

Witness Name: Caroline Leonard
Statement No.: WITN3449023
Exhibits: WITN3449024 - WITN3449025
Dated:

INFECTED BLOOD INQUIRY

FOURTH WRITTEN STATEMENT OF CAROLINE LEONARD FOR BELFAST HEALTH AND SOCIAL CARE TRUST

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 from Deirdre Domingo, Deputy Solicitor to the Infected Blood Inquiry, to Belfast Health & Social Care Trust (BHSCT) dated 24 January 2020.

I will say as follows:-

Part A: Provision of Psychological Support

1. **Please set out your name, address and your role within the BHSCT**
- 1.1 My name is Caroline Leonard. My professional address is BHSCT HQ "A" Floor, Belfast City Hospital, Lisburn Road, BT9 7AB.
- 1.2 I am the Director of Surgery and Specialist Services at Belfast Health and Social Care Trust; as such I have responsibility for most specialist surgery, services provided at NI Cancer Centre, some medical specialities, laboratories and pharmacy. The Regional Haemophilia Comprehensive Care Centre falls within my Directorate and as such, I was nominated by my Chief Executive, Dr Cathy Jack to undertake a coordinating role in support of the Infected Blood Inquiry on behalf of BHSCT.

2. Please outline how psychological services are commissioned and funded in Northern Ireland.

2.1 Psychological services are commissioned and funded by the Regional Health and Social Care Board (HSCB). On some very specific projects, funding may come via the Public Health Agency; however, this is the exception rather than the rule.

2.2 Psychological services can be commissioned as part of a range of different clinical pathways within Northern Ireland. These commissioning arrangements are becoming better organised and utilised, as there is a growth in both awareness of the role of psychologists and also an expanding evidence base for the impact of psychological therapies, both in issues relating to psychological wellbeing and mental health presentations, and also in understanding the psychological impact of physical health challenges.

3. If psychological services are the commissioning responsibility of the BHSCT (either generally, or specifically in relation to those who have been infected with a chronic and serious disease such as HIV or HCV or HBV) please provide details of the services which are commissioned and are available to people who have been so infected, or whose partners or family members have been infected, and who have suffered psychological difficulties as a result.

3.1 The HSCB, not BHSCT, commissions clinical psychology services from each Trust. The normal practice of the Regional Hepatology Service based in RVH at Belfast Trust is to refer a patient to the Trust Clinical Psychology service if there is a perceived need – either by the clinical team or by the patient. This most commonly occurs with the liver transplant population. It is not routine practice to refer a patient to clinical psychology services on the basis of a clinical diagnosis of hepatitis B or C alone.

3.2 Additional clinical psychology support was funded by HSCB in BHSCT in 2012/13 specifically associated with the demand for the service as a result of the increasing number of patients in Northern Ireland with a diagnosis of HIV. The additional funding made available allowed the Trust to increase the clinical psychology team by one whole time equivalent Band 8A Specialist Clinical Psychologist.

3.3 The detail of the psychological services currently available to those infected and affected in Northern Ireland is outlined below in response to Question 5.

4. If psychological services are the commissioning responsibility of another organisation or agency (either generally, or specifically in relation to those who have been infected with a chronic and serious disease such as HIV or HCV or HBV), please outline the kinds of services that the BHSCT would expect to be available to people who have been so infected, or whose partners or family members have been infected, and who have suffered psychological difficulties as a result.

4.1 Not applicable – see answer under question 3

5. The Inquiry understands that:

(a) in October 2018 NHS England announced funding (of up to £50 million) for a new screening service to be put in place to provide long term support and treatment for people with physical and mental health issues following the Grenfell Tower fire; and

(b) a free and confidential NHS service (the Grenfell Health and Wellbeing Service) is available to children and adults affected by the Grenfell Tower fire.

Please confirm whether there is any equivalent or similar service in Northern Ireland for people infected or affected in consequence of infected blood or blood products. If so, please provide details of the service(s). If not, please explain why.

5.1 Services for patients with HIV, HBV and HCV are provided by BHSCT on behalf of the region. Prior to January 2019, no dedicated Psychology service was available to either the infected or the affected patients/relatives associated with the Infected Blood Inquiry. The Trust established a working group in September 2018 to consider the implications of the Infected Blood Inquiry work as this relates to Northern Ireland.

5.2 At an early stage the working group identified a requirement for additional psychological support specifically in respect of the needs of those people in Northern Ireland directly impacted as a consequence of infected blood products. A funding proposal was submitted to the Department of Health and non-recurrent resources were made available for BHSCT to put in place dedicated clinical psychology capacity to meet these needs. A full time Band 8A Specialist Clinical Psychologist is currently funded until the end of March 2021. It is anticipated that further recurrent funding to support this service will be considered in due course.

- 5.3 This Specialist Clinical Psychologist provides assessment, Psychological Therapies, liaison and sign posting as appropriate for HIV, HBV and HCV infected/affected patients and relatives since January 2019. A patient information leaflet attached as Exhibit WITN3449024 is available within clinics and to clinicians to discuss referral to this Service with patients and their families.
- 5.4 This leaflet is entitled the "Infected Blood Inquiry Clinical Psychology Service" and provides a location and contact number for the service. It provides details of additional support services, namely, the Haematology and Haemophilia Complementary Therapy Service, The Infected Blood Inquiry website details for confidential psychological support from the Red Cross, Haemophilia Northern Ireland, RVH Liver Support Group, Macmillan Support and Information Centre, The Samaritans and Lifeline.
- 5.5 The leaflet provides assurances regarding the confidentiality of the process, who the service is for, who provides the service and how the service may assist those who are experiencing distress as a result of their health condition and their family members. It provides a list of indicators to assist anyone affected identify the symptoms of psychological difficulties.

Part B: Treatments for Hepatitis C virus and follow-up care

- 6. Please outline how HCV treatment is commissioned and funded in Northern Ireland.**
- 6.1 Services for people with HCV are commissioned and funded by the Regional HSCB. HCV treatment is provided by the Regional Hepatology service based in RVH at Belfast Trust who provide a service for the region.
- 7. Please describe the current treatments that are available for HCV in Northern Ireland, their effectiveness and availability, including any restrictions and/or delays that may be experienced in accessing treatment.**
- 7.1 All NICE approved specialist drug therapies are available for HCV treatment in Northern Ireland (a table outlining approved drugs is attached, WITN3449025). Over the past 4–5 years, significant progress has been made by the clinical team in Belfast Trust in reducing the time taken for people with HCV to be seen at outpatients. There has also been a significant reduction in the time taken to access specialist drug therapies. These

improvements have been achieved through the development of close working relationships between the HSCB commissioning team and the clinical team providing the service to reform the pathway for patients.

7.2 Prior to November 2017, patients with HCV were offered a routine appointment and waited along with all other hepatology referrals for a first appointment. At its worst, this wait was over 12 months for a routine hepatology outpatient appointment. In November 2017, following agreement with the HSCB, BHSCT commenced a series of waiting list initiative clinics dedicated to HCV patients. Over 40 clinics were delivered and with an associated increase in the drugs budget funded by HSCB, the Trust treated over 200 patients in 2018. This progress was continued and by Autumn 2019, the waiting time for someone with HCV to be seen at clinic was reduced to around 8 weeks with a plan to start treatment within 3-4 weeks of assessment if the patient meets the NICE eligibility criteria for treatment.

8. What scans, blood tests and/or other checks and/or monitoring are, or should be, offered to a person who has been diagnosed with HCV, how often and over what period of time?

8.1 The Hepatology team in Belfast Trust advise that all new patients with a diagnosis of HCV are offered blood tests (FBP, LFT, U+E, Coag, AFP, TFT, Hepatitis C PCR, HCV genotype, HCV viral load), an ultrasound scan and a Fibroscan.

8.2 Those who have chronic hepatitis C and who are fit for treatment are offered treatment. If treatment is commenced, blood tests are carried out during treatment to ensure that liver tests remain satisfactory. At the end of treatment, hepatitis C status is checked (with HCV PCR Test) and again three months after completion of treatment. If the PCR test is negative at end of treatment AND three months post treatment, this indicates successful clearance of the HCV infection. In previous years, it was also the practice of the Regional Hepatology team at RVH to do a check-up PCR test one year post treatment. In keeping with practice throughout the UK, this is no longer required.

9. Following successful treatment, such that the person has received a sustained virological response (SVR), what follow up scans, blood tests and/or other checks and/or monitoring are or should be offered, how often and over what period of time?

9.1 The Hepatology team in Belfast Trust advise that patients who are PCR negative after treatment and who have a normal Fibroscan are discharged from the hepatology clinic.

Those who have an indeterminate Fibroscan result will usually have a follow up Fibroscan at least six months after finishing treatment. If the Fibroscan is satisfactory, the patients are discharged. Patients who have a Fibroscan suggestive of advanced fibrosis or cirrhosis are kept under long-term review at the liver clinic. These patients require an ultrasound and blood test for alpha fetoprotein (AFP) every six months to screen for hepatocellular cancer. In addition, such patients have a six monthly clinic review.

Statement of Truth

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

Signed

GRO-C

Dated:

19 Feb 2020 .