



Witness:
Statement No.: WITN0014001
Exhibits: WITN0014002
WITN0014003

Date signed: 22 November 2018

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 24 August 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference

I, will say as follows: -

Introduction

1. My name is My date of birth and address are known to the Inquiry. I originally came to the UK in the early 1960's and have lived here since then. I am retired and I currently live in sheltered accommodation. I have never married or co-habited with anyone. I have never been able to afford my own property. I have been asked if I am currently legally represented, the answer is no. I am content for my statement to be taken by the investigators from the Inquiry
- 1.1 I intend to speak about my infection of Hepatitis C which I contracted following transfusions I received during operations I had for skin cancer in 1977, I was aged 40 or 41 at that time.
- 1.2 I wasn't diagnosed for 29 years, until 2006, following a hip operation. This infection has had a significant impact on me, over many years from my transfusion, until now.

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How Infected

2. From May 1977, I had a series of 7 plastic surgery operations, as a result of skin cancer to my face. I had numerous transfusions during the initial 2 major operations. These included a scalp-flap and later a reversal of the scalp-flap, plus skin grafts.
- 2.1 These operations took place at Westminster Hospital in Horseferry Road, London. This is now part of the Chelsea and Westminster Hospital.
- 2.2 The operations were under general anaesthetic, I was therefore quite drowsy afterwards but I recall having a drip (with blood) into my arm **after my return to the ward.**
In the medical notes there is a request for additional blood to be given whenever it becomes available. This was done after leaving the operation theatre.
- 2.3 The Investigators have the name of my Plastic Surgeon who was considered to be a 'star' in his field at that time. I have also given them details of my consultant at that time.
- 2.4 I have never had any other blood transfusions and I have a phobia to needles and have therefore never had any tattoos or taken drugs intravenously. I have had intravenous saline drips after dehydration caused by food poisoning.
- 2.5 **Because of my many various symptoms, I was given blood tests on numerous occasions over the years to check for diabetes, thyroid, kidney and liver functions etc.**
On every occasion this happened, I was quizzed about my drinking habits. When I told the GP that I drank very rarely, like for example on special family occasions, I felt that I was not believed.
After a Hip Operation in 2005, I was in constant pain. I was given a blood test in 2006 to check if there was an infection.
It was then, that I was finally diagnosed with chronic Hepatitis C.
- 2.6 **Following my blood test in July 2006, my GP simply said to me "You have chronic Hepatitis C but it can be treated".**
But she did not specifically say how or when this would happen.
She handed me some computer print-outs with information about the illness and its effects on the liver. I was not told what department to ring. I was simply given a piece of paper with a phone number and a password in order to make an appointment. This turned out to be at the Hepatology Department of the University College London Hospital.

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- 2.7 My GP has now retired (the investigators have her name).
The GP had also handed me a computer print-out with some information about the illness.
- 2.8 I did not think this was in anyway an adequate way to inform someone of such a severe infection. I did not realise how serious it was at that time. I feel that this significant information should have been given to me in a far better way to enable me to understand and manage the infection.
- 2.9 Later in the Autumn of 2006, I was dealt with by a specialist Hepatitis nurse, who did give me good advice but I feel this should have happened as soon as I was diagnosed. **He also warned me of the severe side-effects the available treatment would have and that it would aggravate my arthritis and some of the other symptoms I had.**
He also pointed out how much the treatment cost the NHS !
He handed me 2 booklets explaining the illness and also the treatment and its side-effects.
Because of my needle phobia, I asked if the Nurse at the GP surgery could give me the weekly injection. But I was told that I would have to learn to do it myself.
He also informed me, that the chance of clearing the virus after 48 weeks was approx. 45%.
When I saw a Hepatology Consultant a few months later, he gave me the same information and agreed with me, that I should wait till some new treatment was made available.

Other Infections

3. When I was tested for Hepatitis C, I asked to be tested for types A & B as well. When the results arrived, I was told I had chronic type C but I also had the anti-bodies for A & B.

Consent

- 4.1 I do not recall the transfusions I received in 1977 being discussed with me. I certainly was not told of any potential risk of infection, if I had, I would not have gone ahead with the operations.
- 4.2 I am not aware of giving my consent to being given blood transfusions
- 4.3 No information was given to me about having a transfusion or the risk of Hepatitis.

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- 4.4 I am aware that photographs of 'before and after' my skin graft operations were (and maybe still are) used by the plastic surgeon who operated on me. **The whole operation was recorded and also sketches made by the surgeon. Various other surgeons that had observed the operation, visited me on the ward later on.**
- 4.5 I am not aware of any other research being conducted on me.

Impact

5. The mental effects of my infection have been overwhelming, I had so many illnesses that when I was eventually diagnosed with Hepatitis C in 2006, it was actually some what of a relief because I finally knew I wasn't just a hypochondriac.
- 5.1 Other mental effects on me were: Lack of concentration or what I call 'brain fog', depression (which till I was diagnosed with Hepatitis C, I was told by doctors was "without reason"), insomnia linked with being constantly tired and fearful in everyday situations. **Anhedonia - inability to feel pleasure in normally pleasurable activities.**
In relation to my depression, I have been advised to take anti-depression tablets but I am fearful of becoming addicted to them.
- 5.2 My physical symptoms include: Constant aches in joints, arthritis – this was diagnosed many years ago and was therefore not age related, constant pain in my liver area, a lack of motivation, digestive problems, severe Seasonal Affective Disorder and liver issues. Also I still suffer with almost daily spells of unexplained fever with brain fog and dizziness.
- 5.3 I have had many years of chest pain and have undergone numerous tests which they thought was an 'irregular heart beat' but eventually this was diagnosed to be gallstones. I had my gall bladder removed in 1991 in Switzerland via keyhole surgery.
- 5.4 In addition to the physical affects listed above I also have Fibrosis of the Liver. I was diagnosed with fatty liver in 2006.
- 5.5 Following my diagnosis I was offered a treatment mix of Pegylated Interferon, Ribavirin and Telaprevir. I spoke to a lot of other Hepatitis C sufferers and found out that there was a lot of aggressive side effects such as suicidal thoughts, and they were extremely sick for the whole of course of treatment, consisting of pills and injections, could be as long as 48 weeks. Also there was only a 45% chance of it clearing it up. Therefore I decided against taking it.

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- 5.6 I heard about a new drug called Harvoni (which was approved for treatment by NICE in 2013/14) this had a much better success rate and fewer side effects. I pushed really hard to get it but was repeatedly refused in 2014, they originally said it cost too much (£60,000), then that my Fibrosis was not serious enough, I would only qualify when this had got worse. I felt this was a terrible situation to be put in. I even joked that I would start getting drunk, so that I would get cirrhosis of the liver, so that I could get higher up the list of people 'qualified' to receive Harvoni.
- 5.7 In the summer of 2015, I wrote a letter, (which was prepared from a sample letter I got from The Hepatitis Trust) to my local MP Sir Keir Starmer, I received a copy of a letter from George Freeman MP, the Parliamentary Under Secretary of State for Life Sciences written to Sir Kier Starmer dated 15 October 2015 in response.
- 5.8 The investigators have photographed this letter and it is produced as exhibit **WITN0014002**. The letter effectively explains the NICE position, that I wasn't medically suitable for Harvoni. After I had been informed, yet again that I had to wait for treatment as I was only Stage 1 and that my fibrosis was not advanced enough. I asked to be transferred from UCLH to the Royal Free following a conversation with a Consultant Hepatologist that I had met at an APPG Conference in November 2015. He had advised me to get a transfer to the Royal Free. I wrote a letter to the Secretary of that Consultant at the Royal Free and explained the situation. The letter is dated 3rd February 2016. I saw a Hepatologist at the Royal Free at the beginning of March 2016 and I was offered treatment at the end of March 2016 .
- 5.9 Within the last month I saw my GP and asked for an alternative blood pressure medication, as the present one causes very painful swollen ankles, (Oedema). However, when the GP entered a prescription into her computer it flagged up that owing to my liver condition, I was not allowed to take the only alternative blood pressure drug that would help with the Oedema.
- 5.10 I have been taking a blood pressure drug since 2004 but when undergoing the Harvoni, 2 years ago, my blood pressure increased and I have been prescribed this supplementary drug. Ever since then I have suffered with painful swollen ankles but have been advised against stopping it.

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- 5.11 During the treatment with Harvoni, (manufactured by Gilead), I had a high; fever and blood pressure, which had to be treated with further medication. I had a MRI brain scan because of the persistent headaches. Joint pain. My GP kept thinking that these symptoms were purely age related but I knew they were because of the drug because they changed so quickly when I started Harvoni.
- 5.12 I took the Harvoni, (which contained 90mg of Ledipasvir and 400mg of Sofosbuvir) for 8 weeks, and then I was discharged. I am told I am no longer infected but I do not feel like I am, I still suffer from abscesses on my gums. **I have had gum problems for many years and lost teeth because of the abscesses.**
A few weeks after finishing treatment I developed an abscess around one of my front teeth and a perfectly healthy tooth just fell out by itself. Which had to be replaced by an implant.
At the moment I'm waiting for my dentist to remove another 2 of my back teeth because of periodontitis caused by constant abscesses.
I visit the dental hygienist every two months at very high cost to me.
As other Hepatitis patients have told me of similar experiences, I believe this has been caused by the virus.
- Dentists and Hygienists have regularly advised me to get tested for Diabetes because of this problem. The effect on the gums must be the same. They also keep suggesting that there must be a medical reason for the problems with my gums.**
I have recently been told that the gingivitis has now progressed to periodontitis.
- 5.13 I come from Switzerland, **where no one apart from some drug addicts, some of the gay community, sex workers or people who have had medical or dental treatments abroad, have infected blood. But, there are no people that have infections caused by blood products.**
So, because of this reason it's very difficult for me to let any medical professional or friends know about my condition.
- 5.14 My sister still lives in Switzerland and used to work in the medical profession,(she is retired), but even so when I first emailed her to say that I had been diagnosed with Hepatitis C, she told me never to talk about it in an email again, because she shared the email address with her husband and did not want him to know in case it affected our relationship. **My sister gave me strict instructions not to disclose my illness to her grown-up children or any of our other relatives.**
- 5.15 Still to this day my sister sends me every update she can find about infected blood, even though I do not want to see these things as it is just a constant reminder.

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- 5.16 My support group the Hepatitis Trust, has many people who were previously infected themselves. Outside this group I have found it very difficult to tell people. When I have done so in the past, a friend who was nurse, physically moved her chair away from mine.
- 5.17 My friends in Germany and Switzerland, have never heard of infected blood so I never talk to any of them about it.
- 5.18 As I was quite old (aged 40/ 41) when I was infected, it did not have any effect on my formal education, but after the infection, I always found it difficult to study for any courses while at work.
- 5.19 My working life has been affected significantly. I worked in the travel industry, which often meant taking groups of tourists around the UK on trips of varying lengths. Due to my constant tiredness, I would only be able to do shorter tours. Also I could not do 'back to back' tours like the other staff (meaning if a tour finished in York for instance, the other staff would start their next tour the very next day in York). I would have to return to London and take some time off. Eventually I could only manage half day tours in London.
- 5.20 I had so much sick leave due to the infection (I now know) that when I called in ill, the staff picking up the phone, would often make comments before I even said anything like "is it the flu again?", which I found very hurtful.
- 5.21 I knew that other staff were having to pick up all the work that I couldn't do. I found it very distressing to be thought of by my colleagues as lazy.
- 5.22 My work was paid by the day, so if I didn't go in, I didn't get paid. Therefore due to the amount of time off I had to have due to sickness, I earned significantly less than I could have.
- 5.23 Also it meant that I did not achieve my full National insurance 'stamp', therefore I am not entitled to a full pension. I have to have Pension Credit and I am entitled to receive Housing Benefit neither of which I want to have to take.
- 5.24 I received no advice from medical people about the risk of infections passing from me to other people. The only advice I got of this sort was from The Hepatitis Support Group, this advice relating to family and partners. **I was advised by the people at the Hepatitis Trust not to disclose the illness to the Dentist because of problems some patients had experienced.** Some people said that they had told their dentist and had then had not been unable to get treatment. Therefore I have never told my dentist, as they always wear gloves and masks.

Treatment/Care/Support

6. I have faced numerous difficulties in initially getting my infection identified and then obtaining treatment. I went to various members of the medical profession, for many years with numerous symptoms which should have made them suspicious that there was an underlying problem and sent me for blood tests at the very least. I had a check for diabetes but this was negative.
- 6.1 Whenever I raised my various symptoms with the GP I was told "I worried too much". I did have liver function tests, the results of which were always high, but none of the medical staff investigated these results. The GP would ask me how much alcohol I drank. When I told them that I drank very rarely, it was obvious they did not believe me. I feel I should have been sent to a liver specialist.
- 6.2 In 1983 I was taking Benzodiazepam (I do not recall the prescription) for anxiety but the general comment I got from my GP surgery was "don't worry so much". I became dependant on this drug and found it impossible to stop.
- 6.3 For 13 years before I was diagnosed (in 2006), I was treated with Hormone Replacement Therapy (HRT) because for all that time my GP still thought that I had the menopause. When it was eventually established that I had Hepatitis C, the GP commented that "the symptoms are similar" to the menopause.
- 6.4 In 1988 I had a total hysterectomy also related to the menopause, as I was always fatigued.
- 6.5 Throughout my numerous consultations with the medical profession prior to being diagnosed when I was 70 years old, I was constantly asked if I was an alcoholic because of my symptoms. Every time I truthfully answered that I drank very little but it was as though none of them believed me.
- 6.6 Over all this time I never received the service from doctors or nurses to send me for the appropriate tests, to identify my infection.
- 6.7 Then when I was diagnosed I had to fight for treatments to assist me in clearing it up.
- 6.8 I requested counselling in 2009/10 for depression via various parts of the NHS, and this has even been recommended by a doctor treating me for gastrological issues but it has never actually happened.

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- 6.9 I believe I also should have been offered Cognitive Behavioural Therapy because I do not want to just take anti-depression tablets all the time.
- 6.10 I have been recommended by the Hepatitis Trust to take some herbal remedies, I therefore take milk thistle to help with the fibrosis of the liver.

Financial Assistance

7. Since my infection, I have received financial assistance from the Skipton Fund. In 2011 I was given £20,000 as an ex gratia payment.
- 7.1 In 2017, I received £3,500 per year, in 2018 I received £4,500 from the EIBSS; this is for my stage 1 fibrosis. I have been told that I could apply for a stage 2 payment which would be £13,500 per year but the forms are far too complicated for me to be able to fill out.
- 7.2 In 2007 I had to pay privately for a Fibroscan to establish that I had fibrosis (it was minimal at that time) but the NHS would not test me for it at that time. The test cost about £200 which was a lot of money to me.
- 7.3 I find it extremely difficult to concentrate, Therefore it is very difficult to find the details that are required for the various applications that I have had to make over the years. I was 70 years old when this process started.
- 7.4 As far as I am aware there have been no pre-conditions imposed on the payments that I get.
- 7.5 When I received my payment from The Skipton Fund they informed me that it had been put in the bank but unfortunately I don't get this notification from EIBSS, so I do not actually know the money is available. I feel this should be changed.
- 7.6 The investigators have taken a photograph of a letter headed from the Department of Health but stating it has been sent by the EIBSS, it is not dated but is headed 'Infected blood: Special Category Mechanism (SCM) and financial and other support in England. The photographs (2 pages) are exhibited as **WITN0014003**, it lists the payments that are available for hepatitis C infections.

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Other Issues

8. In 2009 I applied to Chelsea & Westminster Hospital to obtain my medical records, specifically in relation to my original operation in 1977. They informed me that they were unable to trace my records. I didn't believe them because I was aware that the 'before and after' photographs of my facial plastic surgery were still at that time being used in lectures by various plastic surgeons.
- 8.1 I did not accept the fact that they did not still have my records, so I kept writing and telephoning them to, saying they must have them. My persistence eventually paid off because 2 years later, I received a copy of my notes, which apparently had been stored on microfiche.
- 8.2 I was invited to meet with a lady from the All Party Parliamentary group, (APPG) at Portcullis House on the 30th November 2015. There were people from medical and political backgrounds there and it was aimed at more people getting treatment with Harvoni. The Inquiry has the details of the lady from the APPG.
- 8.3 There is an issue with my sheltered accommodation.
Up until 2016 anyone over 55 could apply for sheltered housing. Since 2016 the age has to be 65+
Most residents in this building moved in prior to this ruling and the majority are in their early to mid sixties. I find it difficult to explain without sounding prejudiced - there are a high number of tenants with mental health issues, but noise is caused by a few serious alcoholics and some who openly consume drugs on the premises. Some days and mostly nights it borders on rowdy antisocial behaviour.
Before I moved here, I was under the misapprehension that sheltered housing meant housing for Senior Citizens. But it seems to be more, housing for people with various serious issues. This causes me a lot of stress and I feel isolated because of the lack of like-minded people of similar age as me.
Because of cost-cuts, there is no Warden present in the evenings or weekends and some tenants take advantage of this.
That is one of the main reasons I would like to be able to move out of social housing. I could do this if I would qualify for the higher payment from EIBSS.

I am happy for my statement to be read out, but I wish for my name to be taken off the statement.

Statement of Truth

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

Signed GRO-B Dated 22. Nov 2018