



# SIBF Carers Survey

This survey was carried out between 16th January to 6th of March 2025 and was created by SIBF (Scottish Infected Blood Forum) to gauge the challenges and record the experiences of infected blood carers and infected people being cared for, or that will be cared for in the future.

### Context

The Scottish Infected Blood Forum is a Scottish registered charity, SC043464, established in 2012, supporting and advocating on behalf of people infected and affected by contaminated blood with HCV, HBV and HIV, from transfusions and/or bleeding products. SIBF has represented infected people and their families since it was founded. The recent additional May 2025 hearings conducted by the Infected Blood Inquiry confirm the concerns raised by our members about the lack of Government and the Infected Blood Compensations Authority's meaningful engagement with infected and affected victims since the Second Interim Report. The detailed set of recommendations published by the Inquiry in April 2023 was issued to expedite fair compensation, which it appears the government and its entities are incapable of delivering. The UK Government insisted it must wait for the inquiry's final report, (published in May 2024), before making any formal response to the detailed recommendations on compensation set out in the 2023 report. However recent disclosures confirm that the Cabinet Office established an Expert Group, comprising of clinicians and legal negligence lawyers from the end of October 2023<sup>1</sup>. This group was a panel led by the Cabinet Office which developed the compensation proposals using consultants, without any engagement with victims, and with scant reference to the 2nd Interim reports recommendations on eligibility, scope, design, and recognition of loss.

Subsequently the government has developed a compensation scheme, which is almost universally opposed by victims, and which perpetrates rather than addresses injustice. This paper focuses on the experiences of carers and the cared for, relating to the Care Award component in the scheme. SIBF created a survey which asked carers and people who were cared for about their experiences which is something the government has failed to do itself despite its legal duties to uphold Equalities and Human Rights legislation.

This report summarises some of the anecdotal evidence provided by carers and some cared for about their experience. The Care Award is a significant element of the compensation package, considering the impact of viral infections of each and every victim of this tragedy. This award is crucial to those bereaved affected who's care and suffering, we view, remains unrecognised by the tariff frameworks for many carers for past care. Equally in terms of future care, the purpose of the award is to spare victims and their families the same degree of suffering endured by victims in the past in the future. Instead, we believe government-imposed tariffs based on the minimum hourly rate and with deductions of between 25%- 50% and coarse and ill-judged calculations of time spent caring perpetuates discrimination against surviving victims. The government has itself not made any attempt to either assess care from the perspective of victims and or in reference to evidence gathered by the inquiry. Only one expert witness used by the inquiry was marginally consulted. Therefore, the lived impact on the cared for and carers has been not only completely disregarded, but the scheme is oblivious to the suffering endured. This lack of engagement in the design and measuring of impact results in a compensation scheme that perpetuates injury. Carers are not compensated for financial loss, career damage,

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<sup>1</sup> <https://www.infectedbloodinquiry.org.uk/news/inquiry-publishes-additional-evidence>



yet 25% of the past care element of the award is to be deducted because they did not pay tax and national insurance as carers for a relative or loved one. The government has refused pleas to use this deduction to top up the gaps in state pension contributions or to give carers the right to do this themselves. Even though being forced into caring because the state infected their loved ones and failure to provide care denied these carers the right to paid employment and currently a full state pension.

### Background

The Government has consistently disregarded and failed to support the majority of carers for Infected Blood victims. Across the cohort of carers only, bereaved spouses and partners have ever received support from the support schemes established in 2017. In terms of recognition for compensation, in 2022, 927 interim payments were made to spouses / partners. 4519 individuals registered as infected survivors also received interim awards<sup>2</sup>. The figure of 3,000 plus is often cited as the scale of those that have died from infected blood and or blood products. These figures implies that approximately 2073 plus estates had been cared for by someone other than a spouse. None of these carers have been recognised by the support schemes. The Equalities Assessment for the Scottish and English Support Schemes for Infected Blood cohorts produced in 2017, are broadly similar. Both acknowledge only the care provided by spouses and partners. The Scottish Public Sector Equality Duty document states:<sup>3</sup>

*'Those primarily affected by the reforms will be infected individuals and affected family members of infected individuals, particularly those who are/were financially dependent on support given by the schemes. This includes spouses or partners who do not work full-time because of caring responsibilities; bereaved spouses or partners and any dependent children. We are proposing to improve the financial support available for all those affected, who will include many of the equality groups. There are no negative impacts on any equalities groups. All those infected and their families should be better off (or at least receive the same support) under the new scheme as compared to the current arrangements.*

Whilst governments have recognised the role of spouses and partners as carers, and the financial impacts on the family unit, the claim of 'no negative impacts on any equalities groups' are demonstrably false. When this issue was raised with the Scottish Government by one campaigner the Scottish response was to assert that failing to support other family carers was not discriminatory because both genders were forced to become carers not just women. Whilst many men, be they father's, partners, sons or brothers, have also had the trajectory of their lives impacted by being forced into caring for an infected loved one, statistically carers of infected blood victims will be in majority women. The question arises as to the reasonableness of the state to deny responsibility for infection for decades, and consequently to injure so many

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<sup>2</sup> Note on Interim Payments – x **Interim Payments made by Devolved Administration Schemes, IBI 10<sup>th</sup> July 2023**

<sup>3</sup> <https://www.gov.scot/publications/equality-impact-assessment-support-those-affected-infected-nhs-blood-blood/>

victims so egregiously that they required care and the sacrifices of so many as secondary victims. The statement of Richard Gutowski <sup>4</sup>, formerly the civil servant overseeing, Blood Policy in Scotland frames consideration of other relatives as being based purely on a cost basis, despite the introduction of the Equalities Act in 2010 and Human Rights Act in 1998. Given the production of the PSED itself, government should have considered not just the families of the deceased, but also the majority of carers for living infected who were being cared for by a relative or partner or a spouse, who in turn were forced to depend on the person they cared for financially, because they themselves were denied the right to work.

On the 28<sup>th</sup> of April 2023 the Scottish Government published an Equalities impact assessment as part of its National Carers Strategy. This document<sup>5</sup> recognises that, carers tend to be women, who have, under the Equalities Act 2010, protected characteristics. It also recognises that women tend to become carers between the ages of 50-64 years old, (thus recognised by the Equalities Act on the basis of age), and that as a result of caring that *'41% of carers have a health condition and that 16% were deaf or had partial hearing loss, 16% had a physical disability, and 6% suffer long term mental health condition'*. Therefore, many carers have also suffered health impact and qualify themselves as disabled. The report also notes that *'the longer the hours dedicated to care the greater the increase in physical and mental health impact'*. Given the Inquiry recommendation for the government to establish psycho support schemes and the evidence given during the inquiry, prompting the recommendation, it is clear that mental health has been a significant element of the damage endured by both the infected and affected.

### The Governments Assessment of Care in the Compensation Scheme

The recently published documents by the Infected Blood Inquiry reveal the degree to which the government sat in closed rooms and either talked to each other or with commissioned consultants and devised a compensation scheme not to remedy the injustice but what it wished to spend. A document from 7<sup>th</sup> of November 2023<sup>6</sup>, as just one example, states:

*'Our proposal, given the length of time for legislation to pass before an ALB can be established, is to set up an expert committee now, who will support officials in defining the awards/tariffs, but who will work within the fiscal boundaries set by the government.'*

Another document<sup>7</sup> reveals that the scheme was originally costed by the Conservative Government at £14.33 billion with £10.5 billion to be awarded to those infected deceased and alive, and £3.83 billion to those affected. Over the course of 2023- 2025 officials seem to have whittled down the costs of the schemes not based on actual damages, but to reflect governments budgetary desires. The overarching narrative of the recently published working of the Expert Group, direct by Cabinet Office officials and the legal firm Browne Jacobsen LLP, demonstrate

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<sup>4</sup> WITN5292016 - Second written statement of Richard Gutowski; 11 May 2022, sections: 230 & 2.136

<sup>5</sup> <https://www.gov.scot/publications/equality-impact-assessment-national-carers-strategy/>

<sup>6</sup> CABO0000922 - Note on Appointment of Expert Committee - 07 Nov 2023.pdf

<sup>7</sup> CABO0000916 - Infected Blood Compensation Scheme Proposal Follow Up Advice to the Deputy Prime Minister - 13 May 2024.pdf item 22 on page 6

that scant reference was made the recommendations on compensation made by the Infected Blood Inquiry. A statutory body, who has spent 6 years investigating the scandal. There was no involvement or consultation with those impacted or their registered legal representatives, who were unaware that these meetings were taking place. The 'Expert Panel conducted two workshops on Care and Social Care in 2024 and the firm of Bush and Co were used to define tariff bands. This firm had no involvement in the inquiry and claim no expertise in care for infected blood victims. Considerations on the Care Award were covered by follow up discussions which are unclear due to the summative nature of the minutes and the degree of redactions in the published supplementary documents: especially on matters surrounding the affected. There was some engagement with Sir Robert Francis and one reference is made to his limited engagement in a minute dated the 1st of August 2024: *'The Expert Group sought to balance detail and clarity in the information presented, taking into account insights from the engagement and SRF'*. The Government's refusal to engage with and or involve those impacted in this scandal in developing the compensation scheme and specifically compensation for carers can be viewed through the disclosure in a Cabinet Office document related the development of the compensation scheme which states<sup>8</sup>: *'It is important that any engagement, regardless of whether this is as part of a formal consultation or not, does not ask for views on matters which are already settled by the Government'*. Yet this is a government which has only ever conducted self-assessments and disregards the detailed evidence gathered so painstakingly by the Infected Blood Inquiry.

With the exception again of spouses and partners who are afforded better financial tariffs, there is no recognition of the actual physical, mental, social or financial losses for all carers in the compensation scheme. What is clear from the Carers Survey is that carers specifically endured significant impact socially, financially, mentally and physically which went way beyond what could be categorised as 'normal care provision. It is also clear that all carers were similarly impacted. Therefore, the compensation schemes proposals to pay a carer £9 per hour less 25% for 'non gratuitous care, and to concoct a series of estimated hours where care may have been required which only allow for 6 months of 24-hour care is at best derisory, and at worst discriminatory. Therefore, compounding of injury as it fails to acknowledge the injuries of carers or the impact on those infected. This is in large part because the previous Alliance House Scheme and 2017 Infected Blood Support Schemes have failed to assess, consider or mitigate the impact on family carers other than spouses and partners. Excluded families have gone for up to four decades with nothing despite suffering mental health impact and significant social and financial damages. There is no legislated supplementary route for Care claims if for example a carer can evidence, they cared for 24/7 for extended periods through social work records or other means. There is no flexibility other than if the infected person can prove they paid for commercial care.

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<sup>8</sup> CABO0000916 - <https://www.infectedbloodinquiry.org.uk/sites/default/files/documents/CABO0000916%20-%20Infected%20Blood%20Compensation%20Scheme%20Proposal%20Follow%20Up%20Advice%20to%20the%20Deputy%20Prime%20Minister%20-%202013%20May%202024.pdf>



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As it stands many carers have received no financial recognition ever. As of the 2<sup>nd</sup> of April 2025: other than the 2022 interim awards to spouses only 420 interim payments have been made to estates that might have been distributed to carers via this payment, and as few as 108 are in the process of being paid<sup>9</sup>. This infers that to date that approximately 2,472 plus estates have received nothing and 53% of estates are unrecognised. Equally many carers of the living infected who are spousal and non-spousal will receive no acknowledgement from the government until they are allowed to claim in 2029. The spouses' partners of any victim who dies after the 31<sup>st</sup> of March 2025, will also be excluded from the Support Scheme mechanism. This policy generates a discrimination of existing beneficiaries and does nothing to recognise the spousal rights or damage done to the pension rights of spouses and the impact of the loss of support payments of their infected loved one. The government has effectively disregarded what is an established right to support payments for spouses and partners. This means all bereaved of those that die between now and a compensation payment will be left grieving and without any financial support as has been the case for decades for parents, children and siblings and other carers.

The Compensation Scheme also fails to recognise the trauma, distress and pain of bereavement felt by the carer and/ or relative who has dedicated their own life to care and faced the trauma of care. Many carers of IBV have diagnosed PTSD but will only be allowed £12,000 in personal injury as an affected person., There is much discussion and reference to a bereavement award in the recently disclosed Government documents<sup>10</sup> which only offer some, not a full insight into how these compensation proposals were arrived at. Yet at some point the government decided not to include a bereavement award which might have mitigated some of the losses felt by relatives<sup>11</sup>

### The Survey

Without a more comprehensive, properly resourced study, funded or conducted by government we are unlikely to know how many people were actually infected and or who cared for them and how that care was distributed amongst a family. The government's refusal to initiate a registration process perpetuates the view that the government is pursuing attritional policies and creates distress. Not only do we have limited knowledge on numbers but estimates also vary significantly from the tens of thousands, to the current scenario where there are 4519 recognised survivors and only 1458 approx. estates have claimed an interim payment to date. Whilst more await recognition and more may come forward, a registration process would be beneficial to both government and beneficiaries. From a basic accounting perspective, it seems more than poor governance that the government has designed a scheme without developing a means to register and verify beneficiaries to accurately gauge the full liability.

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<sup>9</sup> Figures reported to have been given by James Quinault at a meeting with campaigners dated the 2<sup>nd</sup> of April 2025.

<sup>10</sup> Ibid foot note 1

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The Carers Survey ran between January and March 2025. During this period 163 individuals began the survey, including living infected who had given care to another family members and received care, parents, siblings, spouses and partners, capturing a wide range of the infected and affected. Some completed the survey and some only partially completed the survey. To help make a clear distinction between carers and cared for infected we have broken the survey data down into the following cohorts:

- 128 carers
- 21 infected who have received and receive care or believe they will need care at some future date

Whilst the Care Award is one award, there were often two parents sharing care, a spouse and his or her children, several children or siblings involved in supporting their infected loved one. In cases generations of the same family have suffered in their own way from children whose parent was focused on caring for their own parent. Parents or a parent having to focus on an ill child or spouse. Due to the number of anonymous records, we cannot make any statistical analysis of the gender balance of carers, or to assess relationship, however it well documented that females predominantly fulfil the carer role within a family unit.

*'Massively, the emotional stress of keeping everything as normal as possible for our young children. Trying to bolster your loved one's flagging spirits along with taking on so many other aspects of their health and wellbeing. Plus, my workload had grown with their decline.'* (an extracted impact statement from the Carers Survey)

This report captures the heartfelt experiences, frustrations, and recommendations of individuals—primarily children—who cared for parents infected through the contaminated blood scandal. Comments reveal deep emotional wounds, a desire for justice, and a call for meaningful change in how carers are treated by compensation and support systems. Approximately one third of respondents identified gaps in their national insurance contributions and expressed concerns about lost pensions. In addition, the majority of respondents identified significant financial impact, included losing homes, being forced to give up jobs or careers, losing out on promotions, training. The majority identified a loss of social life and experiences whilst many identified that they underwent personality changes, suffered stress, anxiety, guilt.

A number of people did not answer questions with the reasoning they did not keep detailed notes or diaries about the care they were giving or were given. Keeping notes of times, dates and hours of care given was the last thing in people's minds when they were in a constant state of fight or flight, with the only focus caring for their loved one, or in many cases, loved ones.

Families across the UK have to live each day with the legacy of infected blood and the impact this has had on them as affected people in their own right and as carers. It must be recognised that those who gave care did so selflessly, with compassion and were forced into this position



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because of the legacy and public messaging of the Government who denied and deflected from the serious nature and consequences of infected blood.

Carers must be recognised properly with compassion, understanding and above all trusted that their recollections and the experiences they have lived happened. This is especially true with a compensation scheme that expects carers to provide a wealth of evidence that either no longer exists or was recorded at a time when a carers only priority was giving their loved one dignity, respect and care, the things the Government and the NHS failed to provide and continue to only rhetorically recognise.

# SIBF Carers Survey

Carers						
1. Are you ...? An affected person who has acted in the position of a carer to an infected person	Affected Child	Affected Parent	Affected Spouse/Partner	Affected Sibling	Did Not Answer	TOTAL (Sense Check)
ANSWERS	21	6	19	2	80	128
PERCENTAGE	16.4%	4.7%	14.8%	1.6%	62.5%	100%

Question 2 omitted as answered in question 1.

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3. Please indicate the nature of the care you gave (or currently give) to your loved one during the time you were in the role of their carer. (Select all that apply)	Yes	Did Not Answer	TOTAL (Sense Check)	% Yes
I provided physical care (such as lifting, moving, and handling, etc.)	40	88	128	31.3%
I supported medical care (such as supervising or administering medications, etc.)	46	82	128	35.9%
I provided personal intimate care (such as assisting with dressing, cleaning, washing, bathing, toileting, and shaving, etc.)	39	89	128	30.5%
I provided financial management care (such as dealing with bills, the administration of their finances including banking, etc.)	44	84	128	34.4%
I provided transport care (such as escorting to doctors appointments or hospital visits via public transport, helping into a car and/or driving them places, pushing them in a wheelchair, etc.)	49	79	128	38.3%
I provided household chores care (such as regularly doing the cleaning, cooking, shopping, and laundry, etc.)	59	69	128	46.1%
I provided emotional support care (such as listening, sharing, affirming, assuring, socialising, and reminiscing, etc.)	61	67	128	47.7%
I provided agency interactive care (such as liaising with statutory care providers, managing carers via self-directed care, etc.)	19	109	128	14.8%
<b>TOTAL</b>	<b>357</b>	<b>667</b>	<b>1,024</b>	<b>N/A</b>
<b>PERCENTAGE</b>	<b>34.9%</b>	<b>65.1%</b>	<b>100%</b>	<b>N/A</b>

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**I provided care in other ways, too (please briefly explain)**

### Quotes:

24 hour.... she called me regularly in the middle of the night after dad passed away... I had to talk to her and listen to her crying regularly

As a wife and mother to two young girls, I kept the atmosphere in the home as safe from worries as possible. My two daughters 7 & 10 up to the ages 10 & 13 (for 4 years) as worry free as possible so it did not affect their education. I believe it did initially, however when my husband had to go into Hospital, almost permanently it took its toll on us all. It still does.

Dad was ill, mom had told all the medical staff she wanted him at home she could care for him , when actually she couldn't , she expected her children to take that on board without any consultation or conversation. She wasn't coping so the care in effect is for 2 people just different care needs!

Emotional support for sibling (brother).

Explained to medical practitioners what Infected Blood is every single time over decades as none of them had ever heard of it.

Had to help mum with caring for dad and help look after the younger children to enable her to look after dad. Helped with the childcare of my sister 8yrs my junior.

I also had to deal with my father's family which was really hard work, and I often suffered abuse and accusations and was blamed for everything that went wrong, not based on any evidence but on the prejudice of specific relatives.

I drove from London to Yorkshire on a regular basis to comfort and see my brother.

I had to act as both parents when my husband was unable to help or interact with the children.

I helped my brother caring with his small children as any good uncle would. More so when he became weaker.

I moved in with my dad.

I supported him in the early years through the after affects of interferon treatment and then a second treatment of triple therapy as he was bed ridden most of the time, I became his nurse and care giver, organise his treatment, give him mental support when his mental health disintegrated, I helped him with dressing in clothes and even now I have to lay out clothes daily and have to suggest he washes etc. due to his lack of motivation , I changed his clothes and bedding during his excessive sweating and pleading with him to get him to take in enough fat as this was needed during treatment but he could hardly keep food down, I have supported and cared for him through 15 yrs. of mental health decline , become his advocate in hospitals where I've had to absolutely fight to be allowed to join him and speak up for him as he needs my support due to brain fog to be met with drs who think he's a druggie as he has track lines from yrs of intravenous factor 8 and is incoherent at times during anxiety and panic attacks Due to his mental health! I have to do all the purchasing of food and personal items .I do all household cleaning & washing, organise all bills and household paperwork as he can become very confused, I have to repeat and remind him regularly as he has a very bad term memory! I struggle to get him to take normal family meals so have to sometimes make his meals at different times when he can stomach eating something he, I have to explain and make excuses and change plans with his family to try to explain his chronic fatigue and anxiety as to why he can't

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attend or visit people normally, I attend all appointments in person with him and phone calls on loud speaker as he can get confused and forget what others have told him!

I was involved in every aspect of my husband's care throughout our life together.

I was the oldest of two children living in the same household of my single parent infected with both HIV and hepatitis c. I helped care for my younger sibling as my father was extremely unwell.

I was there all the time for my mum never left her side.

Liaised with Liver Unit at the Freeman and GP Surgery in GRO-C

Made food, sewed clothing, cleaned boots. Went with him to social gatherings when he was able or stayed to be with him if unwell. Also had to be around when he was resting as he also had epilepsy.

Mental, physical, emotional and spiritually.

My husband is severely ill, we have no statutory care providers, and he needs them urgently.

My mother is the 86-year-old widow to my late father. I now care for her.

My two sisters and I supported each other emotionally and physically, taking on tasks in order to support my mother and eldest sister who lived at home and were the main carers for my brother for the last years of his life in particular the last 8 months or so when he was bedridden. It was a shared experience

Psychological support for communicating and supporting the children, protecting anonymity.

Shared 24/7 care with eldest son, he sorted out most of the medication plus shared timetable for each day.

My Brother-in-law and his wife came several weeks during the 9 months providing adaptations and shared time to talk as he became less mobile.

Was always there for mother.



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4. Were you provided with any training or additional support to help care for your loved one?	Yes	Did Not Answer	TOTAL (Sense Check)
ANSWERS	5	123	128
PERCENTAGE	3.9%	96.1%	100%

### QUOTES:

District Nurses provide Palliative care bed, taught handling.

Excellent support from GP Surgery and they provided Home Visits regularly. Liver Unit Team provided excellent support and advice.

None offered.

Trained to give intravenous injections.

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5. How did the need to provide care to the infected loved one have a detrimental impact on your life? (Select all that apply, and use the text box below if you need to briefly explain anything)	Yes	Did Not Answer	TOTAL (Sense Check)	% Yes
I had to reduce my paid hours at work, or I had to alter the course of my career, including missing out on promotions (more about these factors later)	25	103	128	19.5%
I had to stop working altogether	23	105	128	18.0%
It affected my your mental and/or physical health (more about this later)	56	72	128	43.8%
My relationship with the infected person being cared for changed in negative ways	25	103	128	19.5%
A long-term relationship ended as a direct consequence of having to be a carer before anything else (including the relationship with the person being cared for, if applicable)	14	114	128	10.9%
My relationship with other family members changed in negative ways (more about this later)	26	102	128	20.3%
My responsibilities for other dependents had to be compromised	30	98	128	23.4%
My social life and leisure interests were significantly curtailed	56	72	128	43.8%
Aspects of my own personality and character changed, (for example, becoming anxious, stressed, angry, guilt-ridden, untrusting, irritable, etc.)	55	73	128	43.0%
There were times when I felt inadequate and/or hopeless because the task of caring and coping was so onerous	46	82	128	35.9%
I was often left to feel unsupported, particularly in relation to statutory care provision	38	90	128	29.7%
<b>TOTAL</b>	<b>394</b>	<b>1,014</b>	<b>1,408</b>	<b>N/A</b>

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PERCENTAGE	28.0%	72.0%	100%	N/A
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Other (please specify in the box below):

Had no life , still done because of the awful memories

I had to juggle my work schedule with caring and therefore worked extremely long hours to cover both.

It affected my mental health

It was a privilege to look after [GRO-A] in the time that we had [GRO-A] spent a lot of time in Hospital under the care of the Liver Unit at the Freeman pre and post Liver Transplant. I did have to take time off work during this time approximately 6+ months followed by further time approximately 1 Month off after [GRO-A] died.

Knowing he could die anytime brought great depression and sadness that depression has never left

Lost my job and came close on other occasions due to health problems also the anger problems caused by grief and trauma. A promise to carry on campaigning and fight for justice.

My education suffered

School suffered

Traumatised - PTSD - My Dad was in a coma for a week following his transplant. He haemorrhaged over me.

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6. For how many months/years overall were (or have you been) you personally required to provide care? (Number Given in Months)	Highest	Lowest	Average	Did Not Answer
Months	480	5	130	66
Years	40	0.4	10.8	N/A

### QUOTES:

On and off 20 years, of which 6 months were really intense while GRO-A was undertaking the interferon treatment, and now dealing with the side effects.

On my own - 18 months

Perhaps Dads last 6 months of life

So far I've been dad's full time carer for 10 years. But it's massively increased in the last 4 years.

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7. As far as you can estimate during a typical week (before any end-of-life stage was reached), how many hours per week did you provide care? (You will be asked about periods of higher intensity caring later)	Highest	Lowest	Average	Did Not Answer
Hours	168	4	70	87
People Who Needed Care 24/7)	11			

### QUOTES:

16-24hours for 10 years and the year before death about 40-50 hours a week.

20hr+ before and after school, and during the weekend.

24hours for the week with 3 family members.

30 hours. I shared with other member of my family.

40+ hours per week due to physical and emotional requirements, although the mental anguish was 24 hours a day and continues to this present day.

All day every day

At least 20 not including sleepover care.

During last 14 years 24 hours a day x 7 = 168 hours before this he needed approx 12 hours care a day = 84 hours

Every hour.

Everyday throughout Treatment, Liver Transplant, Chemo and then latterly.

I really didn't see what I did as "care" as in paid work. I helped my brother because he couldn't do certain things. Pushed him in his wheelchair, I was between 7-11yrs old, when I was with my brother in his adult care, I took care of everything he couldn't do.

I spent everyday with him that I could. The last five months were spent with him in hospital my Mum and me took turns to be with him as much as possible every day and evenings

I was on call 24/7 and had to physically see her every day of the week lunch, afternoon, evening until I eventually took sick leave from work to look after her all day and be on call when not with her



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I would say roughly about 20 hours each as mum was terrified of anyone knowing about the HCV, so refused to go out of the house.

I've no idea it's just my life now!

Initially it was emotional support, followed by doing more chores to alleviate their exhaustion.

It felt as though the emotional support and organisational aspects were always there. Plus, extra chores my husband could do.

It's hard to say as his ability to manage for himself varied depending on the state of his incapacity  
Many hours

My support and care for my husband increased greatly when he was on his second course of interferon treatment 2009 - 2012. There were mornings when I had to drag him out of bed and help him shower he was so weak and ill. However my husband never missed a day of his work because of his treatment, he was a determined he would not let his employer down so even on his worst days he somehow forced himself to leave the house and go to work.

Several hours a day at worst. Somedays none.

Sill a full time carer

Very difficult to specify, care was ongoing and became more intensive as our son became more ill. As parents you are always in a caring role and caring for a sick child and then a sick adult just became an extension of that role and it's difficult to define exactly when the change from caring as a parent and then as carer actually occurred.

Weekly phone calls 1/2 hour monthly visits 48 hours for a period of a year before death . Less frequently before this for visits

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8. It is common for caring responsibilities to intensify as the person gets closer to the end of life. If you reached this point, as far as you can estimate, during this later period how much greater did the caring activities become in terms of time and intensity?	Highest	Lowest	Average	Did Not Answer
Hours	168	28	140	98
People Who Needed Care 24/7	16			

### QUOTES:

24 hour care between me and 2 sisters

24/7 when I was not there I was constantly on call and or had to administrate the wages and or negotiate with social work and or the NHS.

6+ hours, it was variable dnd hard to define

All consuming

Almost round the clock focus.

Approx 23 hours a day ( 1 hour to freshen / shower ) during hospice admission

As a single parent, when my brother lived with me up until the last few weeks of his life. I was unable to leave the house and as a result my 12 year old daughter had to shop for us all. My children's lives suffered greatly both mentally and socially, they could no longer have friends over and I had to teach them a lie to tell anyone as we had already had a brick through the windows and car damage.

As per question 8 my care for my husband increased during his interferon treatment. Since around 2015 I noticed my husband's mental health decline along with his physical health. Although we were new parents, the decline of my husband's health, mental and physical, can't be put down to becoming a dad. He was always upbeat and fun to be around as my husband. The man he is today isn't the man I married. I love him unconditionally and believe- that he will get some of his spark back but this can only happen once the compensation has been paid and he can truly begin to process all that he has been through.

## SIBF Carers Survey

As stated last 14 years 168 hours per week transfused himself with interferon and approx 3 x week Factor VIII. Intensity increased substantially as side effects of various drug treatments became worse with petit meals, vomiting blood etc.

As time went on our son became weaker and more dependent on those of us who were caring for him, it was a matter of doing whatever was necessary without knowingly recognising the times where the levels of care had increased

Bringing things to hospital the last five months food clothing pyjamas toiletries. It was very intense nit knowing how he would be each day .If the infections would be worse ? Would he be better ? How much pain was getting in ? Had he eaten drank .would he die ?

Constant

Difficult to say many emergency hospital visits

Enormously- round the clock 24/7. Doing everything including when he was in hospital as staff did not wish to do the care stuff just administering medication like morphine

From time of Liver Transplant - 7 Months until [GRO-A] died.

Full time.

in the final nine months of life, about 78-90 hours a week

In the last week of life 48 hours then a return visit for another 48 hours till death =96

Incomparably. The hardest period of my life, no question. I was either working or caring, and it almost drove me over the edge.

Increased significantly 20 hours per day

Intensity of caring responsibilities varied from time to time. After liver transplant was an example and in the last six months intensity increased as his illness progressed until the point of death.

It became 24/7 as my husband wouldn't have any carers or nurses in our house.

It is increasing weekly.

Mam took over and I looked after my younger brother.

Massively, the emotional stress of keeping everything as normal as possible for our young children. Trying to bolster your loved one's flagging spirits along with taking on so many other aspects of their health and wellbeing. Plus my workload had grown with their decline.

Much greater, I helped to care any time I wasn't at school

my husband went into Hospital on 3 August 1982 and died on the 4 July 1984. Extra emotional support for my husband and the girls. Taking on many functions he performed, driving back and forth to Hospital, Hospital visits, his washing, little treats to encourage him to eat and trying to keep life as normal as possible.

My mum was a very proud lady and tried so hard to be independent, but she grew so weak that she needed care for 7 days and 16 hours per day (personal care and practical)

## SIBF Carers Survey

My sister took sick leave the last 6 weeks of mum's life. She stayed with her at night and I came in after taking my son to school, and spent all day with mum, to help my sister sleep. Until the last week of her life and we all stayed there as she would not wake up. We arranged family to see her before she left us all.

## SIBF Carers Survey

<p>9. It might be possible to map out in general terms the time and effort you personally put into caring over the phases when this increased or decreased related to your own inputs (for example, because you shared the caring role with others). Using the table below, indicate the timeframes and levels of intensity you personally put into caring for your loved one. For each phase, please indicate the following in the text boxes: Rough Timeframes, Hours/week and Sample activities. For example: Phase: Earlier, Rough timeframe: Jul 1989 to Jan 1998, Hours per week: 10, Sample activities: Meds, emotional, appointments</p>	Highest	Lowest	Average	People Who Needed Care 24/7	Did Not Answer
Early	168	4	54	4	106
Middle	168	8	68	5	106
Later	168	10	101	11	105

### MIDDLE QUOTES:

1982 to 2001 emotional caring increased during this period as did physical caring as my husband endured three rounds of interferon and ribavirin, none of which he could complete due to the devastating side effects, His health deteriorated until he was put on the liver transplant list. This was a very difficult time emotionally.

1990s acting as chauffeur for medical appointments

2012-now: during the 6 months treatment 40-48 hours a week. After treatment 20-25 a week on average. This depends on how GRO-A feels

40-50 hours a week for 1 year -appointments, emotional, household, all care duties including personal care



## SIBF Carers Survey

87-87 - bringing in meals, helping with meds

Ad-hoc hospital , docs etc

April 2002 to June 2010, hrs p/wk: 20/30, cleaning, shopping, appointments and emotional

Daily hospital visits, sorting out meals and shopping, emotional support about 36 hours a week

Late Diagnosis and not informed at this stage

March 89 to March 92 - Meds, appointments, emotional support, physio, transport, personal care

Still there making sure he was OK. Sitting in his room chatting just being there. Mum cooking I went to get his factor 8 Mum stayed with him

### LATER QUOTES:

1/2 hour per week 1 monthly visits 48 hours

168 hours plus 1983 to 1998 (often needed two people to nurse him)

19 August 2007 24 hours a day

1983 to 88 30 to 24/7 care

1991-1993 - 40+ hours per week ( end of life 23 hours )

1998-2000 22 hrs per day

2000-2006: emotional, meds, physical, financial, travel,

2001 to 2011. my husband's health continued to deteriorate while he waited for a transplant. The call came 10 weeks later and we went to the hospital. When he went into theatre the surgeons found that the donor liver was damaged and he was sent home to wait again. It was 10 months later that he had his transplant. Emotionally and psychologically this was a very difficult time as we waited and his health deteriorated. Post transplant he had eight years of a more fulfilling life, then his health deteriorated and I took him to hospital to try and get to the bottom of the problem. After several weeks of investigation he was told he had secondary cancer and discharged from hospital. He was totally unable to look after himself and was confined to bed until he died 10 weeks later. We had carers for 30 minutes twice a day and no other help. This period was horrendous both for my husband and our family.

2010-2020 16 hours per week emotional domestic

2014-2016 35+ week. Increased to end of Life all aspects of care covered

2015 - present - 20 hours per week

24/ 7 support, for at least two years as our dad was high maintenance and also a suicide risk.

3 August 1982-4 July 1984. As above, only more intense, as my husband's health had greatly deteriorated.

3 August 1982-4 July 1984. As above, only more intense, as my husband's health had greatly deteriorated.

## SIBF Carers Survey

78-90 hours a week for 9 months - appointments, emotional, household, all care duties including personal care  
88-jan 89 - listening to his emotional outbursts and chatting through his concerns and helping with drinks, meals, fetching a straw for his drinks

Dec 1990 to May 1991 Emotional, spirit, hope, reading to him, helping him around the house, cooking, cleaning, looking after my brother

December 2008 24/7. I stopped working to be with her: hospital appointments, medication, taking her to visit areas she wanted to go to b4 she passed away

# SIBF Carers Survey

10. Thinking more about your personal work situation and the related financial impacts due to caring, how did/does providing care for your loved one have a negative effect on your working life and finances? (Please select all that apply),	Yes	Did Not Answer	TOTAL (Sense Check)	% Yes
I had to cut down the number of hours I worked	23	105	128	18.0%
I missed time at work, including offered overtime	22	106	128	17.2%
I turned down at least one a job promotion opportunity	13	115	128	10.2%
I cancelled or missed out on plans for development training for my job role, and/or I did not access other educational opportunities	24	104	128	18.8%
I had to completely change my career to a less lucrative type of work setting	15	113	128	11.7%
I had to give up work altogether	21	107	128	16.4%
I lost my business	6	122	128	4.7%
I lost my house (for example, selling up and moving to rented accommodation)	7	121	128	5.5%
I used up any saving I had accrued	13	115	128	10.2%
I had to cash in early at least one financial savings product	6	122	128	4.7%

## SIBF Carers Survey

I went into debt	14	114	128	10.9%
I had to declare as bankrupt	3	125	128	2.3%
I lost out on regular contributions (for example, towards a full state pension)	19	109	128	14.8%
I have not been able to plan for a financially secure retirement.	25	103	128	19.5%
I missed out on national insurance stamps because I was a home carer but not in receipt of carers allowance.	16	112	128	12.5%
<b>TOTAL</b>	<b>227</b>	<b>1,693</b>	<b>1,920</b>	<b>N/A</b>
<b>PERCENTAGE</b>	<b>11.8%</b>	<b>88.2%</b>	<b>100%</b>	<b>N/A</b>

### QUOTES:

After my brothers death I had to give up work to look after my mother who suffered cardiac arrests and other medical problems due to the stress she had been under nursing my brother.

As my husband had to take early retirement I had the combined responsibilities as wife, mother and sole earner.

Didn't receive much education growing up, father didn't receive any education growing up. Huge impact on any future I had

Full-time caring.

I could only take temp work as I had often to leave work when my husband had a kidney bleed etc.  
I had to delay my education and lost out on my scholarship and specific opportunities.

I had to juggle the caring with my work and worked it out with my mum so that one of us was always available. I didn't get a break from this working/caring routine for several years at its worst.

I missed out on all of my maternity leave as I spent all day everyday caring for my poor nana

I was a child when my daddy first got ill, I studied to become a nurse so my care could be better, I wasn't able to pursue career advancement until my Daddy died & I moved away from home.

## SIBF Carers Survey

I was a child when my mam was ill and then died, but I still cared for her, as there was no one else in the household

I was self employed and had to give up my business and become a carer full time.

I was young so missed out on a lot of school my whole teenage years ruined

I wasn't capable of work at the time as I had my own health issues.

I went on sick leave for months before she died so I could look after her

In 2017 I started my own business, after a very positive 15 year career in oil and gas. It was partly down to wanting to spend more time at home with my husband so I could help organise our household and help look after our two young children as my husband simply wasn't able to organise and run the household and manage our two children.

It affected my mental health; I couldn't focus properly I became withdrawn and secretive; I was worried about anyone finding out my brothers HIV status and if I could lose my job due to the stigma  
It doesn't do your health much good not being able to work

My career progression stuttered and then cost me my job, due to poor physical and mental health and a sheer lack of motivation due to campaigning. I also sacrificed a job opportunity abroad due to mum's health deteriorating.

My education was greatly impacted

My employer was very supportive and allowed me time off when necessary to care for my husband post transplant and in the latter months of his life.



## SIBF Carers Survey

11. How much money overall do you think you personally lost as a result of those items selected in Question 11 above? (Please note down an estimated total amount and then briefly list what that amount is made up from.)	Highest	Lowest	Average	Answered	Did Not Answer
Amount in £	£1,000,000	£8,000	£358,000	10	118

### QUOTES:

I haven't a clue but lost business, house, bankruptcy, wages for 14 years.

I was a child.I worked from aged 9 in Saturdays to bring money in.

I was in a £30,000 a year job that I had to give up to care for dad.

Impossible to say.

Lost funding stream from my partner.

My circumstances were exceptional and my employer continued to pay my wages.

my husband worked through the early stage. He went into Hospital on 3 August 1982 and never returned to work. He earned a good salary as he was in the Senior Management Team. I believe re received full salary for a year, then 1/2 salary for 6 months, then nothing. We lived on our savings. This was over 40 years age and I am still trying to access these details.

No financial loss other than meeting ongoing costs of travelling etc.

No idea as I was in receipt of benefits at the time, which would obviously be considerably less than wages from an employer as I was previously a care assistant.

No idea I had to give up my job after trying to support him during treatment so had disciplinary hearings where my union had to complain about disability discrimination due to me taking care of him and also my children at the same time! I didn't go into the manager program due to putting his needs first and after cutting my hours I eventually had to give up my job. I can't put a number on it but 10 yrs of losing wages and missing out on a career caused thousand of pounds of debt

## SIBF Carers Survey

12. The role of carer often brings significant challenges. The list below includes various difficulties as reported by affected families and individuals.	Yes	Did Not Answer	TOTAL (Sense Check)	% Yes
A - Not feeling up to the tasks involved in caring (particularly towards the end of life)	7	121	128	5.5%
B - Not feeling supported as a carer, or feeling isolated and abandoned	14	114	128	10.9%
C - Not feeling in control of your own life due to the caring role, while at the same time it was not being acceptable to resent the situation.	7	121	128	5.5%
D - Resenting the disruption to a previously happy and mutually satisfying normal life.	8	120	128	6.3%
E - Missing the normal social relations with friends and colleagues, or the pursuit of personal interests, because of being increasingly "tied to the house".	12	116	128	9.4%
F - Becoming physically drained due to the care role.	11	117	128	8.6%
G - Becoming emotionally drained due to the care role.	21	107	128	16.4%
H - Missing out on the naturally occurring shared intimate moments with a loved one due to the pervasive dynamic of care-giver and care-receiver.	6	122	128	4.7%
I - Suffering mental health impact such as depression, PTSD.	19	109	128	14.8%
J - Suffering personal physical injuryPlease briefly explain any thoughts or experiences not listed.	6	122	128	4.7%
<b>TOTAL</b>	<b>111</b>	<b>1,169</b>	<b>1,280</b>	<b>N/A</b>
<b>PERCENTAGE</b>	<b>8.7%</b>	<b>91.3%</b>	<b>100%</b>	<b>N/A</b>

## SIBF Carers Survey

Please briefly explain any thoughts or experiences not listed:

Disruption to schooling, even when in school unable to concentrate

Enjoying together time and talk.

Falling out or having difficult relationships with other family members.

Feeling alone and being unable to tell anyone because of the stigma  
grief at seeing my father's suffering and knowing he was going to die. This is different to the PTSD I suffered.

I can relate to all of the above except suffering physically injury

I felt constantly stressed and unable to sleep. I developed food allergies from stress. I also went deaf as my body over produced ear wax as a direct response to feeling under constant attack.

I felt guilty at not being able to make my husband feel better. That became harder when his natural loving nature changed.

I have been suffering flashbacks from mums final day in the hospital, the horror of the amount of blood from the varicose veins that burst. Now 10 years on, I can vividly still see mum covered in blood as she passed away and it constantly haunts my dreams! My sister has been diagnosed with PTSD, I'm waiting for a diagnosis and trauma therapy, as that last day is the last memory of our mum.

It affected my personal relationships which broke up due to the stress. I lost the opportunity of marriage and children.

little "me" time over extended period. Feeling guilty of taking a break or asking others to step in.

My children witnessed several incidents of hate and vulnerable situations that my brother was in especially during the last stage of his life. We were all traumatised by the experience and given no support.

Negative impact on relationship with children including foster care requirements which continue to date and concerns over potential infection transmission

Never ever won't to see what happen to my mother she bled to death

No way out, no nice outcome

Not being able to help enough, my Dad's illness was so complex not just physical, hospital visits treatments, etc but the total living from appointment to appointment then having hopes of hepc being cleared and this not happening, totally soul destroying. And especially as I had my wee son with me and my dad everywhere we went, day and night

Not knowing from one day to the next what was going to happen. Scared of people being horrible through their own lack of knowledge and understanding

Sleep deprivation

Suicidal, anger, road rage, lost trust in everything and patience. A total feeling of unhappiness and sorrow.

## SIBF Carers Survey

Unable to be a proper mum to my young son

## SIBF Carers Survey

13. How does/did caring for your loved one have a negative impact on your relationships with other family members? (Select all that apply)	Yes	Did Not Answer	TOTAL (Sense Check)	% Yes
I spent precious time away from children or a spouse/partner	31	97	128	24.2%
I missed important family events (such as a wedding, school play, parents' night, Christmas dinner, etc.)	24	104	128	18.8%
I was left with very little time for the other more regular family activities	34	94	128	26.6%
I experienced conflicts within the family about how care should be delivered	13	115	128	10.2%
<b>TOTAL</b>	<b>102</b>	<b>410</b>	<b>512</b>	<b>N/A</b>
<b>PERCENTAGE</b>	<b>19.9%</b>	<b>80.1%</b>	<b>100%</b>	<b>N/A</b>

**Other (please briefly explain):**

2 divorces

As a family we pulled together when possible. Although logistically this was challenging.

At one point I had caring responsibilities for three people, everyone suffered

Because of the times I have to be with dad I am so limited with being able to see anyone!

Due to the trauma and care he needs and we have been through together we isolate from the public and family as much as possible as it is too mentally taxing or our children suffer and don't see us due to his fatigue and mood The campaigning is ever increasing stress when your family brings it up every time we see them!

Her deteriorating mental condition led to confrontations with family and friends and these events were unpredictable.

I could not discuss it because of the stigma

## SIBF Carers Survey

I couldn't be a normal kid, playing out, carefree etc. I couldn't have friends for tea, because my mam was

I'll and we had to hide everything because of the stigma.

I did not have conflict with the immediate family as we were focused on giving love and care to our brother.

I did not see how much pain my sons carried seeing the loss of the future events, he never saw them married, canoeing again, walking and camping with all the words jokes and laughter.

I had no life, and no opportunity for respite.

I haven't spoken to many family members for many years now. They didn't campaign and I have. I was so ill and bed bound for up to a week and I was unable to hold my first born child. The feeling of uselessness to not be able to help my wife or be able to feed my son.

It caused me and my ex husband to divorce because I was taking care of my father who had hepatitis C and my mother who was struggling mentally with the decline of my father.

It changed my life never knowing day by day what will happen next

My brother resented the care I gave my Daddy.

My older sister and myself felt put out a lot. We lost our childhood.

My other family didn't always pull their weight as I felt they should this caused arguments between the family

Negative impact on relationship with younger siblings due to having to care for them as a child. Negative impact on relationship with remaining parent due to the strain of shared caring and guilt of not being able to do more to help her

None really - I didn't do lots, I saw it as helping my brother, it definitely made me grow up faster than perhaps I should have.

Our parents divorced

Ptsd and now a Tick

Relationship with my mother is now non existent

Taking on my husband's chores, Hospital visits, occasional family activities, keeping life as normal as possible for the girls left precious little time to do anything outside the family.

When my family found out my husband (then fiancée) was HIV positive they cut off all contact with me and gave me a choice of him or them. The came around in the end but it was a difficult 2 years, I felt so alone.



## SIBF Carers Survey

14. Have/did you develop any coping mechanisms to try and deal with the responsibilities and stresses of caring for a loved one? (This might include various positive or negative strategies such as mindfulness techniques, taking sleeping pills, etc.)	Yes	Did Not Answer	TOTAL (Sense Check)
ANSWERS	34	94	128
PERCENTAGE	26.6%	73.4%	100%

### QUOTES:

After my husband died I got involved with Meditation, Healing - this was my saving grace, my sanity. Since being involved with the Inquiry I have relied on Therapies to get me through my PTSD and exhaustion.

Alcohol and cigarettes

Anti depressants

Anti depressants, later on alcohol. For years I couldn't touch alcohol, I was too ill

Antidepressants

Drinking

Drinking at a young age. Taking narcotics. I moved away to stop this but my life struggles haunt me still.

Eating disorder

Eating disorder

Have to take sleeping pills

Holistic therapies , including mindfulness and meditation

I drank too much

I gave up other things so that I could provide support

## SIBF Carers Survey

I just got on with it and powered through when I was at the loved one's home and cried in my own home when the relative I shared the care with was with the infected loved one

I saw a weekly counsellor and discussed the various events and attacks I was subjected to and how I should cope or not cope with them

I wouldn't switch off when he was having an angry outburst

I've ended up on medication for chronic pain, stress mental, and emotional issues  
In and out of addiction. Trying to fill the gap of pain with wrong relationships

Just had to get on with everything.

Lost my mind

Mindfulness

Mindfulness techniques

OCD, avoidance, learnt to "switch off"

Reading, not sleeping enough as need to have my own time which means I stay up late and then am permanently exhausted.

Sleeping pills, antidepressants, crying  
spoke to partner (now husband) to try to share the emotional burden

Therapy

Very alone now

Yoga and meditation early morning sessions with tutor.

### SIBF Carers Survey

15. Do you feel enough help is/was offered by healthcare and other statutory service providers such as GP surgeries, housing departments, social work, etc? (More detail on this matter can be included in a later question.)	Yes	No	Did Not Answer	TOTAL (Sense Check)
ANSWERS	5	55	68	128
PERCENTAGE	3.9%	43.0%	53.1%	100%

#### QUOTES:

55 respondents stated 'no overall it was not enough, and only 5 respondents out of a total of 128 surveys stated 'yes overall the support I received was enough'.

## SIBF Carers Survey

16. What examples of support service provision did/do you find helpful as a carer to a loved one, if any?	Yes	No	Did Not Answer	TOTAL (Sense Check)	% Yes	% No
The loved one's GP arranged for additional care support, or other help	6	26	96	128	4.7%	20.3%
The loved one's hospital maintained timeous scheduling of appointments and high-quality medical care, or other help	7	27	94	128	5.5%	21.1%
The loved one's local council arranged for aids and adaptations to the home, or other help	11	26	91	128	8.6%	20.3%
A local voluntary group provided help (for example, befriending, gardening, volunteer driving, etc.)	1	28	99	128	0.8%	21.9%
A local branch of a charity provided assistance and guidance (for example, accessing a Citizens Advice Bureau for help with benefits, or receiving advocacy support, etc.)	6	25	97	128	4.7%	19.5%
<b>TOTAL</b>	<b>31</b>	<b>132</b>	<b>477</b>	<b>640</b>	<b>N/A</b>	<b>N/A</b>
<b>PERCENTAGE</b>	<b>4.8%</b>	<b>20.6%</b>	<b>74.5%</b>	<b>100%</b>	<b>N/A</b>	<b>N/A</b>

### QUOTES:

Didn't receive any support, my dad probably couldn't ask in fear us children would be taken away.

Her GP was completely understanding and helped all he could.

## SIBF Carers Survey

I secured personal assistants for our dad, but they took a lot of work to recruit, train and manage, and I felt it would have been easier to have delivered the care myself.

I did not seek help

I finally managed to convince my husband to see his GP in 2004 and he started a course of anti-depressants to help him sleep better. However his moods have remained mostly the same, sorrowful, angry at times, extremely worried about most things in life that people do not give a second thought to.

Marie Curie nurses at weekends.

No help whatsoever.

No support.

No support provided whatsoever!

Nobody knew much about Hepatitis C in those days even nurses had know idea about Hepatitis's C in those days.

NONE - no help or support at all.

None of the above would have made any difference as my husband was paranoid about anyone finding out he was HIV positive.

None of these have been offered.

None was EVER offered. We were CHILDREN!!!

Nothing.

Once a year family holiday in a caravan. The Haemophiliac group did this .nothing else from any one only the Haemophilia Center offered support for end of life.

Other than the hospital doctor we were on our own.

The most notable aspect was the absence of any support.

The rest of my family helping too.

There was no support.

We had lovely Mcmillan nurses in for the last 2 weeks of my Dad's life when I became utterly physically & emotionally exhausted and was not able to lift my dad anymore.

## SIBF Carers Survey

17. Did you feel you are/were cared for as a carer?	Yes	No	Did Not Answer	TOTAL (Sense Check)
ANSWERS	3	56	69	128
PERCENTAGE	2.3%	43.8%	53.9%	100%

### QUOTES:

Absolutely NOT, there was no care for me as a carer any way shape or form

Absolutely not.

After the diagnosis of Hep C we were left to get on with it

Because the rest of my family were in the same boat, I was ignored as a child.

But I preferred to keep my life confidential as far as possible

Felt i was just left to get on with things.

Focus is on the person who needs the care

I became invisible, and when my dad died there was only some support from the hospice, who said that they were not equipped to deal with my despair and or mental health difficulties as they suspected I was suffering from PTSD.

I can not get regular GP appointments

I don't get any support

I felt totally alone, no one understood outside of family. We were on our own thanks to the Government

I had no care from outside my immediate family

I have cared for my husband because I love him. It is what you do as a person, there is no time for feeling down or self-pity.

I have to look after my husband permanently. I have no personal opportunities or life,

I haven't tried to access help



## SIBF Carers Survey

i looked after myself no help from anywhere

I needed help with practicalities like how do you get shopping, doing the garden, cleaning etc. The Macfarlane Trust suggested we contact local charities but my husband cried and begged me not to incase people found out he was infected.

I was her daughter and that's all people cared about

I was living on nerves, his life and time slipping away.

I was my mums oldest daughter so I felt it was my duty to make mum as comfortable and pain free towards the end.

I wasn't acknowledged at all as a possible carer

I wasn't seen as a carer because I was a child

I've never had help other than a nurse telling me who I could contact, just go on the website

It was or felt its automatically expected

it would have been useful to have support as a sounding board or to give appropriate advice as her condition deteriorated.

Just get on with it

Lack of any immediate support. Confidentiality meant it was impossible to access support.

Lack of contact and support

My brother had to move into my home and my GP said they would pronounce death but nothing else  
Never

Nobody has offered me any support as a carer whatsoever

No one cares.

Not recognised

Received no help or training as a carer especially end of life care.

There is no support

There was absolutely no acknowledgement or recognition for what we were having to endure in caring for our infected son

There was absolutely no acknowledgement or recognition for what we were having to endure in caring for our infected son

there was no support

Through ignorance of the authorities I feel we were left to get on with it

## SIBF Carers Survey

Was a child carer no other adult in the home.

We just provided care as there was no other alternative

We were mostly left to get on with it

We were pretty much left to it; my mother suffered the most

When I was a child caring for my my mam in the eighties I didn't even think of myself as carer, nor did anyone else.

## SIBF Carers Survey

18. Are/were you adequately supported in your role as a carer when you were bereaved?	Yes	No	Not Applicable	Did Not Answer	TOTAL (Sense Check)
ANSWERS	6	37	17	68	128
PERCENTAGE	4.7%	28.9%	13.3%	53.1%	100%

### QUOTES:

Absolutely not! We have never received any offer of support at any time!

Absolutely not! The way we were treated on the day my husband died was scandalous and has had a lasting affect on us all. The Expert Psychological Report agrees with this - that my daughter's will never get over this in their lifetime. Unfortunately this is true.

Again no one contacted us

Again, no one cares. Look at how long this has all taken. Look at how little they've offered. Imagine if that money had been used for Dads life not just to ease their conscious and pretend they've done something for him.

any support came from family but was not wholly effective - took a long time to get over the grieving process

As above, everyone was expected to help out.

GP was fantastic, as were the Hospital Team at the Freeman but no support from any Government department.

I had some minimal counselling. But it was not enough or of good enough quality

I received no help. I was treated for depression and misdiagnosed for years and received no treatment. I could have died myself. I was offered no counselling and the little I found had no clue about infected blood scandal. I was on my own and nothing had been offered to be since for over 21 years

I was her daughter, only my family saw me as her carer as well during that time

I was my Dad's daughter and although living with him and then him with me, only wives & partners count in this instance. I did apply to Skipton who helped with funeral 3000 pounds

I was put in care and was moved about 11 times from age 12 to 18

## SIBF Carers Survey

Just told it was sad and left to get on with it

Lack of contact and support

Minimal / very little support from social worker connected to the haemophilia unit

my husband died in 2015 and there was no provision for support available.

No help given from any organisation

No one said a word no one

No support was given at all. I was 18 when my mum died

Nothing was done to support me. I was left alone with my grief and my reason for being was gone. I had only a few friends and at the time I felt I had no future.

Sister helped when we got older and our fathers mum lived down the road .

Still haven't grieved I feel and it 9yrs later !

Support from some family

There was no support offered

We were completely unsupported and efforts to lobby the Scottish Government were just deflected and ignored which we found heartbreaking and cruel

19. In your opinion and from your experience, please briefly note down what could or should be done to improve the care and support available for infected persons and their carers?

QUOTES:

24/7 helpline with practical solutions as well as listening

A better understanding of infected blood community

A dedicated carers website specifically for infected people would be a positive. It could highlight the most common forms of care someone infected will need including mental health support.

A dedicated key person

A direct contact from IBCA for all registered infected persons and their families.

A help line to support carers through the different stages of the infected persons illness - different people will require different levels of support at different times. Advice could be made available to assist loved ones caring for a dying relative/friend so that they have a better understanding of what may happen as the patient moves towards end of life.

All carers should be recognised by the support schemes and all Carers should receive a pension from the state for what they were put through.

Any movement would be an improvement

Any provision for care will be an upgrade

At the appropriate time a care assessment

Automatic care support after cancer diagnosis. A dedicated care unit for infected people with nurses and medical input so that the infected have peer support and specially tailored care when they are no longer really able to remain at home.

During my time spent caring for my son, now deceased, there was no support provided. For current carers there needs to be emotional and psychological support, practical support, financial support

During our time spent caring for our son, now deceased, there was absolutely no support provided. For current carers should be recognition of how traumatic and draining the demands of caring for somebody you love with emotional and psychological support, practical support and financial support. Thirty to forty years ago we accepted that our son required all the additional care related to his infections and illness and didn't question it. It is only now, looking back, we can see just how abandoned and alone we were, with the expectation from those in authority that we would just "get on with it"!

Every infected person needs to be contacted about the care needed

For everyone, especially medical people, should understand the conditions and not say bad things to the people

## SIBF Carers Survey

For it to be recognised that we all have PTSD from this. It's changed us. None of us are the people we could've been.

For us it's too late for that our father passed away just over 4 years ago. We needed support when we were children. Our whole lives have been affected and trauma is not easily overcome. To learn a new skill I will require one on one support this will best help me in the future so I can become financially independent as this opportunity has already been missed when we were children.

Good information, access to G.P/Hospital monitoring.

Greater understanding of infected persons needs, counselling and training, greater provisions (adaptations etc) provided by hospitals/local councils

I think if any one is expected to be discharged from hospital. A FAMILY case conference should be undertaken to look at a care package not just the care needs of the ill or dying person but to include those that will be expected to care for them. What are their needs it could be a little course on lifting or medication etc which are not offered to family at present

I was left with almost no support, it was shocking. We couldn't even get my mum admitted to palliative care until the last week. She was under medicated and ignored by local services. I still can't think about that time too much, it's too painful for me. I have ptsd from the experience.

I'm not sure what care is currently available. my husband was a haemophiliac and focus was on covering up the wrongs of the medical profession rather than caring for the patient.

I've given up my entire life to care for my dad. I've lost my job, my partner, a chance for a family of my own.

Increase and improve support for those carers living with the consequences of bereavement through HIV / HCV / HBV infections etc...

Infected people should be respected more my mother was badly treated by the N H S big coverup

Make it known what support is available

Mental health support

More help for children who are trying to help care for there parent

More needs to be done as nothing is currently sitting place. No one has ever contacted me as a carer of the contaminated blood victim and this is over many years from 1999. I still have had no support for anybody as a carer.

My experience was very bad as there was no support at all until a relative told us about the Skipton fund

Nowadays because the stigma isn't as bad I think that either the haemophilia centres or GP should put together a care package. Availability for online counselling and help with mental health would be good.

Private healthcare free of charge. To be treated with respect by trained and educated people who have knowledge of the scandal. I expect priority to be given where necessary, that is not asking too much for these innocent people have been forced to endure.

Recognition opening of supplementary route, protected affected estates



## SIBF Carers Survey

Someone to offer support and make sure you are able to care properly and support for medication. In hospital 2 nurses checking medication before patient receives, sent home with a A4 sheet of medication without any assistance, I was panicking in case I got it wrong, also not sleeping as you could not relax.

Speed up compensation process so we can put it behind us and finally stop being forced to relive this pain.

Speed up support

Stigma still needs to be removed, support should NEVER be means tested - my Mammy was never supported as a young widow with teenage children.

Support and training especially in end of life care.

The Hospital who infected them should or gives him his haemophilia care should do though medical and phycological review on all it's patients and carers! We shouldn't have to beg and ask for help! We should be offered the highest care for patients and carers

Through my own experience, and after seeing how my dad was treated, more help needs to be given overall to both and ESPECIALLY at end of life

Truthfully, I can't envisage any improvement. If not apparent before the inquiry, it is now very clear, government does not care about us and wants us out of the way cheaply.

We should be listened to. We should be treated with respect.

What ever each individual needs

20. Is there anything else you would like to put on record related to compensation arrangements for infected blood care and carers?

QUOTES:

I do know that helping my brother pee and poo when we were both late teens was highly stressful and embarrassing for both of us.

All taking far to long to sort out as we feel authorities are purposely dragging there feet.

As an affected person, we are awaiting the Government's approval of the scheme of compensation. It is a concern that while there is to be a supplementary route for those seeking additional compensation that the criteria within the supplementary route appears to be being restricted to certain medical conditions only.

Our infected mother was part of a loving relationship with her husband (dad) for a number of years before her illness was diagnosed and we have every reason to believe that dad may have been infected as well. however the tightening of the supplementary route on medical grounds appears to restrict our ability to claim on his behalf (as he pre-deceased my mum)

As things stand at the moment the compensation does not cover the care given for those on long term interferon when 24 care was needed for such long periods of time. In my brothers case we kept him out of hospital for 14 years which his doctors were very surprised about considering he was so poorly. It is also grossly unfair that a deduction is to be made for care given by the family when it affected them so badly in our case my mother could not work, I had to change to a lower paid job and eventually give up work.

Carers in many cases suffered severe financial impact, interruptions to their careers, incomes compromised, lower NI contributions led to shortfall in pensions. These were not the only financial implications, for example many carers had to move house to somewhere more appropriate, some lost businesses, some were declared bankrupt for which there has never been any recognition or acknowledgement. Marriage breakdowns also created financial implications.

I feel very strongly that no parent, child or sibling should be forced to claim compensation as a carer due to age or address. Since when does a relative cease to be a relative!? I understand carer could be a friend or neighbour or cousin or niece etc

I think it is better now

I think it is morally wrong that many people who were carers will never see their compensation.. because they are old or frail and as it stands their claim will 'die with them 'Shame on the Government !! This makes any apology a mockery

I would like to think that care of the infected and the role of unpaid caregivers would have proper recognition

If someone has supported someone for 18 yrs how can they get the same compensation that someone who was in a relationship for 2 years! Where are our damages for the years of trauma etc

It is dreadful that they they are taking so long to resolve this and establish a plan to pay the people that the government knows they have wronged , both infected and affected. These delays are disgraceful.

It will and is hard to break down the actual hours spent with our loved ones from infection to death .

## SIBF Carers Survey

It will never be enough to compensate for the loss of my Daddy, never.

It's become abundantly obvious that the people making the decisions have no idea what full-time caring is really like. I spent every time my husband was admitted staying in the hospital with him and doing his personal care. This included a stay in the infectious diseases' ward. I'm disabled and during his last hospital stay, I slept on a foldout mattress on the floor by his bed for three weeks. My role of carer didn't end when my husband was admitted to hospital.

It's still neither generous enough or simple enough. They have still not included enough compensation for mental injury for either the infected or carers.

It's all taking too long to complete. We need to try and put this behind us. Compensation would allow us to help our sons and daughters as they have also suffered a great loss.

Make it easier for everyone to understand

Make it fair for everyone it is a 24/7 day every day it takes a toll on you mentally, emotionally, financially, even after you lose your husband, you don't go back to normal life, it cannot be reversed ever. My Mam is now Mute, Bed bound, solid as a rock from head to foot, cannot eat or drink properly, has no human rights left to her name and is going to die with no loved ones surrounding her because she was not listened to. PTSD allowed to suffocate her over the last 30 years. Struggling. Slowly dying of sadness and stress. We need to be listened to and heard properly. If Mam had been able to complete this questionnaire it would have been a sad sorry read.

No amount of money will bring my mother back

Remember that some of us had our childhood ruined. I think you're forgetting this. From infected and affected. Anyone under 18 was a CHILD! We had our childhood ruined and the PTSD from it all still affects us. It changes your brain chemistry. I can't process things like others. I get fight or flight reactions.

Robust follow up for infected and affected

Security of finances and support with clear information.

The 16.5 hours that have been ascribed as a minimum for carers should be flexible. It feels like this figure has been taken from the DWP Benefits handbook as the status quo or somehow the de-facto number. The Affected should receive more recognition for all the past traumas that they had to deal with on their own.

The compensation for HCV is woeful and grossly unfair, with its cruel deductions, layers, and omissions.

Obviously more compensation would help to at least give an illusion of justice, however in terms of care, my son deserves realistic financial redress. We are surviving through a criminal cover up, and should be compensated accordingly.

The process is taking far too long and many people are going to miss out on a considerable amount of compensation because they're in an individual and unique situation. Circumstances are being missed while they're asking to jump through hoops which is very stressful. It should not be this way.

The removal of 25% justified because the care was provided non gratuitously is a sick joke, this money should be credited to carers state pension. The lack of bereavement support and or care for carers who were parents, children and or siblings is disgusting. I am ashamed to be a British citizen. Scottish Government are cruel and have treated carers very badly.

## SIBF Carers Survey

They are not open to under 18yr olds siblings or children who provided care, lost out on education or suffered as a result of trauma looking after a terminally ill adult.

They Need to be either bespoke to each person (even Siblings may have given disproportionate levels of care yet will be awarded some compensation generally. needs to be balanced and fair

Whilst there will be a supplementary route open to those parents who can prove that they were financially dependent on their child, this certainly does not cover the many more reasons for financial loss of carers. Many had to move home to places that were more appropriate to the needs of the infected person, some lost businesses and some declared bankrupt for which there is no recognition or acknowledgement. Marriage breakdowns due to the strain of caring and bereavement also created financial implications for carers.

Whilst there will be a supplementary route open to those parents who can prove that they were financially dependent on their child, this certainly does not cover the many more reasons for financial loss of carers. Many had to move home to places that were more appropriate to the needs of the infected person, some lost businesses and some declared bankrupt for which there is no recognition or acknowledgement. Marriage breakdowns due to the strain of caring and bereavement also created financial implications for carers.

Why are daughter's who lived with (until death and cared for their parent not treated same as wives/partners?

Why has the supplementary element been taken away from the compensation package for the affected? Without that, we are not being "compensated" for our individual experiences at all.

Infected		
1. Are you ...? An infected person who was, is, or will be the receiver of care	An infected person who was, is, or will be the receiver of care	TOTAL (Sense Check)
ANSWERS	21	21

## SIBF Carers Survey

2. Do you currently receive care support, and if so, who provides this? (This could variously include paid-for support from local authority home care teams, or simply family carer inputs.)	Yes	No	Did Not Answer	TOTAL (Sense Check)
ANSWERS	2	2	17	21

### QUOTES:

From family.

My wife helps organise most of our household including managing finances, does everything related to my kids school and education, pretty much is a single parent due to my current mental and physical health issues.



### SIBF Carers Survey

3. What do you expect your future care needs to involve? (Select all that apply)	Yes	Did Not Answer	TOTAL (Sense Check)	% Yes
I expect to require physical care (such as lifting, moving, and handling, etc.)	2	19	21	9.5%
I expect to require supported medical care (such as supervising or administering medications, etc.)	1	20	21	4.8%
I expect to require personal intimate care (such as assisting with dressing, cleaning, washing, bathing, toileting, and shaving, etc.)	2	19	21	9.5%
I expect to require financial management care (such as dealing with bills, the administration of their finances including banking, etc.)	3	18	21	14.3%
I expect to require transport care (such as escorting to doctors' appointments or hospital visits via public transport, helping into a car and/or driving them places, pushing them in a wheelchair, etc.)	2	19	21	9.5%
I expect to require household chores care (such as regularly doing the cleaning, cooking, shopping, and laundry, etc.)	5	16	21	23.8%
I expect to require emotional support care (such as listening, sharing, affirming, assuring, socialising, and reminiscing, etc.)	4	17	21	19.0%
I expect to require agency interactive care (such as liaising with statutory care providers, managing carers via self-directed care, etc.)	1	20	21	4.8%
<b>TOTAL</b>	<b>20</b>	<b>148</b>	<b>168</b>	<b>N/A</b>
<b>PERCENTAGE</b>	<b>11.9%</b>	<b>88.1%</b>	<b>100%</b>	<b>N/A</b>

# SIBF Carers Survey

4. Who do you anticipate will meet your care needs?	Yes	Did Not Answer	TOTAL (Sense Check)	% Yes
Local statutory providers ("council")	0	21	21	0.0%
Family member(s)	3	18	21	14.3%
Private or charity providers (such as a veterans' agency)	0	21	21	0.0%
A combination of providers	1	20	21	4.8%
Don't know (and this may be a worry)	1	20	21	4.8%
<b>TOTAL</b>	<b>5</b>	<b>100</b>	<b>105</b>	<b>N/A</b>
<b>PERCENTAGE</b>	<b>4.8%</b>	<b>95.2%</b>	<b>100%</b>	<b>N/A</b>

5. Do you have an idea of how the cost of your care needs will be calculated?	Yes	No	Did Not Answer	TOTAL (Sense Check)
<b>ANSWERS</b>	<b>0</b>	<b>4</b>	<b>17</b>	<b>21</b>

6. Do you have an idea of how the cost of your care needs will be covered?	Yes	No	Did Not Answer	TOTAL (Sense Check)
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# SIBF Carers Survey

ANSWERS	1	3	17	21
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