

# **Expert Report to the Infected Blood Inquiry: Psychosocial Issues - Childhood Bereavement (Supplementary)**

**November 2022**





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## Introduction

The 2020 Psychosocial Expert Group report to the Infected Blood Inquiry highlighted how the loss or potential loss of a close family member due to infection had a significant impact on an individual's mental health. The Psychosocial Group reviewed witness statements that described the experience of parents who were unable to provide the emotional closeness they believed they should have been able to, as a result of frequent medical treatment and hospital admissions.

The report also highlighted that the death of a family member is a major life stressor, the adjustment to which may take months or years. The emotional changes and physical symptoms, which accompany the normal grieving process, vary considerably depending on a range of individual and situational factors (Stroebe et al., 2007).

The majority of the witnesses who were bereaved as a result of infected blood or blood products experienced what Horowitz has called 'complicated grief' (Horowitz et al., 2003), where the grieving process is much more intense and/or prolonged. Individuals can have trouble accepting the death, feel unable to trust others, and harbour excessive bitterness and anger related to the death (Horowitz et al., 2003). When this happens, rumination is common and tends to be focused on angry or guilty recrimination linked to the circumstances of the death (Shear, 2015).

We have been asked by the Inquiry to follow up on the main report and look in more detail at the evidence of psychosocial impacts on children bereaved as a consequence of their parent(s) having been treated with infected blood or blood products. Using the same methodology as the main report, in this document we have reviewed both the current literature and a number of witness statements in respect of the six specific issues. The witnesses were bereaved after their parents had been infected with one or more of HIV, hepatitis C and hepatitis B. The Further Supplementary Letter of Instruction is provided at the end of this report; sections in this report correspond to the questions posed at paragraph 5 of the letter and are similarly assigned letters a - e. Although each question focuses on a specific area, there are considerable links and overlaps between each section.

- a. Psychosocial impacts of stigma on the children of HIV-positive parents during the 1980s and 1990s.
- b. Psychosocial impacts on children of their parent's terminal illness being hidden from them.
- c. Psychosocial impacts on children who grow up without a father and/or mother describing the impacts of age when bereaved and gender as far as they are understood.
- d1. Psychosocial impacts of childhood bereavement on education.
- d2. Psychosocial impacts of childhood bereavement on future employment.
- e. Psychological disorders that can arise from childhood bereavement.

## a. Psychosocial impacts of stigma on the children of HIV-positive parents during the 1980s 1990s

The [2020 Psychosocial expert report](#) focussed on the impact of stigma in section 13.7.

Goffman first described stigma as ‘a condition or behaviour that in the view of the wider society marks the individual as unacceptably different and inferior and elicits some form of community sanction’ (Goffman, 1963). Having a stigmatised condition and internalising its social meanings has been shown to have a negative impact on an individual’s self-identity, resulting in poorer illness adjustment and mental health (Corrigan & Rao, 2012).

In the early 1980s, high levels of stigma were directed towards individuals infected with HIV/AIDS through transfusions with infected blood and treatment with blood products. The stigma attached to HIV/AIDS was influenced not only by fear of medical risks, but also by the higher frequency of HIV/AIDS infections among already stigmatised social groups, particularly homosexuals, sex workers and injecting drug users, who were seen to be to blame for bringing the condition upon themselves. The public had very limited knowledge about hepatitis C and, as witnesses commented, they therefore drew on their knowledge of HIV, thinking hepatitis C would be very similar, and this frightened them.

Enacted stigma was experienced in social settings as well as in health care settings and in the workplace. In addition to experiencing enacted stigma, many witnesses described ‘felt’ or internalised stigma. This describes an individual’s awareness of having a condition that is socially dis-valued in the community and which differentiates them from the normal non-stigmatised population in a deeply discrediting way (Goffman, 1963). Many witnesses infected with HIV were aware that people assumed they had contracted this feared condition through being a homosexual, prostitute, or drug user, with these assumptions reinforcing felt stigma.

Section 13.7 in the 2020 report describes a culture of secrecy that was encouraged by health care professionals as well as a deliberate choice by parents to protect themselves and their families from enacted stigma. However, despite attempts to keep the diagnosis a secret, bullying, shaming and verbal and physical abuse by the communities in which people lived, as well as abandonment by friends and family, were not uncommon experiences and are graphically described in the original psychosocial report. Stigma in the workplace was also experienced, impacting on career development and ultimately financial security.

Many children were already living with high levels of stigma and trauma prior to the death of a parent. One witness described the bullying that occurred at school while her father was still alive but seriously ill.

*‘The children at school knew I was different and I was having problems at home, and targeted me because of this. They bullied me physically as well as emotionally. Once at the playground at school, some girls came and threw stones at me and tore my dress off.’*

*‘As a result of this bullying, I often tried to hurt myself so I could go to the infirmary and be taken home from school.’*

In some cases, the bullying and physical abuse was described as being so bad that families with young children decided to have a fresh start in a new area, although this move was demanding with the need to get new employment and accommodation.



Many children who experienced stigma by association when they first lost their parent(s) to HIV or hepatitis C, have continued to live with stigma for the next 30 - 40 years. A significant theme of negative social effects and stigma runs through all witness statements of children whose parent/s died. The witness statements identify a number of negative effects of both enacted and felt stigma on the grieving process for those who were left behind after a death which was the result of treatment with infected blood products or blood. Witnesses describe social stigma, stigma from health care professionals and institutional stigma driven by lack of knowledge (ignorance) and negative attitudes (prejudice).

Witnesses describe living with high levels of self-stigma with feelings of guilt, inadequacy, embarrassment and anger. They also describe low self-esteem and self-efficacy, and feelings of isolation.

Witness statements reviewed for this report describe feelings of shame and the need for secrecy to try and avoid stigma by association. One witness described the impact of the media campaign response to the AIDs epidemic and how that influenced people's reactions.

*'...[M]y Year 10 peers just assumed that my parents were divorced and that my father was not around. I never felt inclined to rectify their incorrect assumptions. It was bad enough coming home from school and seeing AIDS campaigns, utilising tombstones, on the television and I could tell you exactly where I was and what I was doing from the age of 13 to adulthood when someone told an AIDS joke.'*

The impact of stigma by association on individuals was often long-term. Another witness, who was only 4 at the time of his father's death, recalled traumatic experiences around the funeral and had limited memory of his father. Years later he was bullied at school, being called 'AIDS boy' and taunted by other children who said his father was gay. He describes feeling isolated as a child, struggling to attend school, and his adolescence as challenging and difficult. He was unable to achieve any GCSEs and described himself as being withdrawn and having difficult relationships with peers.

*'My father's death and the stigma I faced at school definitely impacted upon my education and school life...'*

One witness who lost her mother at the age of 11 but had not been told what her mother had died from, was bullied at school by children who seemed to know something about how her mother had died. As a teen, people assumed she had AIDS, and 'said bad things.'

Another witness described being physically and emotionally bullied at school because of the stigma surrounding hepatitis C. She describes feeling angry and upset and experiencing panic attacks. She has also had a history of self-harm including taking an overdose requiring a hospital admission.

Witnesses also talk about stigma from health professionals and institutional stigma. Examples include GPs refusing to come into the house to make home visits, doctors advising families not to talk about the diagnoses, or witnesses being scared to talk about their parent's death in case it affected their relationships with co-workers or impacted on how they were perceived by their employers.

Whilst new legislation has been introduced and campaigns organised aiming to protect people with HIV against discrimination, harassment and victimisation, and increase public knowledge and reduce fears (National AIDS Trust, 2016), stigma still surrounds hepatitis C (Northrop, 2017) and HIV (Hibbert et al., 2018). There is also evidence that children across countries and cultures still experience stigma by association with HIV (Mason & Sultzman,

2019). One anonymous witness described feelings of isolation. They couldn't mix with people where they lived or go to friends. They were unable to let anyone know about their parent's haemophilia and its association with HIV.

*'...If I tell people about my father having HIV and dying of AIDS, I still have negative responses.'*

The quotes below from three different witnesses clearly highlight how, as adults, the stigma continues to have an impact on their day to day lives.

*'The stigma lives on today, having to lie to people about how my mother died and not talking about my brother. It's been hard at times listening to cruel HIV jokes and staying silent.'*

*'Stigma is an issue and has been since the death of our mother. We didn't tell anyone how my mother died. People tell daft jokes about people with HIV/AIDS.'*

*'The passing of my mother destroyed my life. The person I am today is not the person I would have been if this tragedy had [...] not happened. I have had to carry a massive burden since my childhood broke down. [...] Due to the stigma associated with HIV, I avoid talking about the cause of my mother's death. Only my direct family knows about it and (I) did my best to conceal it from others. However, my two previous partners carried out their own research and found out about the situation and this caused a breakup [...] I tell [people] my mother died of kidney infection because of the stigma associated with HIV.'*

In conclusion, data from the research studies is clearly supported by the witness statements and shows that experiencing stigmatising behaviours from others is associated with poor school outcomes for children, disrupted peer and adult relationships and acute and chronic psychological problems. Attempts to avoid stigma resulted in secrecy and lack of communication within families, which had significant effects on emotional well-being addressed in greater detail in question b. Stigma was also a major factor in reduced educational outcomes (addressed in question d). There is a complex relationship between stigma, poverty and mental health as well as a bi-directional relationship between stigma by association and depression. The impact on mental health is further explored in question e.

## **b. Psychosocial impacts on children of their parent's terminal illness being hidden from them**

The potential impact of stigma created a dilemma for parents who worried about the appropriateness of disclosing their HIV or hepatitis C status to their child as well as the consequences of other people finding out about the diagnosis. This was influenced by their perception of the potential impact on their child (discussed in more detail in the section on the age of the child in question c), and whether or not the infected parent was experiencing symptoms or visible evidence of their condition. In most cases, parents tried not to tell a child until they were about 18 years old to spare them the worry of an impending death sentence, and give them a normal childhood. However, keeping this secret was difficult if the parent began to show signs of illness and could therefore no longer 'pass' as healthy. In the 2020 Psychosocial report, we describe how a family struggled with this. Doctors had told the parent not to tell his family that he was HIV positive, and his son was told instead, *'your Dad is ill'*. Later on, when the son's friends started to ask what was wrong with his Dad, he was then told his Dad was dying of cancer. However, when the son reached 18 years of age, he was told his Dad's true diagnosis.



The 2020 Psychosocial expert report stated that the psychosocial impacts and need for secrecy created greater individual emotional vulnerability.

We continued to see the impact of both disclosure and secrecy in the witness statements we have reviewed for this work. The impact of poor communication was repeatedly described by witnesses as being confusing and painful.

#### i. Lack of communication

One witness described how *'things were kept hidden from me.'* He was not told about his father's diagnosis until six weeks before his father died. His witness statement described being significantly impacted by the diagnosis and death, and feeling that he became socially awkward and shy.

Another witness saw his father's medical records 20 years after he had died which resulted in a stress reaction and significant stress-related medical illness.

One witness had described a positive relationship with her parents, particularly her father. She recalls memories of secrets and distress when her father died when she was 10 years old. No explanation was given to them about the diagnoses and her mother struggled to cope as her father became ill. She was given no information as to why she had to keep a distance when in hospital which was *'sad and confusing'*. The family was unable to stay together.

*'I would define that day as the end of my carefree childhood. [...] From that day on, and for at least a decade if not more, my mother became emotionally and physically unavailable to me at a time when I needed her most. I appreciate that it was horrific for my poor mother who was only aged 32 when she lost my father. However, from my point of view, I was a very lost and lonely child. I was bobbing about and floating around looking to replace what I had lost and yet never came close to doing so. I was angry and resentful and struggled to readjust to life without Dad.'*

#### ii. Keeping secrets

The second theme around secrecy was the impact of having to keep the secret from others, and being scared and worried that people would *'find out the truth'*.

A witness developed enuresis (involuntary bed-wetting) because of the trauma and secrets around the diagnosis. He described the death of his father as traumatic, having an impact on his self-esteem and self-confidence, leading to becoming socially isolated at school where he suffered significant bullying. He described feeling anger and resentment about being forced to keep everything a secret as a child.

*'I believe that the trauma associated with losing my Dad in that way is a major factor in my unhappiness in my adult life. I think the secrecy that surrounded Dad's death had a lasting effect. Not being able to talk about big trauma in my life has caused me to suppress my emotions and feelings.'*

The 2020 Psychosocial expert report highlighted how poor-quality communication from many healthcare professionals may have also had negative effects on the grief processes. It was overwhelmingly the case that the children of infected individuals received little or no support around the time of diagnosis, during or after the bereavement despite many of them actively seeking out support. Bereavement experiences can be strongly affected by the quality of palliative care. Communication and shared decision-making, aligned to the

needs and values of the terminally ill person and those closest to them, are associated with less problematic bereavement outcomes (Sanders et al., 2018). Witnesses revealed that information about their parent's diagnosis and death was delivered insensitively. Trust in healthcare professionals and the way they communicate and inform adolescents and young people as relatives has also been shown to have an impact on bereavement experiences (Grenklo et al., 2013; Marshall et al., 2022).

Good communication around the death of a parent (from cancer) can mitigate some of the trauma and distress (Bylund-Grenklo et al., 2014; Eklund et al., 2020). Children's trust in the care provided to a dying parent is highest when they received end-of-life medical information before their loss. When there is a lack of trust, there is increased risk of depression.

The 2020 Psychosocial expert report described how concealment of these diagnoses was a key coping strategy, because of the stigma linked to HIV and hepatitis C infection and the negative public response. As already reported, there were significant bereavements to contend with, and in some families, parents lost several children, people lost life partners, children lost parents and sometimes extended family members, and siblings were left bereaved. In all of these cases managing the significant burden of the grief that predated and followed the bereavement was managed within the individual families, who supported one another with little if any support from outside agencies.

In 1989, the United Nations Convention on the Rights of Children (UNCRC) clearly defined the fundamental human rights of all children (United Nations, 1989). The Nordic countries have taken a pioneering approach to the UNCRC, in particular with regards to children living with a dying parent. Norway, Finland, and Sweden have enacted legislation placing a duty on healthcare professionals to consider the needs of dependent children when a parent is seriously ill (Bergersen et al., 2022). This approach recognises that this cohort of children have increased vulnerabilities and are at higher risk of negative outcomes in adulthood. In order to ensure their future wellbeing, these Nordic children now have a right to information and support when a parent is seriously ill and dying.

### **c. Psychosocial impacts on children who grow up without a father and/or mother. Please explain the impacts of age when bereaved, and gender, as far as they are understood**

Age, gender, stage of cognitive and emotional development and earlier experiences are all factors that can influence the psychosocial impact of loss of a parent (Tremblay & Israel, 1998; Chen & Panebianco, 2018; Hope & Hodge, 2006; Warmbrod, 1986).

#### **i. Bereavement in childhood**

It is not a recent conclusion that young children have greater difficulty in adjusting to parental death and are at greater risk of developing psychological and behavioural problems (Rutter, 1996). The ability of children and young people to understand and process death is influenced by their developmental level (rather than their age). Up to the age of 10, children's understanding about death lies on a continuum influenced by how they interpret the experience and what others have told them about death. As already discussed above, for children bereaved as the result of infected blood and/or blood products, the death of parents was shrouded in secrecy and lack of information or support.



Younger children may not understand the finality of death, whilst at the same time feeling distress that they have somehow 'lost' a loved one, and may develop feelings of being abandoned (Speece & Brent, 1984). Children can also experience 'magical thinking' and believe that they have 'caused' the death (van Elk et al., 2015). These misconceptions may impact on the child's grieving process and result in a number of psychological and behavioural symptoms. These can include the child developing selective mutism, bed-wetting or poor bowel control. These all require psychological intervention and support, however if not treated can last into adolescence and young adulthood alongside feelings of isolation, low mood and anxiety.

The statement of a witness whose father died when she was four years old describes how she knew that something was wrong and different, but couldn't completely grasp what had happened. The impact of this trauma has remained with her throughout her life. Following the death of her father, she became too terrified to be in nursery. She was closely attached to her mother and developed selective mutism at school. As a result, she was bullied by other children. She described not feeling safe outside of the family home. She was painfully shy, anxious and clingy and describes herself as having separation anxiety.

*'[...] I have battled so hard against shyness for my entire life. I still have the tendency to go inward if I am upset, experiencing emotions and not knowing what to do with them and how to express them.'*

There is also some evidence that early childhood trauma has a long term impact on the immune system and represents 'a significant health risk that continues to exert a deleterious effect in adulthood' (Simons et al., 2019).

*'Reading through my father's medical records and becoming aware of the truth of what really happened to him made me very ill. At one stage I was coughing up blood and my weight dropped five stone. I was diagnosed with IBS, psoriasis and depression (for which I refused to take pills). It was like having to relive everything. I shouldn't have had to go through it all; it should have been dealt with by the Government when I was a child.'*

## ii. Bereavement in adolescence

Whilst adolescents can 'understand' death better than a child, the complex bio-psycho-social developmental changes surrounding puberty and emerging adulthood can render them highly vulnerable to the loss of one (or both) parent(s). This can lead to greater and more complex psychological and behavioural disorders in adult life. Among the most common disorders linked to the loss of a parent in adolescence are anxiety, depression, guilt, anger, low self-esteem (addressed in question e), and significant reduction in school and work performance (addressed in question d). It is important to also highlight how the death of a parent for an adolescent will impact on family structure, financial stability and 'the loss of an expected future'. Following the death of a loved one, in contrast to children, adolescents are able to articulate and understand death (Karlsson et al., 2013). Alvariza et al. (2017) described key factors that increase resilience in the face of bereavement in adolescence. These include (1) to be seen and acknowledged; (2) to understand and prepare for illness, treatment, and the impending death; (3) to spend time with the ill parent; and (4) to receive support tailored to the individual teenager's needs (Alvariza et al., 2017).

Another key factor in determining outcomes for children and young people is the ability of the remaining parent (or adult) to make positive adjustments to the loss of their partner. The stigma and secrecy associated with the diagnosis, symptoms of the disease, and its treatment and subsequent death made this a herculean task for many.

One witness describes how following the death of his father, his mother ‘suffered a breakdown’ and was admitted to a psychiatric hospital a number of times and had persistent and significant mental health issues. Other witnesses were sent to live with grandparents or were put into care when the surviving parent was unable to cope with the loss of their partner.

Going into the care system can mean a number of difficult changes for a child at any time - such as moving to a new location, separation from siblings and other family, changing schools. For bereaved children, any of these changes are likely to be particularly traumatic. In addition, research shows that children in the care system experience poorer life chances and future outcomes (Department for Education, 2022).

What is clear from the witness statements is that none of the best practice principles of communication and support, which were known at the time, were considered or in place when the witnesses lost their parent(s). The consequences of failing to provide sufficient information and support left adolescents feeling unprepared and having to guess and interpret the vague signs of failing health on their own. This resulted in feelings of depression, uncertainty, isolation, loneliness, anger, guilt, confusion, and fear. Witnesses reported diminished energy, loss of sleep and development of eating disorders as well as other conditions mediated by stress but expressed through physical symptoms. They struggled to maintain their daily routine and reported feeling restless and in some cases, aggressive. Young people who are parentally bereaved before the age of 16 are significantly more likely to display anti-social behaviour than those who are not (Draper & Hancock, 2011). One witness reflected on her experience:

*‘I remember visiting the hospital and being confused and frightened because the medical staff made my mother and me put protective aprons and gloves on before they allowed us to see my father. I could see how anxious this made my mother and at no point did anyone tell us why they were making us wear protective clothing.’*

*‘I basically went from the girl who had her school shoes polished for her on a Sunday evening, did her homework and was almost top of the class academically to demonstrating chaotic behaviour which included jumping out of cars, spitting, swearing and running away.’*

The death of a parent influenced witnesses’ hopes for the future by impacting on family structure, having to take on the role of a carer, loss of a stable role model, and significant financial loss.

*‘In terms of the impact upon my childhood and teenage years, in essence, it ended there in October 1985 because at that point I became a carer for my sister whilst my mother was having to work full time to maintain our home and needs.’*

### iii. The influence of gender

Feigelman et al. (2017) found bereaved children of both genders were more likely to have been suspended or expelled from school and to have repeated a grade and, on average, to have completed one year less formal education compared to non-bereaved peers. The 1970



British cohort study (Parsons, 2011) also reported that overall, bereaved children were more likely to leave full-time education at age 16 and less likely to have attained any qualifications at age 16. They were also more likely to express lower educational aspirations for the future.

There is some evidence that the death of a parent places girls at greater risk than boys of developing depression and other mental health problems (Schmiege et al., 2006). Social workers reported in Hope and Hodge (2006) that the male children they worked with tended to externalise their grief, and exhibit more acting out behaviour, whereas female children tended to internalise their grief presenting with depression as well as displaying more physical symptoms. Schmiege et al. (2006) also found that boys with behavioural problems following bereavement showed decreased symptoms over time, with or without an intervention, compared to girls who maintained levels of distress if they were not provided with support. Teenage girls were more likely than boys to report poor family cohesion after losing a parent to cancer (Birgisdóttir et al., 2019). This perceived loss of family continued into young adulthood (Hope & Hodge, 2006).

Parsons (2011) found bereaved teenage boys showed the most disadvantage in terms of education, were less interested in higher education in the future and were more likely than girls to want to leave full-time education at 16, and as a consequence to have no educational qualifications.

Children and adolescents who lose one or both parents do not just lose their carer(s). Younger children lose the support and stability of their attachment figure without being developmentally able to fully understand the reason for the loss and subsequent changes to their life. Whilst teenagers can intellectually understand death, there is significant impact on their identity – with changes in who they are and for many, a loss of who they were going to be. The lack of support in schools (described below in question d) and failure to be provided with psychological counselling has had significant long-term impact on who they feel they have become compared to who they could have been had they not lost their parents. Witnesses describe a loss of friendship groups and significant impact on financial stability. Some were forced to become carers whilst others lost their family and were put into the care of relatives with a culture of secrecy that added to their confusion and distress. It is important to emphasise that many of the witnesses have found ways to develop resilience and carve out positive lives. However, the scars of losing their parents under the circumstances that have been clearly described in the 2020 Psychosocial expert report, have never left them even as some have become parents themselves.

## **d1. Psychosocial impacts of childhood bereavement on education**

The impact of parental loss on education is complex and multi-layered (Beardslee et al., 1998). The witnesses referred to in the 2020 Psychosocial expert report highlighted significant stress on children resulting from a parent's illness and the consequent tensions at home. Witnesses attributed their child's behaviour, such as going to school late or homework not getting done, to the atmosphere in the house and the things that were happening. A mother observed, *'My son preferred going to his friend's house rather than stay in our house because of the way things are'*. Older children often felt they needed to look after their parent(s) and so did not go out with their friends. There is a large body of evidence describing the negative impact of being a young carer (Scottish Government, 2017). A parent described the significant

emotional burden of her illness on their children, because '*... when they were old enough to learn why I was sick, they then had to carry the burden of it, and that has ramifications for them in their own lives going forward ...*'

The research clearly shows that losing a parent during childhood or teenage years has a significant impact on school attendance, exam performance and grades. Large long-term studies in both the USA and Sweden suggest that a parent's death during early childhood or teenage years is more likely to result in premature school withdrawal and diminished interest in college attendance (Feigelman et al., 2017, Høeg et al., 2019) as well as lower grades and school failure (Feigelman et al., 2017). Another large study in Denmark showed that anyone bereaved of a parent before the age of 18 has a significantly lower educational attainment rate than non-bereaved people (Berg et al., 2014).

The majority of witnesses whose statements were reviewed for this report describe being unable to stay in school, being unable to complete their GCSEs or getting much lower grades than they believe they could have achieved. One anonymous witness talked about the impact of losing their father at the age of 6 and their mother 3 years later. They were cared for by several different relatives and lost contact with their eldest sister. They described feeling confused and angry. They became a carer for their siblings. They used drugs and alcohol as a coping mechanism.

*'The loss of my parents had a devastating effect on me. I was bubbly and enthusiastic but after they died, I became quiet and reserved and my mind seemed to be preoccupied trying to establish what was going on and why.'*

*'For this reason, I did not do well at school. When, I first moved [...] I did not know how to channel my emotions. I used to storm out of the classrooms in a rage and this was all due [to] my anger of losing my parents. Upon completing my secondary education, I went to college in my 20s. I completed a B-Tec Business Course but I had to re-sit exams, which I consider I would not have had to do if my parents had not died. I did find it really difficult to concentrate during this period.'*

Another witness talked about how her education was affected by practical and emotional impacts both before and after the death of her father.

*'The run up to his death had a massive effect on my ability to concentrate on my studies, both emotionally and because I had to spend time travelling home to visit him.'*

*'After my overdose at 15, I was told by my school that I could not return to school. I either had to go to counselling or be sectioned.'*

*'I feel as I have been struggling to get institutions to understand what has happened for years, in addition to the emotional stress of dealing with my father's illness and death.'*

Another witness talked about how family breakdown and a disrupted relationship with the surviving parent was also a factor in her emotional wellbeing and educational outcomes.

*'I counted five school moves during my formative years. [...] I was moved down from the top set where I had always been throughout school in Maths and science as I struggled to keep up, my grades went from A to B and C initially.'*



The difficulties of staying in school and further education can be clearly understood within the wider context of the system that surrounded children and adolescents whose parent/s died from HIV/hepatitis C. The stigmatising behaviours from other parents and children resulted in bullying which stopped many young people continuing in education. Mental health problems (described in detail in question e) impacted on the ability to concentrate and pay attention, and affected memory and motivation to learn. Schools were often unaware of the circumstances surrounding the death (because of secrecy) and failed to provide adequate counselling or support. Family breakdown often resulted in constantly moving from school to school. Children and young people found themselves in a vicious downward spiral of rejection and distress that has resulted in reduced educational success for many of the witnesses, with long term consequences as they entered adulthood.

## **d2. Psychosocial impacts of childhood bereavement on future employment**

The negative effects of bereavement on educational experiences, outlined in the previous section, has certainly affected future employment.

Analysis of longitudinal data from the 1970 British Cohort Study found that men who were bereaved in childhood were less likely to be employed at the age of 30. For men who were in employment, they were less likely to be employed in a professional or managerial occupation (Parsons, 2011).

For women who had experienced bereavement in childhood, there was an increased risk of failing to gain any sort of qualification. Compared to men who had experienced bereavement in childhood they were less likely to be employed, or be in partly skilled or unskilled occupations at age 30, and more likely to report symptoms associated with depression.

While there is a lack of academic research data in this area, Inquiry witnesses have provided powerful evidence. They describe the spiralling consequences of having lost a parent, living with stigma and mental health problems, and the subsequent challenges that failing to achieve adequate educational qualifications has caused, as they became adults.

An anonymous witness who lost their mother when they were 12, describes themselves as having been depressed and unable to concentrate. They describe feeling suicidal – for which no support was offered. After leaving school, they ended up working in a hotel and moving from job to job.

*'[...] I suffered from a lack of self esteem and I moved on instead of stepping up the ladder.'*

Another witness described how the initial impact on educational outcomes continued to have an impact throughout her life.

*'This has also seriously affected my prospects of applying for training contracts. [...] Firms were only interested in my undergraduate degree result which was lower than it should have been.'*

For others, bereavement impacted on their developmental journey and prevented them from doing what they might have done had circumstances been different.

*'I did not end up going to university until I was a mature student because I did not feel able to leave home alongside my peers at the time, as I didn't have the financial or emotional security [...] to venture far from home at the age of 18 or 19.'*

Another witness completed an Art Foundation degree but doesn't feel as if she has had a positive career:

*'The devastation caused by this didn't stop at my parents' death; it continues to affect our family to this day. We have been pushed to the side lines of society and left to pick up the pieces.'*

Secrecy and shame has followed witnesses throughout their lives.

*'When the Inquiry started, I had supervision with my manager, during which he asked how best to help and support me during this time. This was the first time in my life that I was able to say confidently that my father died of AIDS. My manager said that he had not told anyone else in the office but I assured him that it was fine and he could tell everyone. It has taken the Inquiry and the fact that I was then part of a recognised group, courage and 35 years for me to confidently walk into court for my day job with my ribbon on.'*

The impact on employment cannot be viewed in isolation and must also take into account the impact of bereavement described in all of the sections above, especially the psychological impacts described in question e, including self-stigma and stigma by association resulting in low self-esteem, shame, and self-blame. Economic disadvantage, loss of social systems, disappointing achievement in GCSEs, and the failure of the healthcare system to support or mitigate psychological distress have combined to impact on self-belief, identity, and aspiration. Indeed, all of these factors will impact on the kind of jobs people might apply for or how they present in the workplace.

## **e. Psychological disorders that can arise from childhood bereavement**

Research shows that children who have lost a parent have an increased risk of long-term psychological distress including depression, self-harm, uncertainty, loneliness, fear and worry (Beernaert et al., 2017). The 2020 Psychosocial expert report described the experience of parents who were unable to provide the emotional closeness they believed they should have been able to, because of frequent medical treatment and hospital admissions. The report also highlighted how the loss or potential loss of a close family member due to infection had a significant impact on an individual's mental health. Negative experiences during parental illness, death and the mourning period afterwards can increase the risk for psychosocial distress among adolescents and young people, resulting in both short- and long-term health problems. Childhood bereavement from parental death is a significant stressor and is associated with increased psychiatric problems in the first 2 years after death. Children who experience depression in combination with parental depression or in the context of other family stressors, including family socioeconomic status, are at most risk of depression and overall psychopathology (Cerel et al., 2006).

Recent evidence from a large national cohort study confirmed that experiencing the death of a parent during childhood increases the risk of a psychological disorder as an adult. Children who experienced early parental death had an increased risk of hospitalisation for depression and anxiety as adults (Appel et al., 2013). The authors also reported an increased risk for use of antidepressants in children and young adults (Appel et al., 2016). Another study by the same group found that bereaved young adults reported significantly more depressive symptoms and lower mental health quality of life than non-bereaved young adults and general population levels (Appel et al., 2019).



Without satisfactory support, adolescents and young people are at risk of developing low self-esteem, behavioural difficulties (e.g. anger and aggression), long-term illness or premature death caused by severe mental illness, substance abuse, self-harm, and suicide attempts. Experiencing the death of one or both biological parents increases the risk of suicide attempts in young people. Whilst losing one parent results in a significantly increased risk of attempting suicide, losing the remaining parent nearly doubles the risk (Jakobsen & Christiansen, 2011).

For example, one witness revealed that:

*'On dark days, I thought about ending my life but I never had any real intent to go through with it. I would go to the bathroom cupboard and get out all of the tablets and lay them out on the bed. I would then just look at them. I would also think about writing a note and what it would say but on reflection I can see it was all just reactive and a cry for help. I was still hurting, and I did not know how to heal myself.'*

The witness statements read for this report make stark and distressing reading. None of the witnesses were offered what would now be considered adequate or specialist psychological support prior to the death of their parent(s), after the bereavement itself or subsequently. As a consequence, levels of psychological distress and long-term mental health difficulties are evidenced throughout.

One witness whose mother died following an infection transmitted by a blood transfusion during childbirth, described poor communication, disruption of the family structure, and a total lack of counselling or support and ongoing health issues in other family members.

*'My personal grief for my mother's death was very much belated due to the family situation. This resulted in an extended bereavement process as, once the stress, drugs and alcohol wear off, one is confronted with everything, the guilt, the regrets and just a general feeling of loss, all anew.'*

One witness, diagnosed with post-traumatic stress disorder (PTSD), suffered from agoraphobia, depression, and anxiety. She is currently planning to return to education at the age of 30 to retake GCSEs.

Another witness suffered from alcohol abuse, anxiety, and panic attacks. At 21 he was diagnosed with globus hystericus (a feeling of a lump in the throat), which is commonly considered to be a medically unexplained condition strongly linked to untreated stress.

The statements below from four witnesses clearly reflect the empirical data of Beernaert et al., 2017, Cerel et al., 2006, Appel et al., 2013 and Jakobsen & Christiansen, 2011.

*'Looking back, I now know that what I felt and experienced during those years was depression [...] I also started to self harm at this time, by running into my bedroom wall and hitting my head extremely hard which caused pain and brought instant relief.'*

*'I am now married and have three children. [...] I feel like this has made me slightly distant from my children. I find it difficult to interact with my children as a father should. It is a big struggle for me. [...] I still cry everyday. This shouldn't have happened. [...] I have never been able to even start the grieving process as what really happened has never been publicly admitted.'*

*'In my adult life I've have had to deal with depression and anxiety. I have struggled with thinking people I care about will die on me and I feel especially anxious that people I love will commit suicide.'*

*'I still struggle with anxiety and worry about dying, anywhere from 1-2 to 7 days a week. My anxiety comes on quite suddenly and intensely and I believe I may have symptoms of PTSD.'*

## Failure of support systems

Currently, modern clinical standards of 'good practice' would dictate psychological support to be automatic for victims of trauma. The 2020 Psychosocial expert report and this supplementary report have highlighted that individuals, who had received infected blood or blood products, as well as their affected family members were rarely offered counselling and psychological support. Many of the adult witnesses, bereaved in childhood, describe being offered no counselling or support at any point prior to or after the death of a parent(s) even to this day.

## Conclusion

The death of parents as a result of being infected with infected blood or blood products has had a profound, long-term negative impact upon their families and has significantly devastated a generation of children who they left behind.

The 2020 Psychosocial expert report highlighted that 'A close attachment with a parent figure is an important factor in the development of resilience and self-esteem in children and adolescents, particularly in those living with chronic illnesses (Doty et al., 2017). The majority of the research focuses on children bereaved as a result of cancer, where there are significant support systems in place. It is reasonable to extrapolate from this that the additional stigma and lack of support will have placed children bereaved as a result of a stigmatising condition at significantly greater risk of distress and significantly poorer outcomes than those bereaved as a result of an 'acceptable' terminal illness.'

Research identifies key factors that put bereaved children at risk of experiencing a more prolonged or intense bereavement response. These include the nature of the cause and circumstances surrounding the death, the quality of end of life care prior to the death, and the support provided both prior to and after the event (Stroebe et al., 2007). Concurrent stressors, such as financial hardship, are also known to exacerbate difficulties in adjusting to the loss. This report highlights a significant lack of information provided by healthcare professionals to families, lack of adequate palliative care prior to and after the bereavement and an almost total lack of social, financial, or psychological support. Children and the surviving family members experienced significant financial hardship as a result of the diagnosis and after the death of one or both parents over a significant period of time.

It is important to consider that each of the strands that have been explored in this report and allocated to a specific question cannot be read or considered in isolation. There are many negative effects arising from the loss of a parent to HIV and/or hepatitis C. These include a failure to communicate information clearly and lack of support before, during, and after the death to address or mitigate the bereavement effects. The impact of these failures was significantly magnified by the negative social impacts and resulting stigma from society, health, and social care, as well as education professionals, all of which resulted in social isolation, a perceived need for secrecy and lack of open discussion. The overwhelming

psychosocial impact on mental health, the loss of financial stability, and socioeconomic status affected - and still affects - these young people's education and ultimately their employment prospects.



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## Verifying statements

Each contributing group member confirms that he or she understands his or her duty to provide independent evidence and has complied with that duty.

All contributing group members confirm that in respect of those parts of the report to which they have contributed:

- (i) They have made clear which facts and matters referred to in this report are within their knowledge and which are not.
- (ii) Those that are within their knowledge they confirm to be true.
- (iii) The opinions they have expressed represent their true and complete professional opinions on the matters to which they refer.



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## Letter of Instruction

This report answers the following questions, extracted from the further supplementary letter of instruction to the Psychosocial expert group.

### Further supplemental instructions

5. Further to your reports dated January and September 2020, please consider the psychosocial impacts on children bereaved in consequence of the use of infected blood and blood products. In particular the:
  - a. impact of stigma on the children of HIV-positive parents during the 1980s and 1990s
  - b. impact on children of their parent's terminal illness being hidden from them
  - c. impact on children who grow up without a father and/or mother. Please explain the impacts of age when bereaved, and gender, as far as they are understood
  - d. impact of childhood bereavement on education, and on future employment
  - e. psychological disorders that can arise from childhood bereavement





