

Witness Name: Caroline Leonard
Statement No.: WITN3449100
Exhibits: WITN3449101-
WITN3449104
Dated: 1 November 2022

INFECTED BLOOD INQUIRY

TENTH WRITTEN STATEMENT OF CAROLINE LEONARD, ON BEHALF OF BELFAST HEALTH & SOCIAL CARE TRUST

I provide this statement in response to a request from GRO-D from the Infected Blood Inquiry for a written statement under Rule 9(2) of the Inquiry Rules 2006 dated 13 September 2022.

I, Caroline Leonard, will say as follows:

Section 1: Introduction

- 1.1 My name is Caroline Leonard. My date of birth is known to the Inquiry. My professional address is BHSCT HQ, "A" Floor, Belfast City Hospital, Lisburn Road, BT9 7AB.

- 1.2 I am the Director of Cancer and Specialist Services at Belfast Health and Social Care Trust (BHSCT); as such, I have responsibility for services provided at NI Cancer Centre, some medical specialities, renal transplant surgery, 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.

- 1.3 In order to address the questions posed in the Rule 9 request of 13 September 2022, I have spoken with colleagues in Hepatology, Haematology, Psychology and Palliative Care currently employed in the Trust. I have attempted to answer the questions as far as I can based on the information I have been able to obtain from the sources indicated and from my own knowledge and experience of BHSCT.
- 1.4 In drafting this statement, I have also referred to previous statements and exhibits supplied to the Inquiry in 2020.

Section 2: Ongoing Liver Care

In the statement you provided to the Inquiry [WITN3449023] you set out the arrangements for follow up for a patient with cirrhosis. Please provide any updated information on this issue.

- 2.1 I have been advised by Hepatology colleagues that the follow up arrangements outlined in paragraph 9.1 of my statement to the Inquiry (WITN3449023) of 19 February 2020 remain the same, with patients kept under long-term review at the RVH Liver clinic or their local hospital. However, as a result of the subsequent Covid-19 pandemic, waiting lists have grown for all Hepatology outpatient clinics such that a 6 month review appointment could possibly be delayed by several weeks.

Section 3: Palliative Care

The inquiry has received evidence (both written (EXPG0000043) and oral (INQY1000190) from a group of experts in palliative care in advanced liver disease. One of the issues raised by the group was the variable access to both palliative and end-of-life care for those with advanced liver disease. What if any plans are there in place to tackle this inequality?

- 3.1 In Northern Ireland, patients with advanced liver disease can be referred for assessment, advice and provision of palliative care at any point in their clinical pathway. Specialist Palliative Care Consultant colleagues advise it is well

recognised that non-cancer patients are less likely to be identified as having palliative care needs and to be recognised to be in their last year of life. Exhibit WITN3449101 is a copy of a 2015 report from Marie Curie entitled “Triggers for Palliative Care.” This report explores the evidence around access to palliative care for people with terminal illnesses other than cancer, including those with end stage liver disease (ESLD). It also uses existing evidence to identify factors that trigger palliative care referrals for people with these conditions. Earlier identification of patients with palliative care needs is a regional priority in N Ireland and is being championed by the Palliative Care in Partnership Board (PCiP), chaired by the Department of Health (DoH).

3.2 However, issues of social isolation, addiction and sometimes homelessness make it difficult for some patients with advanced liver disease to access usual healthcare and these patients tend to under-use primary care, and overuse the Emergency Department (ED), bypassing the usual supports and access to palliative care points. It therefore makes sense to identify patients having multiple ED attendances for assessment of palliative care needs.

3.3 At the PCiP Clinical Engagement Group meeting of 12 October 2022, data from a recent Emergency Department audit across NI Trusts to identify patients attending with unmet palliative care needs was discussed. Exhibit WITN3449102 is a slide from the PCiP Update presentation illustrating that this 1-day retrospective audit of attendances at NI Emergency Departments found:

- 76 patients (21% of all patients admitted to hospital from ED on that day) had unrecognised palliative care needs.
- Main reasons for attending ED were functional decline and uncontrolled symptoms.
- 67% of the identified patients had two or more ED attendances within the previous 12 months

3.4 I am advised Palliative care colleagues find it challenging to encourage other health care professionals to parallel plan for active treatment and palliative care in advanced liver disease. This challenge is partly due to the fluctuating course of the disease, with periods of recovery in between decompensation. The

patients and their relatives often expect recovery “like the last time” so it can be difficult conveying the need for advanced care planning and support.

- 3.5 In terms of Palliative Care education on offer in NI at present, colleagues are keen to make palliative care training part of mandatory training for all clinical staff to raise awareness of triggers and needs; however, this is still an aspiration and not a priority for development at this time.
- 3.6 There are no specific initiatives that Palliative Care colleagues know of at present to target access for patients with advanced liver disease. Hepatobiliary colleagues and GPs have a key role in initiating palliative care and onwards referral to specialist palliative care in hospital/community.

Please outline any plans as to how the palliative care system (particularly for those with advanced liver disease) might be improved in Northern Ireland.

- 3.2 I am aware that a regional Palliative Care in Partnership approach operates across N Ireland, with leadership from the Department of Health via the Palliative Care in Partnership Programme Board (PCiP), with membership from the Public Health Agency, all Health and Social Care Trusts, Hospices, charities, independent sector providers and general practice. I understand the current focus of the regional team includes:
- a. Early identification of people who are likely to be in their least year of life -
- In Primary Care via use of coding within the GP Information Platform to capture people on the Palliative Care Register
 - In Emergency Departments via implementing improvements arising from audits undertaken in NI Emergency Departments, (described in paragraph 3.3) which indicate a significant number of people presenting with unrecognised palliative care needs.
- b. Assignment of Palliative Care Keyworkers -

- the development of a quality indicator project for palliative care key workers so that everyone identified as having palliative care needs has a key worker, whether in the hospital setting or in the community.

c. Improving Palliative Care services in general:

- NI HSC Trusts to take forward the learning and recommendations of the National Audit for Care at the End of Life (NACEL) and participate in Round 4 of NACEL in 2024/25
- Pilot of a regional referral form for Specialist Palliative Care
- Consideration of a regional Individualised End of Life Care Plan in discussion with DoH professional leads.
- Workforce planning in the specialty and development of extended roles in nursing and allied health professionals.

d. Continued partnership working with the All Ireland Institute of Hospice and Palliative Care

3.3 Promoting Advance Care Planning with all healthcare professionals is a significant NI regional priority at this time. Advance Care Planning (ACP) is an umbrella term covering personal, clinical, legal, and financial planning to prepare for a person's future care. It is defined as an on-going process of discussion between an individual, those close to them and health care professionals that ensures people have the opportunity to have timely, realistic and practical discussions about what matters to them and to consider and record their wishes, feelings, beliefs and values, if they wish to do so.

3.4 The NI ACP policy was launched on Wednesday 19th October 2022. Exhibit WITN3449103 is a copy of the policy entitled "For now and For the Future". This launch will be followed up with a public messaging campaign, raising the concept of planning ahead when a person's health deteriorates. There is a planned programme for engagement of healthcare professionals on how to deliver ACP and identifying who needs it; again encouraging acknowledgement

of palliative care needs/last year of life in people who may have been previously unidentified.

Please provide any comment you consider relevant to the Inquiries Terms of Reference arising from the evidence from the expert group.

- 3.5 Palliative Care colleagues identify with the evidence that there are many innovative ideas therein that are limited by lack of funding. This reflects the experience of the team in securing the funding to commission the expansion of palliative care. It may also be helpful to conduct further research on the unmet needs for this particular patient group; the evidence secured therein hopefully leading to funding for service development and expansion.
- 3.6 Regarding expanding access to palliative care services, notwithstanding the present political circumstances in NI, Palliative Care colleagues anticipate the Health and Care Act 2022 will likely be adopted in NI in the future and will promote integrated working and better access to palliative care for all patients. This Act brings a new legal duty for Integrated Care Partnerships to commission specialist palliative care services; however, the outcomes as ever will rely on prioritisation, resourcing and implementation.

Section 4: Psychological Support

The Inquiry understands that there is a dedicated clinical psychology service available to all those affected directly or indirectly by infected blood, provided by the Belfast HSC Trust. Please provide an update as to

- (i) *whether this service continues to be funded and the extent to which future funding is guaranteed;*

- 4.1 I can confirm that the Trust has continued to provide this service. The Trust has secured funding for this service for the duration of the Inquiry from DoH, and is working with service commissioner colleagues to secure recurrent funding for the service. The Trust has no plans to discontinue the service.
- 4.2 The need for psychological support for patients living with chronic conditions in general has been increasingly recognised in recent years, including the needs

of those with Haemophilia and other blood conditions. The Haemophilia Comprehensive Care Centre has valued the availability of psychology as part of the multidisciplinary team as a result of the input related to the Inquiry. I am advised that the work with patients and families has continued to highlight this need as part of wider service provision as can be seen in the issues raised during therapeutic discussions. The BHSCT will continue working with service commissioners to look at the permanent funding of Clinical Psychology provision into the Haemophilia and wider blood condition services.

(ii) any information you have on the uptake of this service; and

4.3 Exhibit WITN3449104 is a report on the uptake of the dedicated clinical psychology service provided to those affected directly or indirectly by infected blood as at 27 September 2022. In summary, since the service began in November 2018, 1,406 clinical psychology appointments have been offered to 34 individuals who had either received contaminated blood or have been affected as result of a family member receiving contaminated blood.

4.4 Exhibit WITN3449104 also outlines a high-level thematic account of the concerns addressed during therapeutic discussions.

(ii) the services offered to those who apply.

4.5 The service offers individual psychological assessment, support and therapy for concerns noted in Exhibit WITN3449104.

Section 5: Patient Advocacy

Under what circumstances are patient advocates available for people with complex health conditions, such as advanced liver disease consequent to the use of infected blood and blood products?

5.1 The NI Patient and Client Council (PCC) was created on 1st April 2009 as part of the reform of Health and Social Care (HSC) in Northern Ireland. The role of

this organisation is to act as an independent voice for patients, clients, carers and communities. My understanding is the Advocacy Support Team employed by the PCC are available to advocate for any patient in navigating the health and social care system and/or to assist patients in making complaints to health and social care organisations.

- 5.2 Individuals with complex health conditions are well known to specialty teams because of the frequency of hospital attendances and they often have long-standing relationships with the clinicians. As such, I am advised that often these clinicians will advocate on behalf of their patients in accessing statutory benefits and support.
- 5.3 Many clinical specialties whose patient population consists of individuals with long-term chronic health conditions are supported by charities and patient groups that offer insight and advocacy to improve patient care. An example of this is the RVH Liver Support Group; an independent Northern Ireland based registered charity (NIC100892) with a network of volunteer liver patients and their carers providing confidential, compassionate, emotional and psychological support for all adults, teenagers and children coping with any liver condition. This group operates throughout Northern Ireland.

Statement of Truth

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

Signed

____ GRO-C _____

Dated

____ 1 November 2022 _____

Table of exhibits:

Date	Notes/ Description	Exhibit number
June 2015	Marie Curie: Triggers for Palliative Care: Improving access to care for people with diseases other than cancer.	WITN3449101
12 October 2022	PCiP Programme: Update Presentation to the PCiP Clinical Engagement Group – slide containing data from a 1-day audit of unmet palliative care needs across NI EDs	WITN3449102
19 October 2022	DoH: For Now and For The Future: An Advance Care Planning Policy for Adults in N Ireland.	WITN3449103
27 September 2022	BHSCT: Report on the uptake of a dedicated clinical psychology service to those affected directly or indirectly by infected blood	WITN3449104