Information resource for psychological professionals working with clients affected by the infected blood tragedy

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Introduction for people affected by the infected blood tragedy:

If you have been affected by the infected blood tragedy you might want to read this information pack to know what your therapist or other psychological professional has been told. However, we are aware that this could be emotionally challenging. Therefore, please think about any support you might want whilst/after doing this, or equally if you do not wish to read further, then that is not a problem. People affected by the infected blood tragedy have helped write this pack on your behalf.

Introduction for Psychological Therapists and other psychological professionals:

This information pack has been commissioned by the Department of Health and Social Care (DHSC) and coproduced by people affected by the infected blood tragedy and psychological therapists to provide you with background information and signposting, to allow you to inform, research further and upskill yourself in this area.

This was based on feedback from clients that they were spending too much time and energy educating psychological therapists about what happened. Some of your clients will have been those receiving blood products, whilst others may be family members, partners or friends affected. We consider all possible clients in this pack.

As with all aspects of therapy, you should gain supervision on this and follow the best available evidence-base whilst working within your professional competence. On behalf of those you will work with, we thank you for taking the time to engage with it to help them.

What is the infected blood tragedy?

In the 1970s and 1980s a significant number of people with haemophilia (or other bleeding disorders), or who had blood transfusions, acquired Hepatitis C and/or HIV because of receiving blood or blood products unknowingly containing these. This has also been referred to as a 'crisis' or 'scandal', and some people use the word 'contaminated' instead of 'infected'. The DHSC uses the term 'infected blood tragedy' which is the language we have therefore used in this document.

We have used 'quotation' marks because there are no correct words to use. It is important to explicitly check with your client what language they would prefer to use, as the words will have personal and political meanings to them; such discussions can be the start of sensitively assessing and formulating this with them.

What are blood transfusions and blood products?

Whole **blood transfusions** are a medical treatment in which a person (recipient) is given the blood of someone else (donor). Transfusions are delivered intravenously, meaning the donor blood is introduced directly to the recipient's blood stream.

Reasons for a one-off, whole blood transfusion can include injury, surgical procedure, or pregnancy and childbirth (i.e. any event with significant blood loss).

Other types of transfusions occur when it is only a specific *component* of blood that is needed, known as **blood products**. Reasons are usually when an individual has an inherited or acquired condition that means their blood can't carry out all the usual functions for healthy living.

One such condition is **Haemophilia**, a bleeding disorder in which an individual's blood does not clot properly to stop blood loss once it has begun. The most common type of Haemophilia, type A, is due to an insufficient or absent protein in the blood plasma called **Factor VIII**. Haemophilia only affects males. There is another bleeding condition call **Von Willebrand Disease**, which can affect both males and females and can also be associated with deficient levels of Factor VIII. Factor VIII therefore is not blood nor a blood transfusion, but is sometimes described as such in the media, which can create confusion.

People with bleeding disorders can be at risk of serious harm, and even death, so many require regular treatment with blood products to remain well. Today, Factor VIII products can be produced synthetically. Previously however Factor VIII transfusions did not just come from a single donor, they were made up of **pooled donations**, of up to 60,000 donors.

It's important to know your client's reasons for requiring a blood transfusion/product (or the person known to your client) and learn more about the condition or incident that led to this to understand and make sense of the psychological reactions caused.

What happened?

Today anyone who wants to donate blood is first **asked questions** about their health, any known blood-borne conditions they may have (notably HIV or Hepatitis C), and questions about any recent activities or situations which may mean the potential donor has been at increased risk of acquiring a blood-borne virus. If they are not deemed to have a condition or be at risk of having a condition, they can then donate blood. As an extra safety measure, donated blood is also then **screened** to ensure that it does not contain these conditions.

Historically this was not always the case. An individual who receives a donated blood product that contains HIV or Hepatitis C is at **high risk** of acquiring that condition. For blood products pooled from thousands of donors, it only required **one** of the donors to have HIV of Hepatitis C, for the entire product to contain the virus.

In the 1970s and 1980s, the UK government **imported** blood products from the USA to meet demand for Factor VIII. In the US, blood products were made using donations from **paid donors**, including those from populations with statistically **higher risk** of HIV and/or Hepatitis C such as people in prisons. As a result, many individuals who received factor VIII transfusions acquired HIV and/or Hepatitis C.

It's important to know when and how your client first started to learn about what happened to learn and make sense of the psychological reactions at that point, and how these may or may not have changed over time.

The Infected Blood Inquiry :

Over the years, there have been many inquiries on a national and international level, that for many of those affected by the tragedy were unsatisfactory.

In 2017, the UK government launched an **independent** statutory '**Infected Blood Inquiry'** (www.infectedbloodinquiry.org.uk) to "examine the circumstances in which men, women and children treated by National Health Services in the United Kingdom were given infected blood and infected blood products...".

The inquiry is ongoing and has led to various reports and a compensation scheme. The Expert Statical Group to the Inquiry has estimated that in the UK:

- around 1,250 people with bleeding disorders acquired HIV, of whom around 300 are still alive today
- between 2,400 – 5,000 people with bleeding disorders acquired Hepatitis C
- about 100 people acquired HIV through blood transfusion
- approximately 26,800 people acquired Hepatitis C through blood transfusion

On 29 July 2022, the Chair of the inquiry, Sir Brian Langstaff, published a first interim report on the subject of interim compensation for victims of infected blood. On 17 August 2022, the Government announced the interim payments of £100,000 to infected and bereaved partner beneficiaries of the current infected blood support schemes. In England, these payments were made by October 2022. The interim payments that were made as a commitment that met, in full, the recommendation.

On 5 April 2023, Sir Brian Langstaff's second interim report was published outlining the chairs 'final word' on compensation. The Government is currently considering the recommendations.

The final report from the Inquiry is expected in Autumn 2023.

The Inquiry has led to a range of feelings within the infected and affected community, with some feeling that the Inquiry has been positive and provided them with an opportunity to find community; whereas other have felt that the Inquiry can put additional distress and burden on them.

Your client may have taken part in the inquiry or may have received interim compensation. It has also meant that the tragedy is regularly in the news when reports are released. You should find out your client's thoughts and engagement with this, and the impact this may have had.

The role of the UK government and NHS:

Many infected and affected people feel mistrustful of Government and the NHS due to their believing that the Government knew about the risks of infected blood earlier than acknowledged, that there was concealment of infection across Government and in the NHS and therefore that people receiving blood products during NHS treatment continued to be exposed to the risks of infected blood longer than necessary. The inquiry was established in 2017 to explore circumstances surrounding the tragedy, including the actions of Government. The Government has accepted the moral case for some compensation to be paid Some infected and affected people would want the Government to accept legal liability. Infected and affected people have described that the delay in an Inquiry being established, and the Government response to the Inquiry as causing them unnecessary additional distress and burden in addition to the direct physical, psychological and financial issues that having acquired and lived with the viruses causes.

Due to previous role and view of the NHS and government it is important to consider how this might impact on the level of trust your client feels able to put in you. This is especially for NHS therapists, though trust in healthcare providers in general may also be lower.

What is HIV?

HIV (Human Immunodeficiency Virus) is a type of virus that weakens the human immune system. HIV mainly targets "CD4 cells", a type of white blood cell used in the immune system to manage infections and diseases.

Today, if the person living with HIV has access to medication ("antiretrovirals", mostly daily pills but some new forms are monthly injections) they can control the virus, the aim being for the "viral load" to become undetectable. This means HIV cannot then be acquired by others (aka U=U, Undetectable = Untransmittable) and that the person will have a normal life expectancy. There is currently no mainstream 'cure' for HIV that fully removes it from the body, although there have been rare accounts of this happening when people have had major invasive treatments for other illnesses (e.g. gene therapy, stem cell transplantation).

If untreated, or if medications no longer work ("antiretroviral resistance") HIV can progress to AIDS (Acquired Immunodeficiency Syndrome), where the immune system is severely compromised, making the person vulnerable to serious infections (e.g. pneumonia, tuberculosis, brain infections) and cancers (e.g. Kaposi's sarcoma, Non-Hodgkin's lymphoma, cervical cancer, anal cancer, Hodgkin's lymphoma). Without treatment HIV could be transmitted through specific bodily fluids such as blood, semen, vaginal fluids and breast milk.

There are also medications people without HIV can take to reduce their chances of acquiring HIV (known as PEP and PrEP, Post Exposure Prophylaxis and Pre-Exposure Prophylaxis). These would only be needed if a sexual partners viral load was detectable or unknown.

Medicine has advanced significantly in the treatment of HIV, and it is important that everyone is educated about this to continue to challenge stigma. However, this was not the case when many people acquired HIV during the infected blood tragedy. No HIV treatments or tests existed initially, and it was considered a terminal diagnosis. Furthermore, there was little understanding of how HIV was transmitted. All of these factors contributed to the stigma and discrimination those living with HIV were subjected to, and for many the trauma this caused.

Due to the timing of the infected blood tragedy (1970s-1980s) many people died as medication was not advanced. Further, people who are living with HIV from this today will have had very different prognosis and experience compared to people recently acquiring HIV.

What is Hepatitis C?

Hepatitis C (HCV, Hep C) is a type of virus that mainly affects the liver. Whist there is no vaccine currently for Hepatitis C, antiretroviral medications and ‘interferon’ (a treatment based on proteins) can ‘clear’ (remove) the infection. Many people living with Hepatitis C do not show any symptoms in the first couple of years, and people have been known to live with the condition for 20 years without diagnosis, and so may be unaware they have the virus. As the virus progresses, if untreated it can cause chronic and serious liver disease, such as scarring of the liver (“cirrhosis”), liver cancer, and liver failure. If untreated it can also be acquired by others through blood exchange. Whilst medical treatment is improving, there remains significant stigma against people who have had, or have, Hepatitis C.

Treatments have improved considerably since the beginning of the infected blood tragedy, so those who were diagnosed earlier are more likely to have experienced serious side effects of the treatments.

People who acquired Hepatitis C through the infected blood tragedy might not otherwise have known they were at risk and so did not get tested, and may be likely to have experienced more serious effects of Hepatitis C. Due to differences in diagnosis and treatment over time, it’s important to understand different experiences people may have had, and the impact of this.

What is HIV/Hepatitis C co-infection?

HIV and hepatitis C co-infection is when someone has both HIV and Hepatitis C. It can complicate the treatment of both and lead to more rapid difficulties, as the medications used for each can cause negative interactions with each other.

From the infected blood tragedy, although some people may have been living with one of the viruses before acquiring the other, the majority of those co-infected will have acquired both from the infected blood products used to treat them. This may had added to complications in diagnosis and treatment, as well as the impact it had on those affected.

Diagnosis and psychological adjustment:

Everyone's personal psychological reaction to a diagnosis of HIV and/or Hepatitis C will be different. There are, however, some common themes people have reported to be mindful of.

It is crucial to understand the context within which someone received their diagnosis. For many, they would not have had any idea that they had acquired HIV and/or Hepatitis C, as little was known about the conditions or how they were acquired. Moreover, it's important to listen to **how** people were told about the diagnosis. Many people report not suspecting or being prepared for the diagnosis, being told in a blunt way and/or given a poor prognosis with little support. There are reports that children may have been told alongside other children without their parents present. When chronologically someone's diagnosis occurred is also very important, as the messages and treatment about the illnesses has changed dramatically over the past five decades. Likewise, age at diagnosis is important: if they were a child, they would have still been in the process of forming their self-identity and learning about the world and others; if they were an adult, a previous sense of identity and world view may have been shattered. There is no such thing as a 'good' or 'better' age or time to be diagnosed, rather this must be considered when understanding and formulating in a person-centred approach.

Someone's personal beliefs and knowledge about HIV/Hepatitis C before and after diagnosis will be important (e.g. do they know others with the illness, do they hold any stigma themselves, do they think it's a 'death sentence'?). Many people report initial trauma and shock, then anticipating a negative change in life trajectory and length, with uncertainty and fear for the health of themselves and loved ones, as well as concern regarding stigma from others.

General beliefs around illness will also apply (e.g. is it seen as 'fate', a personal responsibility, a test or punishment from God(s)?), that might affect how someone adjusts to the news.

From the infected blood tragedy, an additional point is knowing that if they had not received the blood products at all they could or would have died, but that the blood products have also negatively affected their quality of life by transmitting HIV/Hepatitis C, and for some been an expected "death sentence". It may be important to explore this ambivalence around something that simultaneously potentially saved one's life whilst also threatening it and/or changing the course of it.

Day-to-day impact of living with HIV/Hepatitis C:

Some daily impacts of living with HIV/Hepatitis C are shared with other chronic long-term health conditions, whilst some will be unique, especially those related to stigma and changes in medicine meaning for those alive now a terminal prognosis may have changed to a life-long condition. Again, the individual experience is important to formulate, and can be guided by enquiries into some of the below areas.

Physically, there can be impact from the virus and/or side effects from treatment and medications that can cause fatigue, pain, nausea, and changes in mood, appetite, body shape and image, and sexual and/or cognitive difficulties (e.g. problems with memory, concentration, or problem solving). As well as being unpleasant in themselves, these can impact on the ability to participate in, or enjoy, relationships, hobbies, travel, socialising and education/work. If they do not know anyone else with the condition it can also be a very isolating and lonely experience, with people feeling different to, and cut off from, others. Therefore, it may be important to check out local/national sources of support, and whether the person you are working with is already aware of/open to accessing this.

In addition to managing the physical effects, there can be a fear of, and experiences of, rejection and stigma from family, friends, colleagues and partners. This leads to understandable anxiety and low mood, and potentially negative impact upon self-esteem, as well as navigating who to tell, and who not to tell, about their health condition (legally, practically, and emotionally).

There can be concern that they may have unknowingly transmitted, or might transmit, the virus to others, which may have caused feelings of guilt, anxiety and fear. Especially during times when there was inaccurate information about how the viruses could be transmitted (e.g., false ideas that sharing a toilet, cutlery, hugging etc. was a risk) They might also know and have lost others living with HIV/Hepatitis C, and they themselves may have planned for death, only to find themselves still alive (sometimes termed 'survivor's guilt').

There is also the concept of 'post-traumatic growth', in which people say that whilst they would never have wished to acquire HIV/Hepatitis C, that it has taught them positive things about themselves/others. This is not a view shared by everyone however and should be asked about sensitively.

From the infected blood tragedy, an additional point is that the person may have a health condition that required the initial blood transfusion/product(s) that also requires management. Furthermore, some people may find it hard to identify with people or resources in which HIV/Hepatitis C is acquired through other means, such as sex, drug use, or childbirth.

Stigma and social reactions:

These diagnoses were (and still are) heavily stigmatised. For HIV, the lack of effective treatments until the mid-1990's meant for most a diagnosis meant death. This coupled with limited knowledge about how HIV was transmitted and national campaigns, created a pervasive sense of fear. Many people living with HIV were shunned, experienced prejudice and abuse. As HIV in the UK was largely associated with gay men, people who acquired HIV often experienced homophobic abuse and discrimination regardless of their sexuality. Similarly, Hepatitis C was often associated with intravenous drug use, and having a diagnosis often came with stigma and judgement from others. Thus, many people experienced rejection by society whilst others hid their diagnosis and lived in fear of it being "discovered". Sometimes this stigma is 'internalised', affecting self-image and self-esteem. Although societal views mostly (though not entirely) continue to improve; many people who were diagnosed in the 1980's and 1990's understandably remain traumatised by the stigma and discrimination they experienced at the time.

Those who acquired HIV/Hepatitis C through the infected blood tragedy might have had incorrect assumptions made about them, and faced social stigma, judgement and rejection.

Impact on relationships:

These same processes may have also occurred within existing relationships. Partners, family and friends may have been worried about acquiring the condition themselves, be unsure how to support the person living with HIV/Hepatitis C, or be worried about how to cope with their presumed death. Sex and intimacy may have been significantly impacted from fear of putting partner(s) at risk. Many people living with HIV/Hepatitis C express concerns about how to broach the topic with new people out of concerns they will be rejected, or that the person may not keep their confidence if they are not public in their HIV/Hepatitis C status. In addition to this, treatment for Hepatitis C can result in impotency and people are advised not to conceive during treatment.

Combined, this may have led to isolation, rejection, and loss, all when connection was most needed. It may also change the expected trajectory people have for their lives. For many people who imagined a future with children, this became no longer possible (either medically and/or practically) which led to grief for a lost future.

Some of those who acquired HIV/Hepatitis C through the infected blood tragedy might have had mistrust from those close to them when diagnosed, including not knowing how someone acquired it.

Affected family members:

For parents or partners who may have already been worried about a child or loved one with a serious bleeding disorder, they now had to manage that the person had an additional health condition and would likely die. This may have been further complicated for some by thoughts about their role in supporting them to have blood products (despite no knowledge of the danger, and that not accessing blood treatment carried a risk of death in many cases).

It's important to consider the loss and grief of family members of the person who acquired HIV/Hepatitis C, whether they are your main client or not.

Intersectionality & Inequality:

Intersectionality means that everyone's experience of a given situation is unique because of their personal set of circumstances and identity. This allows us to understand how one person's experience of the tragedy, and the impact it had on them, may be very different to another person's, based on other discrimination and oppression they may have faced before acquiring HIV/Hepatitis C, and in the time since. This means that people who have experienced systematic discrimination due to a combination of their race, sexuality, gender, class, age, physical and cognitive ability, etc. may have been impacted by what has happened differently to those who have not.

Whilst the infected blood tragedy may be what has led to the client meeting with you, it should not be seen in isolation, and any other aspects of disempowerment should also be formulated.

Summary:

We hope this information pack has been useful in updating you about the infected blood product tragedy, its political context, and the physical and psychological aspects of living with HIV and Hepatitis C, some of which may be unique for those who acquired the virus this way. Each client is unique and will have different experiences and relationships to the above. We hope this pack provides areas and ideas for a compassionate assessment and formulation from which supportive treatment can emerge. Our goal is that it will reduce the burden of clients having to explain the fundamentals of what happened and their conditions, allowing more time for psychological therapists to provide a meaningful intervention that understands and improves the wellbeing of those affected. Thank you for your work in this.

Acknowledgements:

We would like to thank the support and hard work of all stakeholders involved in the coproduction of this information pack, and we have done our best to represent and balance all views. We welcome further feedback on this as it is used, so that it can be further improved and refined.

Please send your feedback via the England Infected Blood Support Scheme who will forward on to relevant parties.

Email: **eibss**@nhsbsa.nhs.uk. **Phone**: 0300 330 1294

Further resources:

In addition to supervision and this document, you may find some of the following resources helpful depending on the specifics of the client you are working with.

Briefing papers

- Standards for psychological support for adults living with HIV (2011)
- BHIVA Standards of Care for People Living with HIV (2018)
- Reports from the Infected Blood Inquiry (2022-present)

Websites

The infected blood inquiry:
https://www.infectedbloodinquiry.org.uk

English Infected Blood Support Scheme:

www.nhsbsa.nhs.uk/england-infected-blood-support-scheme

Various online support and campaign groups exist, below are relevant Charitable status organisations

HIV:

- https://www.tht.org.uk
- https://www.bhiva.org
- https://www.nat.org.uk
- https://positivelyuk.org

Hepatitis C:

- http://www.hepctrust.org.uk
- https://britishlivertrust.org.uk