

Consultation Response: Infected Blood Compensation Study

The Hepatitis C Trust, December 2021

Background

The Hepatitis C Trust is the UK charity supporting people who have, or are at risk of, hepatitis C. We have been in operation since 2001, and opened our Helpline Information and Support Service in 2004 which has received over 55,000 calls. Over the last 17 years many thousands of these calls have been from people who received infected blood or blood products and their families.

In the main, these calls have been people who received blood transfusions although we also support many people who contracted hepatitis C through blood products, and others who, for example, contracted it following organ transplant.

Aside from the numerous views and concerns that we have heard over recent months regarding the compensation framework through our helpline, as specific preparation for providing you with our response, we held focus groups with people directly infected and affected to gather their views.

We hope to reflect these within our response, but should highlight that we write this from the perspective of our organisation and the concerns we have heard, but also that we represent only a fraction of people affected by this tragedy.

We have also sought legal advice to ensure we can answer these queries in full given the legal nature of many of the issues raised.

In this regard, we are very concerned that there is no funded legal support available to the people affected, and would like to strongly urge Sir Robert to ensure funding is made available for the wider patient population to seek legal representation within this process.

Asking lay people, many of whom suffer significant ill health, to comment upon questions such as *To what extent should the measure of assessment be guided by the law of damages?* and *To what extent should the scope of compensation be limited by the principles applicable to legal claims for personal injury caused by negligence?* without legal advice is unfair and systematically disadvantages people affected, acting as a barrier to their taking part effectively.

Response to specific queries

Scope of compensation scheme - persons entitled to claim:

Entitlement to claim should be anyone significantly affected. This should include those directly infected, and family members or others whose lives have been significantly affected and impacted by this. In particular, this should include:

Relatives

Children of the infected

Parents of the infected

Siblings of the infected

Parents who have lost children

Children who have lost parents

Other categories:

Individuals whose infection occurred after the cut-off date of September 1st, 1991.

Individuals who have had their medical records destroyed by the NHS.

Carers

Others who are in a close relationship to the infected, who can demonstrate that their lives were significantly impacted by the infection/s and their consequences

The estate, and/or surviving families or carers or others significantly impacted, where the person given infected blood has died.

Categories of injury and loss for which compensation can be awarded:

We would expect the losses to include the physical, psychological, financial, and social (including loss of consortium) impacts of receiving infected blood and its consequences.

Additional categories to be acknowledged for an award of compensation should include awards for loss of consortium, and exemplary damages.

Principles for personal injury caused by negligence: key elements to establish a claim

- Duty of care.
- Breach of that duty.
- Damage (which is caused by the breach)
- Foreseeability of such damage.

Relevance of fault:

Compensation should be paid irrespective of proof or acceptance or fault on the part of a public body or employee or agent of a public body.

Measure of assessment

The individual people affected have all faced very different circumstances, challenges and outcomes as a result of their infection through NHS blood and blood products.

We believe that a tribunal system in isolation would not be effective for the families affected. For many, this is likely to mean being involved in yet another lengthy and traumatising process, which may provoke additional stress and trauma for some.

We believe that a hybrid system of damages, with an interim fixed rate in combination with an assessment of damages based on individual circumstances, would be more appropriate. It is likely some people may prefer a fixed tariff being available also, to entirely avoid any type of tribunal.

We would also stress the need for a prompt and responsive system which administers payments with ease, as many individuals have multiple health problems, increasing age, limited life expectancy and increasingly difficult financial circumstances as a result of their infection, so monies need to be administered swiftly.

General damages are regarded as insufficient. Special damages may be appropriate for past and future losses and, in some cases, exemplary damages where for example medical records have been destroyed resulting in late, terminal diagnoses.

Types of award: compensation for past, present or future injury, loss or detriment

Compensation should be paid for past, present and future injury and loss and many people's health will progressively deteriorate, and this deterioration will have impacts on other parts of their life. Aside from liver damage, failure or cancer, hepatitis C infection and also the older interferon treatments for it, are both known to predispose people to a variety of additional health problems (for example, type 2 diabetes, thyroid problems, rheumatoid arthritis)

Types of award: one off or periodic assessment.

We feel that a one off assessment is preferable without the need for periodical assessment. Those infected and affected feel the continued assessment causes prolonged anxiety and psychological distress.

Compensation should allow for reassessment if there is a substantial change in circumstances, however, which may be a change or deterioration of health, similar to the provisions available under the Irish tribunal system.

The award should look holistically at the range of impacts caused by hepatitis C and HIV. As described above, this must include the physical impact, loss of earnings, impact on family and relationships, social health, mental health and associated illnesses (type 2 diabetes, thyroid issues, rheumatoid arthritis, for example) as a result of infection itself, and of side effects from treatment.

Awards should consider the impacts upon children of the deceased and the bereaved, which can be significant and complex.

Types of award: lump sum or periodical payments:

We believe that an effective system should provide an immediate financial lump sum as an interim payment. Alongside this, the tribunal element would assess individual compensation accurately.

Ongoing periodical payments offer stability and is the preference of some patients in order to ensure they are able to meet their financial needs and obligations over the long term.

With regard to the ongoing blood support scheme payments, which are ex-gratia and categorically not compensation. These provide the basic support to enable people to continue to live full lives in spite of the physical and mental health impacts of the virus(es) given to them. It is essential that these continue for exactly this purpose.

Time of infection:

Since the helpline started in 2004, we have heard of multiple cases where claimants to the Skipton Fund/or the current support schemes have been deemed ineligible because their infection occurred outside of the time frames currently defined; i.e. they were infected after September 1991.

We know from the Infected Blood Inquiry, that there was potentially infected blood in the blood supply after this date, which in fact reflects the point at which blood began to be screened. Any cut-off dates for infections acquired should reflect these findings. If the Inquiry does not provide conclusions for how long HCV may have remained in the blood supply, a specific piece of work should be undertaken to establish an evidence-based estimate of when hepatitis C would no longer have been present in any UK NHS blood or blood products.

Time limit for claims:

People are still contacting us who have just been diagnosed with hepatitis C, and whose only risk factor is an historic blood transfusion or receipt of a blood product. We hear from approximately two people per month in this situation. The most recent of these calls, received today, was from an individual who had a blood transfusion in 1981: 40 years' ago.

Any date that is established for this mechanism must take into account that some people who contracted hepatitis C through blood transfusions are still undiagnosed. Many of them will be very, very unwell by the time of their diagnosis as a result of a long term infection. Giving them time – at least several years – from the point of diagnosis to find out about this mechanism and make a claim is imperative.

Continuation of existing schemes:

The existing support schemes do not compensate the individuals affected and were not formed in order to do so; they are entirely separate from compensation. We believe the support schemes should be continued and guaranteed for life on a statutory footing.

We do not agree that any monies received through the support scheme payments should be offset through the compensation scheme as we see these payments as entirely independent. The people infected and affected by contaminated blood have suffered a variety of immense harms and long-term injustice; a core principle of any new compensation framework must be that this process does not make claimants worse off.

Availability of state funded medical treatment and social support:

Assessments of entitlement to compensation should not take into account NHS treatment and state funded social support when creating a framework for compensation.

Proof of entitlement:

The onus of proof should not be placed on the claimants to prove injury, loss, damage or detriment for compensation.

Proving the receipt of infected blood, under the current assessment systems, to access support payments for many is a complex and difficult task as people often find they have had their medical records destroyed or they are incomplete. It is then extremely difficult to have a successful claim. Therefore, responsive, professional and compassionate support should be provided throughout the process, to assist people swiftly and guide them to ensure people can gather any evidence required.

Tax and state benefits:

Compensation awards in relation to liability for tax should be treated the same as the current support scheme payments and have no liability for personal income tax.

Most of the people we have spoken to are aware that if lump sum compensation is paid this would make them ineligible for continued state benefits as they would be significantly over the threshold.

Scheme Administration:

If it is deemed appropriate that an individual assessment process is required, we believe a panel would be preferred. We would suggest a panel of experts comprising a judge, healthcare professional, an individual who was infected or affected themselves, and a psychologist or similar expert.

We also believe that the process should be inquisitorial and supportive, rather than adversarial in nature. Unfortunately we have heard many reports of people who have been made to feel that they were “begging” in the past when making applications to the blood support schemes, which in itself is a long and drawn out process for many.

If individual assessments are to take place we reiterate that the process should be clear, concise and completed as quickly as possible.

Advocacy and support

It is recognised that whatever system is implemented, some claimants will need assistance in making applications and requesting evidence. Much of our work on the helpline is to support individuals with their applications to the current support schemes.

Many of the people we support, and who would be entitled to compensation, suffer with brain fog, are older and may have multiple other health conditions. In addition, many are often not IT literate, or have access to computers. This means that advocacy, clear accessible information and support are essential for ensuring equal access for all

We would like to see dedicated advisors who can assist claimants on an individual basis. Some claims are quite complex, in particular where they require claimants to research historic NHS records, obtain expert medical opinions (required to show likely transfusions where not recorded or are no longer in records) or similar. Support should be available for claimants to assist with this, from the beginning.

We would emphasise that while we have supported people through this process with the current schemes, this is extremely time consuming and almost impossible to gain external funding for; funders believe this type of work should be paid for by Government or NHS bodies. We do not expect our funding will extend to providing ongoing support to people through compensation.

If paid large sums, additional access to financial advice should be provided to ensure people have the opportunity to plan accordingly for the future.

Right to claim damages:

There should be no double recovery under the terms of the scheme.

Devolved nations:

Compensation should be a UK unified system across the devolved nations that further advances parity across the nations.