

Witness Name: Carolyn Challis

Statement No.: WITN0622

Exhibit: **WITN0622 001**

Dated: 25/02/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CAROLYN CHALLIS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 2 January 2019.

I, Carolyn Challis, will say as follows:

Section 1. Introduction

1. My name is Carolyn Challis but most people know me as Caz. I was born on GRO-C 1956 and my address is known to the inquiry. I live alone near the village of Hartland in North Devon and have three adult children (two daughters and one son). I have been one of the main administrators of a large hepatitis C online support group for the past five years but otherwise I am no longer able to work due to my health.
2. My initial infection and the way this disease has affected my life is intertwined with my experience of and eventual recovery from cancer. I intend to speak about the circumstances surrounding my infection, the nature of treatment or support I received and the overall impact of this illness on my family and myself. I am aware that the scope of this inquiry is largely limited to infected

blood and blood products but my experience of infection cannot be understood in isolation from other health issues that combined with or were influenced by my hepatitis C.

Section 2. How Infected

3. I was infected with hepatitis C between March 1992 and July 1993, a period of time in which I received three NHS blood transfusions as part of diagnosis and chemotherapy treatment for Hodgkin's disease. Alternatively, there is a slight possibility that I was infected through the use of contaminated medical instruments during my prolonged and intensive cancer treatment.
4. The infection would have occurred in North Devon district hospital (NDDH) or Derriford hospital. My medical consultants all agree that I most likely contracted hepatitis C from one of the blood transfusions, as part of the many medical interventions for my cancer. The details of the transfusions I received are as follows:
5. The initial transfusion occurred at NDDH (Highfield maternity ward) on 3 March 1992 and consisted of two units of blood. I was 24 weeks pregnant with my son at the time. The transfusion was for pregnancy related anaemia prior to a surgical biopsy of a lump that turned out to be cancerous (Hodgkin's disease).
6. The second transfusion occurred at NDDH (Trinity ward) on 20 May 1993 and consisted of four units of blood. I required this transfusion because I was suffering from lymphoma, anaemia, fever and pancytopenia (low platelet count due to chemotherapy).
7. The final transfusion occurred at NDDH (Trinity ward) on 1 July 1993 and consisted of three units of blood. This transfusion was needed for my on-going anaemia.
8. I was informed by the medical staff at NDDH that NHS blood was screened from September 1991 onwards for donor exposure to hepatitis C and HIV; yet the cause of my infection is complicated. All of the transfusions I received can ostensibly be traced back to nine individual donors. Because these individuals each later decided to donate again, the NHS were subsequently able to test these donors for hepatitis C. This test came up negative for all involved.

9. However, there remains a possibility that a donor with hepatitis C could have evaded the screening process. The HCV antibody tests used at the relevant time were renowned to be fallible and in addition, early on in any viral infection an individual can be infective yet have negative tests for the virus. Alternatively, it is possible for someone to have been infected at the time they gave blood but not at the point of the next donation.
10. As well as these uncertainties, there is a possible mismatch between the batch numbers for the units of blood listed in my blood reports and the units of blood that were subsequently tested for infection. Dr Attock, my consultant haematologist at NDDH, requested for them to be checked in 1997, but the batch numbers recorded in his letter do not appear to exactly match the actual blood reports. I have asked the blood bank to recheck this but was told I did not have the authority to ask for such information. If a clerical error were made with the batch numbers of the blood in the transfusions that I received, any assurances I was given about my specific donors being uninfected would be inaccurate.
11. In addition to the transfusions, I also had two needle biopsies, a surgical biopsy and a variety of blood tests, venesections, Hickman lines and other minor procedures during the cancer treatment that began in early 1992. It is impossible to designate any of the transfusions or specific medical interventions as the source of my infection due to the nature of hepatitis C and the time it takes for symptoms to manifest. Most importantly, across many years of correspondence, three separate medical consultants agree that; "Infection most probably arose through NHS treatment."
12. In a letter written in 2005 Dr Cramp wrote "In Mrs Challis's case her only risk factor for acquiring hepatitis C appears to be the use of blood and blood products during her treatment in 1992." This letter is attached to my statement.
13. Neither the NHS nor any of my doctors have ever presented me with a likely source of infection other than becoming infected through NHS treatment.
14. When I received the blood transfusions I do not recall ever being warned of the potential risks involved. My mind was occupied by on-going cancer treatment but I'm sure I would remember if they had mentioned the significant risks involved in transfusions at that time.

15. In the summer of 1993 during the screening process for my autologous stem cell transfusion at Derriford hospital in August, I was diagnosed with hepatitis C and subsequently informed of my infection at my hospital bedside by Dr Hamon. At the time it was conveyed in a manner that seemed casual due to the stakes of the upcoming high dose of chemotherapy for my stem cell transplant, so I barely registered it. I was later provided some information on this disease and encouraged to see a liver specialist at NDDH who could provide further information. I was not specifically told about how to minimise the infection risk for others regarding cleaning up of my blood, nor was I asked if I wanted to have my children tested.

Section 3. Other Infections

16. I do not believe that I have ever received any infection other than hepatitis C from being given infected blood or blood products.

Section 4. Consent

17. I do not believe that I was ever given any form of treatment without my consent or used as an unknowing research subject by medical practitioners.

18. However, at the time I received each blood transfusion, there was a complete lack of information provided as to the risks involved, risks that should have been known to the relevant medical professionals at that time.

Section 5. Impact

Mental and physical effects

19. The effects of being infected have profoundly influenced my lifestyle over the past thirty years. My relationships and interactions with family and friends changed completely and irreparably. For many years I forgot what it was like to feel normal and even my 'good' days could only be considered good in comparison to really awful ones. This section describes the effect of my

hepatitis infection whereas I will discuss the effects of being treated for that infection at Section 6.

20. I experienced near constant symptoms of 'brain fog' for around a decade, starting in the mid 2000's. Brain fog feels similar to severe jetlag; it is a deep fatigue where both coordination and cognition are heavily impaired. This affected me to the extent that I would struggle to finish sentences and be challenged by basic tasks such as operating a vehicle. It was immensely frustrating being unable to rely on my brain and my body. I could not make any commitments to those around me, having no idea when brain fog would incapacitate me to the extent that everyday activities were impossible.
21. This lack of clarity was accompanied by continuous bouts of chronic fatigue. Fatigue severely limited my attempts to lead a normal life. I would be forced to lie down and rest even after relatively non-strenuous activity such as taking a shower, stripping my bed or hanging out washing. The tiredness is hard to describe, comparable to having utterly flat batteries that never recharge. When I did attempt to be slightly active this would generally lead to muscle aches for many days after the event.
22. Fatigue was also an aspect of health that was challenging for those around me to understand. Everyone deals with being overly tired, so the way this constant tiredness was actually taking over my life was difficult for some of my friends and family to accept. Hepatitis C fatigue is not helped by sleep, and is not something you can "push through" with willpower. It is completely incapacitating at times. Sometimes I was too exhausted to even turn over in bed. Without assistance I would spend many days effectively confined to the house, just lying on the settee. Pre-planned social engagements became a curse rather than a joy, due to my anxiety about not being up to them on the day and having to let loved ones down, again.
23. As my symptoms progressed, effects of the infection included high stress, fibromyalgia, exhaustion, depression and flu-like symptoms. I further suffered from serious digestive upsets, an almost complete loss of appetite and an inability to digest some everyday foods such as onions or red meat. Some days I was housebound because I needed to stay close to the bathroom. This naturally led to weight loss, which exacerbated the lack of strength that I was already experiencing.

24. I never considered myself to have depression separate to my overall health. The lack of progress in treating the disease did weigh heavily on me for many years, sometimes giving rise to a sense of hopelessness and despair. This was compounded by the rejection of my applications for compensation or financial help from any of the relevant organisations.
25. Looking back, one of the things that grieves and frustrates me the most is the sheer amount of significant occasions in the lives of my family and friends that I had to miss out on due to this illness. When my GP suggested antidepressants I declined them, telling him that when they could get rid of this virus any depression I had would disappear!
26. My lengthy medical history and the treatment for my infection cannot be understood separately to my treatment for and recovery from cancer. I will describe the treatments that I was given and the effects of that treatment at Section 6 below.

Impact on my private, family or social life

27. As mentioned above, I was pregnant with my son when I was first diagnosed with cancer, and he was under a year old when I was told I also had hepatitis C. I could not adequately care for him due to the combination of my cancer treatment and the hepatitis C that accompanied it and unfortunately I had to foster him out when he was just six months old. This was an agonising decision that I was only able to take when I considered the very real risk of my son growing up without a mother should my I lose the battle with illness. He remained in foster care throughout his childhood, with a shared care arrangement between his foster mother, the social care team, and me.
28. My eldest daughter was 10 years old when I became gravely ill, so it was a big shock for her. She was suddenly growing up in an environment where my health needs were a dominating concern. Our lives were filled with hospital appointments, inpatient stays, social workers, and in-home help, and seeing me so ill of course she feared I might die. Her distress alongside puberty, combined with my incapacitation, created a lot of friction between us at times. I was no longer the super-strong, capable mother she once had.

29. In 1994, when she was twelve years old, I again found myself unable to look after her due to the combined effects of my illnesses, and she had to return to live with her father, who by now had moved sixty miles away. She was ripped away from her mother, her siblings, her friends, her village and her school. She was unhappy in her new school in a strange town and pleaded to move back in with me. While I longed to have her home with me again, I wasn't capable of looking after her by myself at that time and so I had to refuse.

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30. My granddaughter was born to my eldest daughter in 2011. Unfortunately, by then I was fully gripped by hepatitis C symptoms and so I could not take on many caring responsibilities even though I would have loved to. My daughter sometimes took my inability to make commitments to look after my granddaughter as a sign that I did not want to.

31. In general, being infected had a serious and longstanding negative effect on my family and prevented me from bringing up my children in the way I would have wanted. I was denied the opportunity to properly mother my son from birth and I was unable to guide my eldest daughter through her troubled teenage years. My younger daughter was farmed out with family or left to her own devices a lot during this difficult time, and although she was resilient and coped well I regret not being able to give her more maternal time and care. All three children sadly spent a lot of time apart from each other, and when at home had to put up with me complaining how ill and tired I constantly felt.

32. The inability to parent fully due to my poor health and constant fatigue led to frequent family arguments and upset. I believe that my children's experience of my illness throughout their upbringing meant that their childhoods were not as carefree or easy as I would have wished. I missed many key moments in their lives, such as my youngest daughter's university graduation.

33. My infection with hepatitis C also triggered the breakdown of two significant relationships. In 2004, I signed up for 48 weeks of gruelling interferon and ribavirin treatment. My partner at the time felt he could not stay around to support me during this treatment, and so "ran away" in order to pursue his active, outdoor lifestyle without me. The treatment is renowned for causing anaemia, flu like symptoms, insomnia and severe depression, and the combined effects of the treatment and his abandonment of me plunged me into

a deep abyss of despair and depression. I only lasted 14 weeks of the prescribed 48 weeks as I became far too ill from all of the above and had to be pulled off treatment.

34. When I met my husband in 2005 I had been cured of cancer, and the hepatitis C symptoms, which had begun to manifest in the early 2000s, were present but not all encompassing. We were able to have some good days together, although my energy levels were erratic and the effects of my hepatitis C were becoming more problematic. Many occasions, such as my honeymoon weekend in 2006, were ruined by my insurmountable fatigue.
35. By 2010 the effects of the hepatitis C had worsened to the extent that I was overwhelmed by the symptoms described above. Because of my illness we could no longer provide each other with the elements of a successful and happy marriage and we decided to separate initially, and then later to divorce as I began the clinical trial of Epclusa in 2014/15.
36. When I was first affected by hepatitis C my friends would continue to invite me to places and events despite knowing I wouldn't be strong enough to make it or could only attend for a limited time. Eventually they stopped inviting me to social occasions and consequently I grew increasingly socially isolated. I previously had an active and outgoing personality when I was healthy and therefore the loss of this part of my life was a huge blow to my spirit and confidence.

Impact on my education, work life and finances

37. At the time I was diagnosed with Hepatitis C I had already completed a university degree in psychology, and during the late 1990s I was still just about well enough to take a part-time counselling diploma over four years, some essays of which were written in hospital. The infection impacted my education greatly however when I enrolled at Art College in 2008. I was only able to attend this course part time, and I received little understanding from the tutors and administrators of the programme with regard to the serious health problems I was dealing with on a daily basis.
38. I used to come home from my one-day-a-week at college and have to crawl into bed. I had to give the course up mid-term due to this immense fatigue. In

addition to the financial cost of the illness, I now realised it was also going to cost me any chance to engage with educational activities such as this, and this was a huge blow to me. Art school had been my dream since I was a teenager, and now this had been taken away from me too.

39. Without Hepatitis C I would undoubtedly have continued to practice as a therapeutic counsellor, specialising in working with people who were dependent upon alcohol. I loved my work and found it immensely rewarding to be able to use my skills to help people in need of support. By 2003 I had to stop all of my counselling work due to the strain on my own health, effectively ending my career as a counsellor. I found some occasional work in a pottery studio but in 2008 I was forced to give this up too because of overwhelming fatigue and my declining overall health.
40. Outside of these direct effects, when making job applications I feel like I have been looked over because of my medical history. I consistently faced rejection for various roles that I was more than qualified for without adequate explanation.
41. I have been unable to earn an income due to illness for many years, including what should have been the prime earning years of my life. Instead I have been forced to rely on government benefits for the last 26 years, and I have had to expend precious time and energy fighting to obtain and to keep these. I will discuss seeking financial assistance in relation to being infected at Section 7 below.

Section 6. Treatment/Care/Support

42. I was initially infected with hepatitis C during the course of NHS treatment for my Hodgkin's disease. It was only after I had spent several years getting over my cancer that I paid attention to my hepatitis C. I wrote to my consultant haematologist Dr Hamon at Derriford Hospital in 1995 with many questions, and he replied that "the majority of exposed patients do not tend to run into major problems and, indeed I would be hopeful that in the long term we are not going to see particular problems in you related to hepatitis C."

43. On many occasions I have found that my medical professionals were ignorant or mistaken as to the nature of my condition and its symptoms or treatments. At one point a GP told me that "hepatitis C would not make me tired" and consequently refused to write a supporting letter that I required for an upcoming work capability assessment. On another occasion, my GP was confused when I asked whether GRO-C could be tested, clearly unaware that the disease was infectious and GRO-C was at risk.
44. There was also an incident when I had to interpret my latest test result trends for a GP who was entirely unfamiliar with both the measurements and test procedure. The GP I was with during my clinical trial was not particularly interested in engaging with the process, so there was a lack of continuity between my visits to him and my visits to the research unit. I have found in general that GPs appear to be under-trained regarding hepatitis C.
45. In 1998 the cancer returned, requiring the surgical removal of a large tumour in my leg and a month of radiotherapy. Then ensued a variety of long-term health problems including my left leg being unable to support any weight due to damage to the femoral nerve, and lymphedema in the same leg. From 1998 onwards hepatitis C significantly worsened my condition. I suffered from chronic fatigue, felt sick and was generally weak and unwell. During this period it is not possible to separate the effects of the chemotherapy damage from the hepatitis C symptoms.
46. My liver was further compromised by transfusional iron overload, caused by the multiple blood transfusions I required for cancer treatment. Iron overloads cause many problems including fatigue, joint pain, heart attacks, cirrhosis and cancer of the liver. Prior to beginning interferon and ribavirin treatment in 2004 and in order to make such treatment more viable, I spent a gruelling year of tri-weekly venesections.
47. I initially had declined to try the interferon and ribavirin treatment due to the horrendous side effects, but in 2004 Dr Cramp, my hepatologist at Derriford, persuaded me to attempt to eradicate the infection with a 48-week treatment. The fortnightly appointments required a two-hour drive each way to Plymouth because I was not permitted to have any appointments at NDDH or my local surgery.

48. I did not respond well to the treatment and was withdrawn from it after just 14 weeks of the 48-week course due to my dangerously low blood counts, and the fact that my viral load was beginning to rebound. The side effects of the treatment were horrendous: insomnia, inability to get out of bed, anaemia, depression, hallucinations, flu like symptoms, and mental and emotional breakdown. I was left with a chronic viral illness to compound my other health issues. I would describe the effects of being on these drugs as like falling into a deep and terrifying abyss of pain and despair, and I told Dr Cramp over my dead body would I ever take interferon again.
49. I relied on holistic techniques to manage my condition while I waited for better treatments to become available. I used nutrition, acupuncture, meditation, yoga, exercise and a lot of hope to get me through. This included a range of traditional Chinese herbs and other herbs bought out of my own pocket from the US. Dr Cramp was supportive of my holistic approach and told me "Whatever you're doing, keep on doing it because it's working!" I was able to lead a relatively normal life until about 2007, after which my symptoms steadily got worse.
50. Gaining access to alternative medicines (which outperformed conventional approaches in my case) proved to be problematic. My local surgery was no longer able to allow my prescription of Chinese herbs but for as long as I could afford it I would spend my disability living allowance on medicinal herbs and other approaches that worked for me.
51. A long-term outcome of having had cancer and a bone marrow transplant was consistently suppressed blood counts. Consequently, I had to wait patiently for interferon and ribavirin free treatment and it was ten years before this became available to me. With Dr Cramp's support I was invited to try for a place on a clinical trial of Epclusa at Derriford hospital in October 2014. I contacted the research nurse every week because I was so determined to be included.
52. When I was finally accepted, I thought that the trial was going well and my symptoms were improving but 12 weeks after its conclusion I found out that I had been part of the placebo control group. Undeterred, I reapplied for the next round and was eventually accepted. I began a 12-week course of Epclusa in May 2015.

53. While on Eplusa I effectively locked myself away in my house with the supplies I needed for the course of treatment and thankfully it was effective, my viral load dropping from over 2 million at baseline to 356 after just one week. The virus was undetected after four weeks. In February 2016, I was declared cured and discharged. I did however develop tinnitus after about 6 weeks of the treatment (along with some other members of the trial), which has remained with me to this day.
54. Being discharged, over the phone, was a big shock; after 24 years of constant appointments and care I felt adrift. I asked for a repeat PCR test a year later and was initially refused until my GP agreed to perform one. I recently asked for a repeat Fibroscan to check my liver was doing well three years post cure, and was refused this also.
55. Counselling was never offered to me throughout all my years of interaction with the NHS, not after my diagnosis, not at any stage during treatment nor after my eventual recovery. Being experienced in the profession myself; I know how much counselling could have helped me deal with my infection and its overwhelming impact on my life. When I did decide I needed therapy I was obliged to find it and fund it myself.

Section 7. Financial Assistance

56. In 2004 I learned about the Skipton fund through a Department of Health leaflet and was encouraged to apply by Dr Cramp, I subsequently applied in December 2004. At this time I was a single parent of three children, and was unable to work full time due to my health.
57. My application was rejected on the basis that the likely date of my infection by the NHS fell after the September 1991 cut-off date. The NHS argue that this date represents the point at which all transfusions were screened for hepatitis C infection.
58. With the support of three of my medical consultants I formally appealed the decision of the Skipton fund. I sent many letters and compiled a large amount of evidence to explain my circumstances and show how my infection almost certainly occurred as a result of the treatment I received from the NHS. This

appeal was also rejected on the basis that the appeal panel had no authority to adjust the arbitrary September 1991 cut-off point for providing support.

59. While I understand the NHS's desire to maintain the assurance that no blood products were contaminated after September 1991, I do not understand how that can result in my situation being approached so differently to someone who was infected prior to that date. The effects on my health and lifestyle were no different from those experienced by other infected individuals who were eligible for grants from the Skipton fund. I spent over ten years unsuccessfully attempting to receive compensation and the stress and wasted time involved only compounded the negative effects of my infection. Additionally, because I was never granted Skipton stage 1 payments, I am now unable to claim from the new EIBSS scheme. I was told by them over the phone that there was little point me applying as I would almost certainly be refused again.
60. The rejection of my application has meant that for many years I have had to endure the humiliation of work capability assessments just to have income support to live on. I was often judged to be 'work capable' when any medical professional with the slightest knowledge of my condition would have known that was not the case. When my 3-year "stay of execution" is up next year I imagine that I will again have to undergo one of these assessments, conducted by individuals who lack the required knowledge to make an informed judgment about my situation.

Section 8. Other Issues

61. A fellow hepatitis C advocate urged me to engage with this inquiry and to write my experience down, given that I am typical of many who are affected but fall outside of the arbitrary Skipton period. Previous inquiries into the infected blood scandal have not resulted in truth, justice or satisfactory answers.
62. A major concern I have is the continuing ignorance or misinformation within the medical profession about hepatitis C, its effects and possible treatments. On multiple occasions I found that I personally knew more about the condition than the doctors who were examining or treating me.

63. The years I have spent as an administrator of a hepatitis C support group have taught me so much about how the disease impacts people's lives, how much support is still needed, and how important it is to spread awareness, especially regarding routes of transmission. There are likely many within the UK who remain undiagnosed, untreated, and unaware of why they constantly feel so ill.
64. I'm not angry with the NHS for infecting me, I'm angry that I haven't been heard for all these years. Once the government has listened to my story and those like it, they should ensure access to treatment for anyone living with this disease. I would like for this inquiry to show that when a tragedy such as this occurs, the criteria for receiving assistance should be the needs of the individual and not the legal position of the government.

Statement of Truth

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

Signed _____

GRO-C

Dated

1st March 2019