounted this option.

55. I am not sure now whether in fact Gilly should have been offered the Interferon/Ribavirin therapy and to what extent her wrongful diagnosis as an alcoholic impacted on her ability to access this treatment.
56. Fortunately for Gilly her HCV status did not impact on her treatment for any other conditions or her dental care. Her dentists started wearing face masks and the GP took a few more precautions but that was it.
57. Gilly's HCV had a huge impact on her, but also on our private, family, social and financial life.
58. Financially, Gilly's illness had a huge negative effect. Gilly never went back to work from 2000 onwards. There is no way that she could ever have held down a job by that point because of her HCV-related symptoms. I ran my own business manufacturing military recognition models, as I still do, but around 18 months before Gilly died, she needed constant care. I therefore had to give up work and employed somebody to take my place. In the interim we lived off our savings and Skipton Fund payments. This was not a lot of money but we could not get any other form of help. This period had a real knock-on effect on my business. While I was away from work, my finance director mismanaged the company's accounts and I therefore had to lay people off when I returned to work, which obviously had a consequential effect on the lives of my employees. I eventually managed to get my business back on track, although on a much smaller scale.
59. Throughout Gilly's illness, we had continual battles with various authorities and administrations in an attempt to get the support Gilly and we deserved. In particular, we had extremely negative experiences with the DWP, which I must single out as particularly pompous, overbearing and unknowledgeable. At this time, the DWP was simply not interested in Gilly's case as somebody with HCV. Whenever we had medical assessments, which Dr Clayton tried to avoid at all costs for Gilly when she was poorly, the doctor appointed by the DWP would express dismay and state their view that Gilly should be on full

benefits. However, we never got a thing from them. It was as if HCV simply did not exist and, according to DWP, there was simply nothing wrong with Gilly. The DWP's doctors were generally good and compassionate but, apart from that, the way the DWP worked from start to finish was dire. I feel it was not there to help, but instead its officials saw their job as to avoid handing out any money whatsoever. They did a very good job of it I can confirm.

60. We also had bad experiences with Macmillan Nurses. Gilly's GP Dr Clayton rang them up and spoke personally to try and arrange care for Gilly. They said that they could not help, even after she was diagnosed with hepatoma.
61. This leaves a certain bitterness. Gilly worked throughout her entire life, and I also had had to give up my job. However, we were left in a position where we could not get any help or carers.
62. Fortunately, Dr Clayton had contacted the Joseph Weld Hospice in Dorchester and, for the last few days of her life, Gilly had the best help they could offer at short notice. I cannot praise this organisation enough.
63. We also had a generally negative experience with those responsible for Gilly's medical care in hospital, her consultant gastroenterologist Dr Hovell excepted. I was first elected as a district councillor in May 2007 and I felt it was only from this point that I was able to get my voice heard in the hospital and have some influence over Gilly's care. I can only describe those clinicians involved in treating Gilly as "rubbish". For example, in April 2008 Gilly had been taken into hospital. I went to visit her when she was admitted. It turned out that Dr Hovell had not even been informed that Gilly had been admitted. She desperately wanted me to take her home. I can recall then that some nurses who were supposed to be assisting with a scan for Gilly displayed completely unprofessional, uncaring behaviour, talking openly in front of her about their sexual relations the night before. This was just one awful experience in who knows how many. In numerous hospitals Gilly went to, there were serious issues with cleanliness. I remember once going to King's College Hospital in

London with Gilly for an MRI scan. The medical wards were filthy. The medical area where Gilly had to change for her scan was filthy and stank. It was like a football club locker room and Gilly had to sit there waiting for half an hour. Yeovil Hospital similarly was vile.

64. The worst experience in the medical context occurred just after Gilly died. One of the clinicians either at the hospital or the surgery told me that I might have problems getting Gilly buried, because she could be considered “contaminated”. This was deeply distressing. An undertaker firm I consulted told me that this was nonsense and conducted Gilly’s funeral arrangements with perfect care. I find this ironic that Gilly had perfect care from undertakers but not from the medical profession.
65. While Gilly was alive, we were unable to get a disabled badge even though she evidently required one. This was because, at that time, HCV was not on the register of illnesses that qualified for a disabled badge. Gilly’s GP, Dr Clayton, tried very hard to obtain one for her but got nowhere. The last refusal of a disabled badge arrived at our home on the Monday after Gilly died. I phoned the County Council and was put through to the Blue Badge Team. I was able to speak to them directly because I was then a district councillor. I asked them what their policy was and informed them that I had been applying for a badge for my wife, who had HCV. I informed them that we would no longer require a badge because my wife had died, and I recall that I told them to remember that they were dealing with humans when they carried out their functions. To me, it felt like we had not been treated in a humane way as Gilly had been continually refused a badge.
66. We had a further poor experience with the Occupational Health department of our local Health Authority. We had requested a special bed for Gilly among other equipment, such as a walking frame. Despite our repeated requests, this equipment arrived only two days before Gilly’s death. When it arrived, the mattress did not even fit the bed. This was unacceptable.



67. After these hugely negative experiences with various administrations, including the NHS, I made it my business as a councillor to try and effect change and to bring about more humane and respectful treatment of those with illnesses and their families.

68. Gilly suffered greatly in terms of her private, family and social life because of her HCV. Given the stigma that was and is associated with HCV, when she told her family about her condition, they virtually shunned her. Her family GRO-C GRO-C assumed that she had been “sleeping around” to contract HCV. HCV also had a stigma at that time because it was linked to HIV, which in turn was linked to being gay (itself stigmatised at the time). Only one of Gilly’s five brothers continued to have any real form of contact with her after finding out about her illness. Gilly also had to be careful about which of her family and friends she told about her HCV because of stigma. We did not really tell anybody, pre-empting a negative backlash, and instead shared Gilly’s HCV status with a very controlled group of friends and those who were liable to come into contact with her if, for example, she collapsed. As such, our two close neighbours knew more about Gilly’s condition than many of our friends. I do not think that most of Gilly’s friends from the hospital where she had worked knew that she had HCV.

69. We also had some negative experiences with my family members. GRO-D  
GRO-D  
GRO-D  
GRO-D I do not think I could bring myself to say anything in response. We came to realise that as an HCV sufferer you are treated with stigma, even by those who are supposedly part of your support network.

70. Gilly’s HCV had a huge effect on me, physically mentally and emotionally, and on my private, family and social life. The most difficult thing is watching somebody you love falling apart day to day. I can only describe it as like watching an old car with bits progressively breaking and falling off it. Caring for somebody with HCV was mentally and physically exhausting, but the

hardest thing is that you cannot show how you are suffering. You must become the rock to which your loved one clings and you cannot afford for that guard to slip at any time or for even a single moment.

71. There is a madness to taking your loved one to interviews with the DWP, the doctors telling them, you should not be here because you are so ill, then administrators turning around and saying, you are perfectly fit, nothing is wrong with you.
72. It is like there is a paleness, or greyness, to every day. But you must try to keep your loved one cheerful and keep them going. All you can do if you feel overwhelmed is go out into the nearest field and shout. In those days, there was nobody who could help you, and there was no counselling service that you could go to. I was fortunate that I had some friends from the army who I could talk to bluntly. I did therefore have a little bit of a support network, but I was essentially on my own getting on with it.
73. I believe that this took a huge toll on my physical health. At Gilly's funeral, I felt a tearing pain in my chest, together with nausea, which may well have been the first manifestation of the heart disease that led me to suffer a heart attack in 2018. The treating medics could find no reason for this, for example relating to high blood pressure, cholesterol or blood sugar, and concluded that the most likely cause was historic stress.
74. One of the things that did help me was a private blog by a man in the US who was diagnosing his own HCV. The things that were happening to Gilly mirrored his experience, particularly an inability to concentrate that felt like a fog. He said that he did not realise how badly it was affecting him. His wife had bought him a load of old dinner plates to smash in frustration. It really helped me to read this blog and to understand what Gilly was going through.
75. One of the most challenging things was coping with Gilly's temper and mood swings, before she learnt to manage this better after her diagnosis. I could not

always handle it and in all honesty got a second job to be out of the house more. Gilly would at times lash out at me with force, even though she was only 5 ft 4. I was often worried that she would catch me at the wrong time and I would react. It was wrong, but simpler then, to walk away. Although it is distressing for me to discuss this, I feel it is very important. I would like to think that if somebody else reads this whose partner has HCV and at points has displayed nasty behaviour towards them, they can better understand that it is not "them", but the disease. I hope that this can help someone else cope better.

76. As Gilly became more and more unwell towards her death, I found that my own social life simply vanished with it. This is because I had to be on call and I had to be with her more and more.
77. Gilly's death had a huge impact on me. You never expect to become a widower in your 40s and nor does society. As such, the support out there for people in my position was pretty slim. I found that the only support on offer was from the Joseph Weld Hospice, but even that was generally aimed at those who had lost a parent rather than a spouse at a young age. You expect to lose a parent, but you do not expect for your spouse to die. You try to find any support you can, because you are dumped on your own with so many familiar things around you. I found that even finding a pair of Gilly's shoes under the table felt like hell on earth. Again, I would reiterate that I was lucky. My ex-army friends were tough with me and that support helped me, but there are many who have no one.
78. I realised that what was really required for people like me was some form of support and peer support. People need to be able to talk to somebody else who has also lost a loved one, but specifically someone who has experienced the same type of loss as they have. This support needs to be something that is genuinely effective rather than just a tick in the box.

79. I remember one day shortly after Gilly died, I got a call from the Council telling me that I had not paid my council tax. I had completely forgotten to do this because Gilly had always been the one in our household who paid it. It was ironic that I had forgotten to pay given that I was a councillor. Because of my experiences with Gilly, through my work as a councillor I managed to get our council to be more aware and compassionate in terms of supporting the bereaved in our area. I tried to get the message across that when somebody is bereaved, their whole world has just turned upside down. They can easily forget things like council tax, or to pay an electricity bill. I feel that some sort of understanding or briefing note needs to go through government and local government departments to ensure that we develop a more understanding and compassionate culture towards the bereaved.
80. My financial difficulties continued after Gilly's death. Given, as I explained above, I had had to hire somebody to take over my role in my company while I was caring for Gilly at the end of her life, when I went back to work, I was effectively working for free because there was not a job for me in my own business. After about a year, the last of our savings had gone and I had no income. I recall that I received a funeral allowance as a widower of about £1000 and that there was also a widow's benefit that I did not qualify for because I was male. From some source, which I now cannot recall, I received £70 a month that lasted for ten months. All in all, I felt completely and utterly alone. I needed financial support in that period – I got through our savings, the Skipton Fund payments (see below), and my credit cards were maxed out. Fortunately, I had no mortgage or I would have been homeless but I felt like nobody cared one bit about me. It has taken me until now to financially get back on track after Gilly's death.

#### **Section 6 – Treatment/Care/Support**

81. Gilly did not face any obstacles in obtaining care, treatment and support in *consequence* of being infected with HCV, although I reiterate that she

received no treatment for HCV (as explained above). This is, I consider, likely to be as a result of her misdiagnosis of alcoholism.

82. No counselling has ever been made available to me from the NHS or any other government organisation.
83. Moreover, no counselling was offered to Gilly at any point. I cannot say whether she would have utilised any service if it had been offered, but it is possible she would have used it when she received her terminal diagnosis. Gilly remained very calm, though, and I believe we probably counselled each other.

#### **Section 7 – Financial assistance**

84. Gilly received stage 1 (£20,000) and stage 2 (£50,000) payments from the Skipton Fund in 2005. In 2017 I also received a £10,000 payment as a spouse.
85. Gilly found out about the Skipton Fund by accident, not because of any formal notice we were given by those responsible for her care and treatment. Gilly heard about it somewhere in the media and then we looked it up online.
86. In terms of the process of applying for financial assistance from the Skipton Fund, Gilly did face some obstacles. Gilly started the application process in 2004. Most of the application forms were filled in by medical professionals in charge of Gilly's care and treatment. At least once, the forms were returned to Gilly as they were incomplete. Completing these forms required Gilly to request her medical records to provide evidence of the means of her infection with HCV and of her blood transfusion. Gilly did face obstacles, however, obtaining her medical records from Southampton General Hospital. I recall that the hospital refused to hand over Gilly's medical records to her directly and would only give them to Dr Hovell. The only reason we now have a copy of Gilly's medical records is because Dr Hovell handed them over to us when

he gave Gilly her terminal diagnosis. If it had not been for him, we would have been completely in the dark. Given that Gilly and Dr Hovell both requested her records in around 2003/2004, and they were not given to her until about 2005, there was an awful lot of mucking around in the meantime.

87. The conditions that were attached to the financial assistance were that it was ex gratia and without prejudice. However, we made sure when we accepted the payments that it would not preclude participating in any litigation in the future.
88. Although our means of finding out about the Skipton Fund was awkward, our experience once we had made contact was that the staff were generally good, knowledgeable and helpful. They were easy to talk to and willing to assist. We did not find them to be judgmental in any way. When Gilly died, everything transferred to my name and the process was seamless. Indeed, I have no complaints whatsoever about the level of service from the staff.
89. However, I believe that the amount of financial assistance we received was woefully inadequate. As Gilly was misdiagnosed as an alcoholic, she could not work for eight years from the time we moved to Dorset to the time she died. It has a significant impact on a household when one of the earning parties, such as Gilly, goes from earning £15,000 a year to nothing. It also meant that Gilly was no longer clocking up money on her pension and I had to stop paying into my pension because funds were so tight. If we had not sold our house in Southampton for a considerable lump sum, and if we had a mortgage, we would have been really stymied. In the final year of Gilly's life, she received approximately £60-70 a month in Disability Living Allowance. However, apart from that she never qualified, despite our battles, for any other sort of incapacity, disability or council tax benefit or concession. Overall, this meant that our financial hardship was quite considerable and it impacted on our lifestyle and everything we could do. Gilly calculated that in the last two years of her life we were losing out on £40-45,000 a year between us because of losing our two salaries, and that was not even taking into account

the impact on our pensions. Therefore, I firmly believe that while the financial assistance from the Skipton Fund was welcome, it was completely and utterly insufficient.

### **Section 8 – Other issues**

90. Since Gilly died, I have tried in my own way to spread information about HCV through my work as a district councillor. As I described above, I have also tried my best more generally to promote issues around bereavement and a culture of compassion towards those who have lost loved ones. I really hope that the Inquiry can continue this work, and that it can recommend that some kind of note of understanding or briefing note is circulated to government and local government departments to ensure that those bodies take a more compassionate approach to the bereaved, for example when they forget to make payments such as council tax in the midst of a loss.
91. In terms of my hopes for the Inquiry, while I would like to see the Inquiry be able to draw specific conclusions on which person or persons are to blame for this whole tragedy, I am not confident that will be possible and I am concerned that the Inquiry will do no more than reveal a culture of general incompetence to the highest level in the NHS but nothing much more.
92. I hope that the outcome of the Inquiry will be that any recommendations made are actually considered and upheld by central government, rather than contested. Considering things from my perspective as a councillor, if this had happened at our council, we would be holding our hands in the air and admitting we had messed up. I very much hope that the Government and/or the NHS finally recognise that there has been a foul up and takes full responsibility.
93. Furthermore, I am of the view that the Inquiry should make recommendations for greater financial assistance or compensation for the infected and affected persons. When the Inquiry first started, I was of the view that nothing would

bring Gilly back and that compensation was pointless. I have now revised my view as, again from my experience as a councillor, I know that authorities rarely sit up and take notice until their budgets are impacted. I really hope that the Inquiry will recommend financial compensation payments are made to the infected and affected. This, crucially, will allow those with HCV to live a better life for whatever years they have left. It would be unconscionable for the Government or the NHS to ignore any such recommendations.

**STATEMENT OF TRUTH**

I believe that the facts stated in this written statement are true.

Signed

GRO-C

Dated

18 / 02 / 19