



Rebuilding lives after the  
sudden loss of a child

- Embargoed until Tuesday 13th December 2016 -

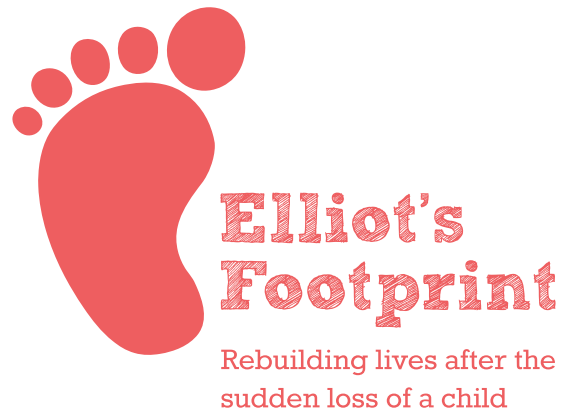
# Our Research

**Identifying the support needed by families  
in Leeds after the sudden death of a child.**

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Results of research conducted for Elliot's Footprint by Brainbox Research





**Sign the petition to give all parents  
adequate support following the  
sudden death of a child at  
<https://petition.parliament.uk>**

# Elliot Footprint's Executive Summary

## Our Research Objectives

1



To **explore** the support bereaved families received



To **understand** what can go wrong when services are delivered



To **identify** the gaps in existing bereavement services



To **make recommendations** about providing support

## We interviewed 7 families...

2  
MAIN  
THEMES



7  
SUBTHEMES

2

This included the need for **immediate, intensive** support, that none of them received, as well as **family-centred, coordinated care** that was flexible enough to address their families' individual needs and **available for as long as it was needed**

ONLY  
**16%**  
of professionals

said child bereavement support in Leeds was **effective**

3

OVER  
**50%**  
of professionals

said **they did not know** who coordinated child bereavement services in Leeds

**45%**  
of professionals

saw the need for a **single organisation** to coordinate child bereavement services in Leeds

**68%**  
of professionals

felt that support for families could be improved in two main areas: with **coordinated** and **proactive** services, and by **publicising existing services**

4



As a result of these research findings Elliot's Footprint recommend that after the sudden death of a child, **families should be automatically referred to immediate, intensive and family-centred care.**

Families should have the **support of a named person working as their advocate**, joining up services for them, explaining and supporting them through legal processes, and helping them identify and access the care services they need.

5

Healthcare and other services across social care and education settings need to **communicate effectively** with each other about the needs of families, the services available to them and the individual care and support pathway being accessed by individual families.

Give all parents adequate support following the sudden death of a child.

6





Rebuilding lives after the  
sudden loss of a child

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## Executive summary

This report describes research undertaken on behalf of the charity Elliot's Footprint to analyse the support services available to Leeds families after the death of a child. The market research company, Brainbox, undertook interviews and a survey with families and professionals in Leeds to explore experiences and perceptions of child bereavement support.

The interviews with seven parents identified two main themes and seven subthemes describing families' experiences. This included the need for immediate, intensive support, that none of them received, as well as family-centred, coordinated care that was flexible enough to address their families' individual needs and available for as long as it was needed. Parents described needing support with and guidance through the legal and administrative processes and how they had had to rely on informal networks for support after finding the availability and quality

of support to be inadequate. They described care ceasing once their child had died because the child – as the patient – had been the focus of care.

**Only 16% of professionals who participated in a survey thought that child bereavement support in Leeds was effective.** They believed that services were inconsistent and often available to those who met specific criteria, such as their child having died from a specific condition. These services were believed to be primarily provided by charities, and professionals thought that they were poorly publicised, uncoordinated and difficult to access.

The majority of professionals thought that bereavement support services should be coordinated via the NHS. In qualitative interviews, healthcare professionals explained that in primary care they have limited experience of child death and so did not know what services were available to families. They described how families need care that is family-centred and coordinated via a single contact person.

Families' emotional and psychological needs often go unmet after the death of a child – whether that death is sudden or after a period of hospital care – and current bereavement services are poorly communicated, are not proactive and cannot respond to parents' immediate and ongoing needs. This means that families are unsupported and this may lead to additional demands on the health service as they struggle with depression and other emotional and psychological needs.

Services for families do exist but health professionals and families are often unaware of them and cannot easily access them. There is also limited joined-up information sharing between professionals in different organisations about the care and support needs of bereaved families.

**As a result of these research findings we recommend that after the death of a child, families should be automatically referred to immediate, intensive and family-centred care.**

**Families should have the support of a named person working as their advocate, joining up services for them, explaining and supporting them through legal processes, and helping them identify and access the care services they need.**

**Healthcare and other services across social care and education settings need to communicate effectively with each other about the needs of families, the services available to them and the individual care and support pathway being accessed by individual families.**

## 1. Introduction

To explore the support that families in Leeds receive following the death of their child, Elliot's Footprint commissioned this research with families and professionals. Elliot's Footprint is a charity that was set up in 2014 following the sudden death of Elliot when he was two years old. His parents, Andrea and John, were devastated by his death, and founded the charity to help other families in a similar situation. The charity helps other parents who are grieving to cope and to navigate the system of processes they need to go through. Elliot's Footprint has so far concentrated on providing information and support to families, training to professionals and fundraising.

To focus its future work the charity needs to better understand the support that families need following the death of a child and the gaps in current service provision. This information from the research will be used to develop the future strategy for the charity.

The death of a child is a traumatic experience for a family and has been described as the most stressful event that parents and siblings can experience (Endo et al., 2014). Grief can be felt on a daily basis years following a bereavement (Dyregrov & Dyregrov, 1999) and the psychological consequences continue to manifest, and can

even increase, over time (O’Conner & Barrera, 2014). Parents are at risk of depression and anxiety (Boyle et al., 1996; Kreicbergs et al., 2004; Kreicbergs et al., 2007), and some develop post-traumatic stress disorder (Turton et al., 2001) and substance abuse (Li et al., 2005). Siblings are also at higher risk of psychological morbidity, including anxiety (Powell, 2001), guilt (Fanos & Niclerson, 1991), behavioural changes such as aggression (McCown and Davies, 1995), and are at increased risk of suicide (Rostilla et al., 2011).

Garstang et al. (2014) report a systematic review of what bereaved parents want from professionals following the death of their child. The review covered children from birth to 18 years with any cause of death. Their narrative comprised three different themes: to be able to say goodbye to their child; to know how and why their child died; and to feel supported. The review identified many ways that parents want to be supported by professionals. Practical and emotional support is important, which includes professionals themselves showing emotions (Meyer et al., 2006), and this support needs to extend beyond the immediate time of death (Finmore and Dallimore, 1991). Parents can feel abandoned by professionals both following the sudden death of their child (Wisten and Zingmark, 2007) and when there has been ongoing support leading up to their child’s death (Meert et al., 2009).

## 2. Approach to the research

The objectives of the research were to:

- Explore the support that bereaved families in Leeds received, and the support that did or would have made a difference to them;
- Understand what can go wrong in how services are delivered that means that families do not get the support they need;
- Identify the gaps in bereavement services that currently exist;
- Make recommendations about the support that should be provided for bereaved families in Leeds and how it should be provided.

A mixed-methods research study was designed, based on in-depth interviews with seven families, a survey of health and social care professionals in Leeds (231), and qualitative semi-structured interviews with healthcare professionals (5). The project ethics, stages of the research, and the questions can be seen in Appendices 1-4.

### Interviews with families

Participants volunteered to take part following publicity of the research by bereavement charities. While the focus of the research is on sudden and unexpected death rather than from a long-term condition, the experiences of everybody affected by child death were included regardless of the age of their child or the setting in which they died. An overview of each family interviewed is provided below, but details are not provided to protect their anonymity.

#### Participant 1 (P1)

Mother and father were interviewed around five years after the death of their son, who was two weeks old when he died. Although their child required surgery they had been reassured by the hospital staff that it was 80-90% certain that he would recover and come home with them shortly. His death was therefore unexpected. They have two older children and subsequently had another child.

#### **Participant 2 (P2)**

Mother and father were interviewed around two years after the death of their son when he was nearly three years old. He had not shown any sign of illness and his death was sudden and unexpected. Their two older children also contributed to the interview.

#### **Participant 3 (P3)**

Mother was interviewed around nineteen years after her son died when he was four years old. Although he had a life-limiting condition he was nevertheless not expected to die at that point. She has one younger son, who was aged two at the time.

#### **Participant 4 (P4)**

Mother was interviewed around nineteen years after her first child died at birth. There had been no problems during the pregnancy and no indication during labour that her child would not live. Three years later she had another son and now has six children.

#### **Participant 5 (P5)**

Mother was interviewed around eighteen years after a series of unsuccessful IVF attempts. She became extremely depressed afterwards. She subsequently adopted two children.

#### **Participant 6 (P6)**

Father was interviewed around five years after his son died when he was fifteen years old. A few weeks before he died, he had been investigated for a possible health condition, although no problems were found. His death was therefore sudden and unexpected. He was an only child.

#### **Participant 7 (P7)**

Mother was interviewed 12 weeks after her one-year old daughter died. A few days before she died she had been diagnosed with a minor virus. Her death was sudden and unexpected and the family has not yet received the coroner's report. The family have another child, age five.

Four families chose to complete an online survey: three of those parents had lost their children within the last five years, and one more than five years ago. Their children's ages when they had died varied from still-born at full-term to just over 15 years. One death had been expected and the other three deaths unexpected.

### **Interviews with Professionals**

Five healthcare professionals completed qualitative semi structured interviews and this included three GPs, a neonatal consultant and a safeguarding service lead.

231 professionals in the Leeds area took part in an online survey that included healthcare professionals, teachers and police.

## **3. RESULTS**

### **SECTION 1: Understanding the experiences of bereaved families in Leeds**

The findings from the families have been broken down into a set of key themes by the research company which are in Figure 1. They demonstrate that there is a lack of support to help families cope with the loss of their child, and in helping them to understand the formal processes involved.



One participant contrasted the support offered to him when he was a victim of crime with the absence of anything available after his child had died. He found this incredible.

**Its just ironic: I was asked if I needed counselling when somebody had stolen my car. For God's sake, it's just a car. We had our door kicked in at three in the morning and the guys grabbed the keys and drove off. It was shocking and startling but two years after my son's death it was almost inconsequential. (P6)**

Figure 1 shows two main themes that came from the families interviews. “Aftermath” talks about the emotional support following their child’s death, how helpful they found that support, and any area in which they felt unsupported. “Process” describes parents’ experiences of the legal and administrative requirements and the extent to which these needs were met.

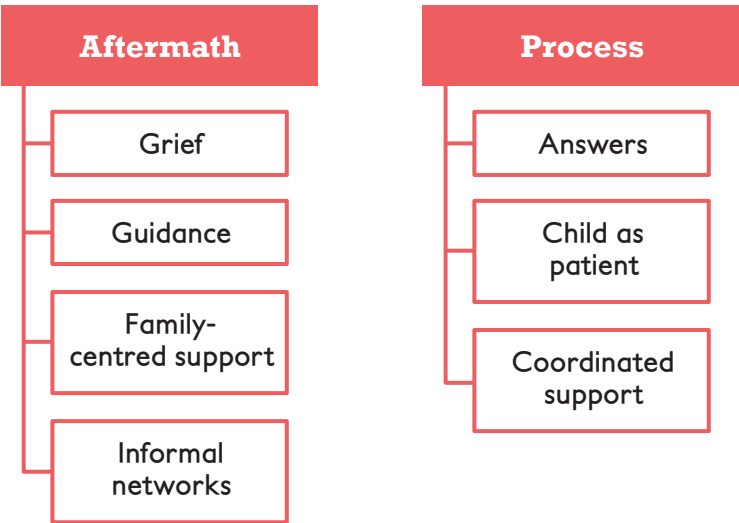


Figure 1: What are parents’ experiences of support following the death of their child?

3.1.1 Aftermath

People say to you that the worse thing as a parent has happened to you and you therefore think if the worst thing has happened things would kick in and the support would be there. The schools would know what to do, it's not down to people not caring, it's people saying "I don't know what to do". To this day we have had no advice or support. You have to do it all yourself. (P2)

The four sub-themes describe the grief that families feel, their need for guidance at a time when they feel too shocked and bewildered to function, how they need family-centred support that addresses the individual needs of the whole family, and how they are typically forced to rely on informal networks to fill their support needs.

## Grief

Families described the most overwhelming, paralysing grief when their child died. The pain they experienced was harrowing. Their world simply stopped.

Individual staff members were described as trying to make things less traumatic but nothing could ease the pain that they experienced. All of the participants talked about needing immediate intensive support to help with the grief they felt at the time of their child's death. Nobody received the support they felt they needed, and for some families the only support was being given a leaflet before they left the hospital or the morgue.

The staff were fairly sensitive but no-one said much really, they explained some practicalities and gave us a leaflet on Sands and it was a case of going home. There wasn't any kind of, what I might call counselling, or somebody to sit down and start to talk things through with you. The support was just a case of being given a leaflet and off you go, which I thought was pretty poor. (P1)

When the time came that we had to leave him, we did just literally leave with this leaflet. That is it. And I read the first [part] and basically it said something like: "Your baby/child has died." I just thought that's not talking to me. One, you can't comprehend that that's the situation you're in but also, it's not my baby/child, it's [child's name]. (P2)

Participants found it impossible to function and this debilitating period could last a long time. All participants talked about how their own life would never be the same again.

People say about leaving a big hole and I think one of the biggest things for us is that it went quiet. Because there's that saying: silence is deafening. And it just was. (P2)

For many, no longer being a parent, or the parent of a child this age, brought about changes in their social identity. For example, overnight they found they were no longer involved in a school or nursery group, no longer being involved in children's sports, or no longer having to make hospital visits. Part of their social identity disintegrated.

For families with a child that was ill, and the family's life involved care routines and hospital appointments, the change that happened when their child died was especially marked and parents found this abrupt change to their daily life and responsibilities difficult. They no longer had contact with, or access to, the healthcare professionals they had come to rely on. Yet this was the time that they needed support the most.

It was always busy, it was always noisy, sorting the medicines out and my other son running around in the middle of it all and then it just sort of stopped when he died. I can always remember thinking how quiet it was and it was quite abrupt for me because I was used to all those people and then there was nothing and they all went away. Within a week they were in to take out the oxygen concentrators and the bed, because we had a special bed for him, before we even had the funeral they had that out, so that was quite hard at that point. (P3)

Some participants talked about how terrible the hours and days after their child died seemed even more incomprehensible because their home had become a crime scene. Police needed to examine where their child died and to interview them and their family. While they knew that they were innocent of any crime, this nevertheless

added additional trauma. The support families received at this point made a big difference to how traumatic this experience was. Allowing the family to stay together and asking questions gently, rather than in an accusatory manner, helped make the process more bearable.

The police tried to be as sensitive as they could be, but nevertheless it is still a pretty harrowing thing, you have got all that hanging over you for some time whilst they carry out their investigations because until they are satisfied there is no foul play, you are under suspicion. (P6)

The police did what they needed to but they did it really respectfully. They let the hospital lead on the questions. (P2)

Many participants developed depression and could take years to recover; and some have not yet done so. Whilst some received treatment for depression, others did not. Most participants who developed depression described how it was left to their family to seek help for them, for example insist that they go to the GP to get help.

I got really depressed and I lived with death for a long time. It was like death was very real. I was walking with death and it was almost personified: it was just me and death. I wasn't functioning, I was aware of things but I didn't want to get involved with anything else. If I stayed with death that is where my children were and I won't let go of it if I had a choice. That is where I was, I couldn't let go of death because it was so hard. (P5)

## Guidance

Participants all talked about how their child's death had been shocking and unexpected. They felt bewildered about what had happened and utterly lost. Even if their child had been ill they had nevertheless not expected that they would die at that point. They did not know how best to handle the situation, who to contact, or what to say. They felt too shocked to function and they needed guidance. Advice from professionals at this point was extremely valuable, especially as they felt paralysed with grief and yet were expected to make lots of decisions, and decisions that they would remember all their lives. Practical advice was particularly important, such as how to make the phone call home to relatives desperately waiting for news, how to tell friends and employers their child had died, and selecting a funeral director.

The support you need is not just about counselling. It is about all those practical things and to help you make decisions and how you liaise with the school. (P2)

What do you do? Start ringing people? Ring your boss to say I'm not coming in today because my boy is dead? What do you say? (P6)

One of the participants described how actions taken at this point can have long-term effects for how the family come to terms with the death in the future. If children are excluded from the grieving process it can have long-term effects on their emotional development and behaviour. Parents need guidance on how to talk about their child's death with each other and with the rest of their family.

A friend came round with some picture books and we read them regularly with our twins and they were the most helpful things we had because they helped explain death to young children. I would often read them in tears but at least it was our way of trying to communicate what had happened. (P1)

Most of the participants described individual professionals whose words or actions had made a difference to how they coped at this point. Professionals treating them with respect, kindness and empathy was particularly important.

The lead nurse took my daughter to one side as she said “I just want to tell you that you did everything right. There was absolutely nothing you could have done any different to have helped your brother.” And that was, you know, tremendously important, because obviously that’s something we had said which hopefully helped, but the fact that it was coming from a professional was good. (P2)

## Family-centred support

Families talked about how their emotional and practical support needs varied over time, and that there is no one right or wrong way of grieving so different people will respond in different ways. Any support service would need to recognise this and to be sufficiently flexible enough to tailor the service. One person might need support to help them as an individual, as a couple, and as a parent.

When we left that hospital we had to figure out as individuals how the hell we were going to deal with this, as a couple how do we deal with this, and how do we deal with this as a family? What do you do to support each other? (P2)

Participants believed that people should be able to access the service that is right for them at the point when they need it. It therefore needs to be flexible rather than it being a very structured package so that families are able to choose which aspects of the service they access. They talked about how the support provided should be on an individual-needs basis, rather than any bureaucratic definition of the child or their death. For example, one participant talked about how all her children had been born very premature, including one child who is now perfectly healthy having been born at 24 weeks. Yet when one of her children had not survived the birth, the leaflet she was given was not about losing a child but about miscarriage.

He died at birth. I find it a hard one because if you lose a child at least you have got something to remember or you can talk about what they are like, how old they were when they first walked, when they first talked, the favourite things you can remember, times you have spent together. Whereas I feel like mine has been stolen. So I wouldn’t say my pain is any worse than anybody else’s because everybody feels it differently but I don’t think it’s any easier. (P4)

Similarly, another participant talked about how her failed IVF attempts had been devastating and yet the depth of her grief and despair had gone unrecognised. To her, these were all her children.

I went to a church service for the death of children and people of all ages. When we first went in you said what month your child died in, and so you have a season, and you choose a flower for your child. For the first time ever I chose something for my child. I couldn't even choose a name, I couldn't choose anything, everything was taken away from me. And that was a bit of healing, having them recognised because I never thought they were recognised before, only I knew and my husband, no-one else did. (P5)

Participants therefore perceived a need for a support service that families can use as and when they need help without being judged about whose grief is worthy or unworthy, and more or less painful. As well as parents, participants highlighted that other children also need support, including siblings born after the death of a child.

Sibling death is a different kind of loss for the children because not only do they lose their brother or sister they also lose their parent for a bit because the parent is caught up that grief. (P3)

He had difficulty settling into school, and I met my Mum's friend who used to be a family systems therapist. She talked to me all about how trauma at a young age can stunt the emotional development of children and we were expecting him to behave like a seven-year old but his emotional development had stopped when the trauma happened. That we needed to go back to behaving with him at that point of emotional development. (P1)

## Informal networks

Thankfully we've got a close circle of friends and a stronger wider network. So outside of our close circle of friends we've got a shed load of people who care about us and that's what made the difference. (P1)

All the participants talked about having no choice but to rely on support from informal networks, either through their own friends and family, or from the wider community.

Some participants had contacted the counselling service listed on their bereavement leaflet but all had found the service unsuitable. They described a long wait for an appointment whereas they had needed help immediately. Some who had used the service talked about how the bereavement counsellors had lacked expertise in child bereavement and there is a need for bereavement counsellors who are specialists in this area of work. The location of the counselling service also received criticism, as it is based in the maternity unit where their child had been born.

I did try to access bereavement support and I found the bereavement counsellors were incapable of dealing with me because I was so distraught. (P6)

The person was really nice but it was just general counselling. It was very nondescript. I'm not here because I've had a tough week at work. I strongly believe that bereavement counselling, especially after the loss of a child, should be something that is skilled. I have spoken to another bereavement counsellor and it was a really negative experience because I felt she didn't know what to say. She spent more time talking about her own kids and I just felt "What do I say?" I spoke to this woman three times and I had to say "I'm sorry, I can't speak to you anymore. It's doing more harm than good." (P2)

Some families felt they had to source their own help and support and that their only option was to search the internet for advice or sources of support.

You find some good stuff (on the internet) but you also find that you are likely to get divorced, your friends will leave you and your kids will get bullied. You just think, well those might be factors but what you want to know is how you prevent that. (P2)

I am the one that has had to get the help and without the internet and the research that I have done we would have had no help and if I hadn't have pushed for help we wouldn't have had anything. They said we will leave you for six weeks well my child has been gone 12 weeks on Saturday and we have still yet to see absolutely anybody (P7)

Some participants talked about difficulty contacting bereavement charities. Others talked about support only being available to parents of children who had died of specific conditions or in specific settings. All the participants desperately needed help and were surprised by the lack of a formal support mechanism that they assumed would be made available.

Participants had different experiences of support provided by their GP. Some talked about their GP making contact with them and trying – although failing – to find sources of support on their behalf. Others had not received any contact from their GP. One participant suspected their GP had deliberately distanced themselves because they were concerned that they would be blamed for not recognising their child's condition. They were surprised and hurt by this. Participants were surprised that more proactive support had not been offered to them.

If you are really ill you get treatment for whatever is wrong with you. If you have lost a child or a family member they give you a few sessions or weeks or months worth of tablets and think you will be fine. It doesn't work like that. Grief can be just as detrimental to your health and wellbeing as a sickness bug. (P4)

Instead of formal support, participants were forced to rely on informal networks, such as friends, community members, or religious organisations.

The most helpful support received was often described as contact with another person whose child had died. Many participants found the shared experience comforting: they believed it is impossible to appreciate the pain of losing a child without having experienced it. None of the participants received this support through any formal routes and would have welcomed more proactive offers of support of this sort from the NHS.

## 3.1.2 Process

These three sub themes highlighted families need for answers and understanding why their child had died, the experiences of their child as a patient and the need for services to be co-ordinated.

### The need for answers

Every day when the phone went I thought: is this the day I'm going to find out why my son died. (P2)

They could have made, every so many weeks, a courtesy phone call saying we haven't forgotten about you but we don't have any more information to tell you. Because every time the phone rings I am looking to see who it is wondering if it is going to be them [the coroner's office] that ring today (P7)

I'm the one who was with him constantly that day, so it's like, what did I miss? Did he complain of a headache? Was he not well? (P2)

To help facilitate healing, families needed to know how and why their child died. For definitive answers they must wait for the coroner's report, and they described this period as one full of anxiety. However families described how they often felt overlooked or forgotten, or that they had not been kept informed about what was going on with the investigations into their child's death

Families did not typically know the process around a coroner's report, and some said that the process wasn't explained to them. This period of waiting was painful as it delayed the time at which parents could start to understand and make sense of what had happened to their child. Some described how administrators would refer to their child as "a case" or "a file". Families talked about how it would have been useful to be kept informed during this period, even if the only news is that there is a further delay.

### Child as patient

This sub-theme is about how the NHS views the child as its focus and when the child dies, the care ends. The needs of the bereaved family are not recognised. Most families described how they felt they had been ignored by the NHS and that they felt the system lost interest in their 'case' when their child died. As there was no longer a patient, there was no longer any need to provide care.

I think if someone from the hospital had come in and sat down to see how we were because it was almost like – right, he has died and you are not getting our support. I don't think they did it purposely, I think they were leaving us alone to get on with it, maybe they thought they didn't want to bother us but I think, for me, somebody to just come and see we were alright. (P3)

You're not seen as patients, it's the end of the medical situation. But you need to be seen in a different light, they need to understand that if your child has died, potentially you need additional services as a patient would. (P1)

Families talked about how they have regular contact from many different health professionals during the pregnancy, birth, and their child's early years. When their child died there was 'radio silence' from these professionals at a time when their own wellbeing needs were only just beginning; but those needs were never acknowledged or explored.

This links back to the "Grief" section as many participants developed depression after their child died, and some suggested that this could have been anticipated and support put into place to prevent parents' mental health deteriorating.

This kind of experience sends people flying into depression and all sorts of other health issues. There's a lot of really good preventative work that could be done there. (P1)

## Coordinated support

This sub-theme is about how parents needed somebody overseeing and coordinating the processes following the death of their child, including helping families make decisions about what would happen to their child, liaising with the different professionals and organisations involved, guiding the family through the legal processes, supporting the family and facilitating their access to the help they need.

Everybody we've spoken to thinks somebody else has picked up the bereavement support, because the geneticist said "So have you had counselling and support from the hospital?" and we were saying no. And he said "I'm really surprised about that because I think the SUDIC team are supposed to pick that up, so I'll get in touch with them." That's when we got a phone call from the SUDIC team to say they didn't provide bereavement counselling. (P2)

Parents described how they felt utterly bewildered and had no concept of what might need to happen or what they needed to do.

Someone should have said "Okay, this is a bad time, you're traumatised, we won't go into it all now because you won't remember it but in a few days' time we'll get back in touch and I'll give you some book titles for your kids, because they'll be affected by this, and I'll talk through how you're doing and the options for you, and if you need contact details for a funeral. But there was none of that at all. I don't know where the system expects you to get all that from. (P1)

When you are in a state of shock and bereavement you need somebody who can coordinate the help you need because you don't even know where to look. (P6)

Some families talked about how the nurses had set questions they felt they had to ask, about taking photos, locks of hair, and footprints and handprints. Many talked about the need to have these options explained and somebody working with them to ensure they are given the time to consider what they would like.



They took his footprint but what was difficult is how they asked us. I found it horrendous, watching them do it, but it was hard to say no. It would be better if they had asked us “Would you like us to do this? Do you want some time to think about it? Would you like to come back and do it another day?” They were trying to do his hand and they couldn’t and it was just awful. I felt traumatised. (P2)

I didn’t want the photos at the time but I went home and phoned up and asked for them to be sent to me but they were all blurred and I was mortified because I had blurred pictures and all I wanted to see were those little fingers and toes. (P3)

Similarly, when signing forms parents can need somebody to spend time explaining what the forms are for, and to become their advocate by representing their best interests and helping to ensure they have the time to understand what is being asked of them and that their wishes are properly considered.

If I had somebody there to go between me and the nurses and say “Hang on a minute, her baby is dead, do you have to take these forms now? Can she have some time to look over them?” An extra 24 hours would have made a massive difference to me; it probably could have changed my life. (P4)

Some parents did not understand why a post-mortem was needed and they wanted somebody to explain why this was the case and help them accept the situation.

I had to go home without him, knowing he was stuck in them freezers was heart breaking, then knowing they were going to cut into him broke my heart again so it was just one thing after another. I couldn’t understand why they needed to do an autopsy. (P4)

One of the parents interviewed described not being involved in her child’s funeral arrangements as the hospital had assumed that she would want no part in it. She only later found out that her child had been cremated, and not being a part of her child’s funeral had haunted her, and she explained that somebody liaising between her and the hospital would have prevented this situation from arising.

I still feel guilty that I wasn’t there for him. I could choose his coffin, it’s like I wasn’t good enough for whatever reason. When he died and I couldn’t take care of him at least I can do my best by his funeral and then I can’t do that either, I haven’t been able to do anything at all. You feel you are a let-down, like you have failed him. (P4)

Families experienced varying levels of contact between health professionals. Some families’ GPs were notified and others not. For one family, this lack of notification led to them receiving a card from their GP practice congratulating them on the birth of their baby.

Some schools were informed, and others not. Families received very different levels of support and sympathy from the individuals and organisations they had been in touch with. One parent described how the school had been very supportive, and the teachers had researched what they could do to support the siblings in school. In contrast, another parent described how the school had been insensitive to the extent of not allowing his son’s school friends to attend his funeral. Parents suggested that a coordinator could make contact with schools to explain what had happened and advise them on how they could be a source of support rather than of further pain.

### 3.1.3 Parents' survey responses

Four parents chose to take part in the research via an online survey rather than be interviewed. The findings were very similar to responses received from the families who had been interviewed. Parents responded to a series of questions about the support they experienced after their child had died.

- 75% strongly disagreed that professionals actively reached out to help them. They felt they were left on their own to understand forms and legal processes and to access the support needed.
- 100% disagreed that they received support that was tailored to their families' needs
- 75% disagreed that different services worked together to support them and their family
- 100% agreed that they had to rely on informal support, such as friends and faith networks.

Parents were asked how the support they received could have been improved. They reported that communication between organisations should be improved, along with needing better access to bereavement services. They also thought that they had needed better and proactive follow-up care and support from people who could understand their experiences.

## 3.2 SECTION 2

### How effective do professionals think bereavement support services are?

This section describes the results of the feedback from professionals and comprises of in-depth interviews with 5 healthcare professionals and a survey conducted with Leeds health, social care and education professionals. A total of 231 professionals responded to the survey.

Of those who completed the survey the majority (51%) were from GP practices. 17% were from NHS Hospital Trusts (29% nurses/7% Dr's) and 11% were from local authorities. A further 10% were from charities and 9% were from other organizations including NHS Community trust, Police and the Ambulance Trust.

### 3.2.1 Survey responses

Only 5% of professionals thought that bereavement services in Leeds are 'very effective'

Professionals were asked a range of questions which about their experiences and knowledge of bereavement support in Leeds (see Appendix 3). One of the first questions professionals were asked what they thought overall of the bereavement support available to families. Figure 2 below shows the breakdown of responses.

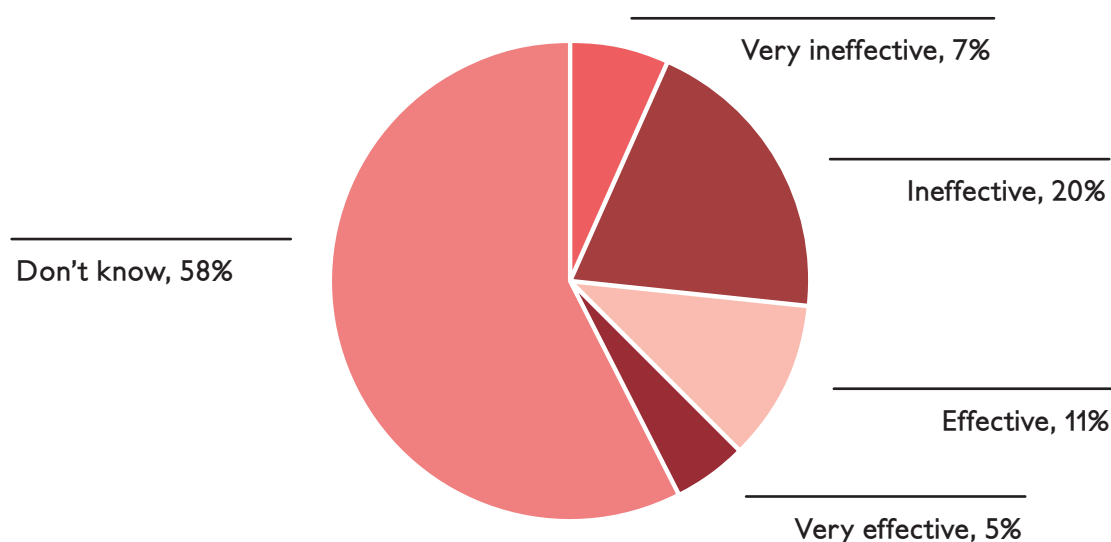


Figure 2: How effective or ineffective professionals think bereavement services in Leeds are.

Respondents were asked to explain their views about the effectiveness of child bereavement support services. The majority of participants (55%) offered a reason for their answer. We found five categories:

- Inconsistencies in services
- I have no experience
- Explanatory comments.
- I don't know what is out there
- I know of good practice

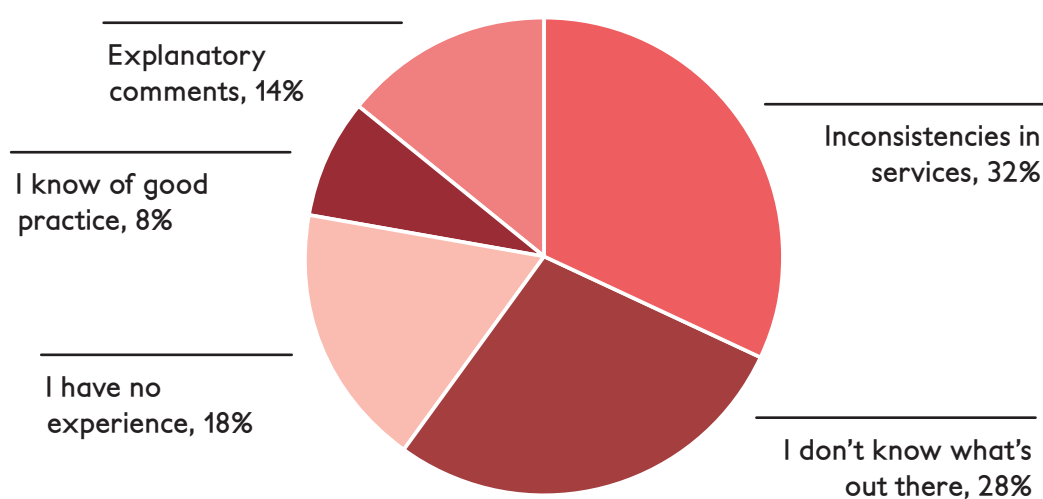


Figure 3: Professionals views of how effective services for bereaved families are.

## Inconsistencies in services (32%)

Professionals explained their opinions of the availability and consistency of services available to families. They commented that:

- some services were offered by a range of organisations; others thought that there was little available either for them to refer families to, or little that proactively reached out to families.
- Some explained how the availability of services depended on the circumstances of the child's death and the medical or care teams involved.
- Others talked about their frustration at the lack of child bereavement support services available to families; or how services are difficult for families to access or find out about.

[It is] not currently an equitable service for families. Other children's hospitals have dedicated bereavement teams with in-house counselling available (e.g. Alder Hey). Martin House [is] available if [the] criteria [are] met. (Hospital nurse)

I don't think there is enough of it – not enough staff with this sole role who can encompass and cover support for all families, whatever their child died of. (Hospital doctor)

## I don't know what is out there (28%)

Respondents explained that they lacked awareness of the services that were available to bereaved families after the death of a child. Some explained the reason for this:

- they had not received any information about services;
- they only knew of one or two organisations;
- they did not know who coordinated services;
- that services were not well publicised.

There is no information anywhere about support services that are available, if any. (Hospital nurse)

[I am] unaware of specific support services – no advertisement. (GP)

## I have no experience (18%)

These respondents explained that they had little or no experience of child bereavement, or their experiences were in the past so their knowledge of what is available to families is not current.

Death of a child is a very rare event in general practice. I have no recent experience of services available. (GP)

## I know of good practice – 8%

A small number of respondents offered examples of good practice or instances where they felt the support offered to families had been effective or appreciated. Sometimes respondents qualified their comments with perspectives about how widely available good support might be to parents, for example that services might only be offered to specific groups.

Those who attend Martin House find it very helpful, but not everyone does. (Hospital doctor)

## Explanatory comments – 14%

The remainder of respondents' comments were brief and directly justified their assessment of the effectiveness of child bereavement support. For example, they explained that they had made their assessment based on experience.

### 3.2.2 What type of services do respondents think are available to bereaved families?

To explore professional views of where services are available in Leeds, respondents were asked which services they thought were offered to families by a range of organisations: GP practices; hospitals; charities; the local authority; and other organisations.

Overwhelmingly, respondents believed that charities provide bereavement support to families:

- over half of respondents thought that charities provided every type of support;
- 65% believed that charities provide group support for parent and 64% face-to-face support for parents in the home. This indicates that respondents perceive care to be provided mainly outside the NHS.
- GP practices were thought by respondents to provide face-to-face support for parents at home (30%) and away from the home (30%).

Comparatively few respondents thought that support for siblings and for other relatives and friends were available from providers other than charities.

Respondents explained how services are available for families who have experienced a stillbirth or a neonatal death and drew a distinction between the services available to those families and to families whose children die suddenly.

Many children we care for who are known to have life-limiting diseases are also supported by Martin House and local palliative care teams. These and other specialist hospital teams have carers and specialist nursing staff who can go and see family and siblings at home. This is obviously a very different situation than for a family who suddenly and completely unexpectedly lose a child.  
(Hospital doctor)

Professionals explained that although mental health services are available through TaMHS, CAHMS, and charity organisations such as MIND, waiting lists were long. Others explained that school-based counselling is available and that the importance of bereavement counselling in schools is being increasingly recognised. Some respondents explained how they work in partnership with external organisations to provide support to families, although they expressed a wish to provide better support.

This certainly seems to be an under represented area of support in Leeds. There is Cruse, the hospices offer support to certain groups, The Market Place (Leeds based charity) provides counselling and support to 11-19 year olds specifically for bereavement, and also 13-23 year olds on any issue including bereavement. I believe social services offer support through the SAD events team too. (Charity counselling manager)

## Who offers child bereavement services in different organisations?

To find out about the other organisations professionals know to offer support, participants were asked which other organisations offer bereavement support to families. They were free to describe any organisations and services they were aware of. Participants made several suggestions, which were predominantly charity-led or funded initiatives. Amongst their other suggestions were hospices, parents' employers, and national and local charities.

We explored the responses of participants in the charity sector in more detail because of the professional perception that charities are the providers of services. However of those respondents from charities

- Only 13% reported offering face-to-face support from parents at home and 30% away from home
- Only 9% offered face-to-face support for siblings at home and away from home 22%
- Only 13% from charities said they themselves offered written or online information for parents and 35% offered written or online information for siblings.

So there is a difference between what professionals perceive charities provide in terms of bereavement support and what is offered in practice.

### 3.2.3 Which organisations should coordinate child bereavement services in Leeds?

Over 50% of people who responded said that they did not know who coordinated bereavement support for families.

I'm not aware of any [organisations] that coordinate services. There are small pockets of support around and professionals may know of each others' work and meet, but not coordinate. (Social worker)

I am not aware of any organisation that should be coordinating bereavement support for families. I understand that Cruse Bereavement has been commissioned to do some work but I'm not sure if they have a coordinating role, my impression is of a lack of coordination. (Maternity services)

Others made suggestions about who they thought is currently coordinating support. Answers included hospices, the specialist team that had been caring for the child, the hospital, Cruse Bereavement Care. Some also suggested that social services may coordinate support, CAMHS and children's services. SANDS, SIDS and SAD and the CCG and Macmillan key workers were mentioned on one or two occasions, along with Winston's Wish, GP practices, and the Leeds Bereavement Forum.

Respondents were asked how child bereavement services in Leeds should be coordinated. Their responses are shown in Figure 6.

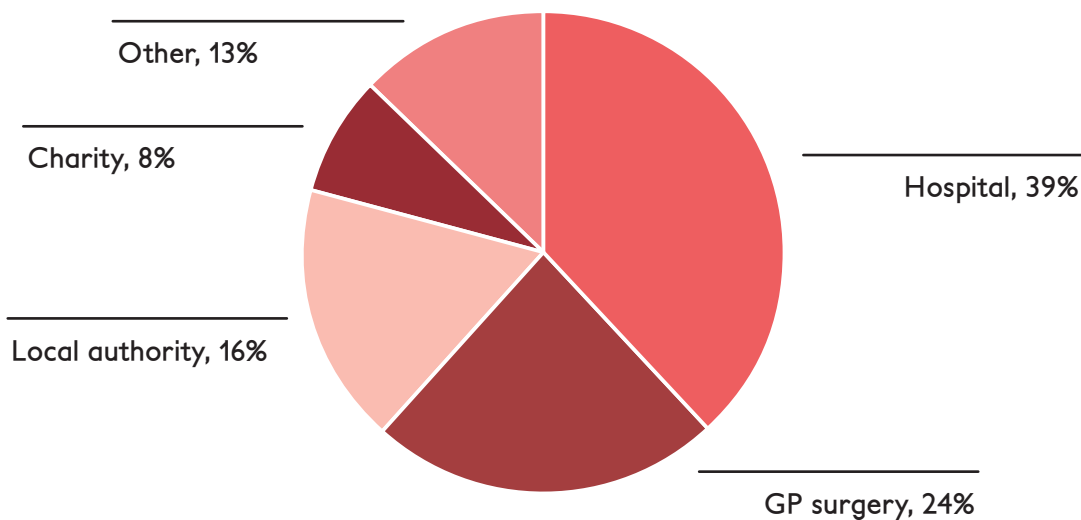


Figure 6: Professional perceptions of which organisations should coordinate bereavement services.

There is no one size fits all. If I know the child and their families then it is led from our team; if they are known better in the community then they should lead. What is essential is that this is discussed in every case and a plan made so no-one is left out. (Hospital doctor)

### 3.2.4 What gaps did respondents identify in child bereavement support?

There needs to be more bereavement support staff, a more systematic approach to providing sibling support, online or written resources and overall resources made available to develop these services.  
(Hospital doctor)

We asked respondents if there are any gaps in the support available to families after the death of a child. They were free to answer in any way they chose. A total of 41% of those who took part gave answers, the categories identified are presented in Figure 7.

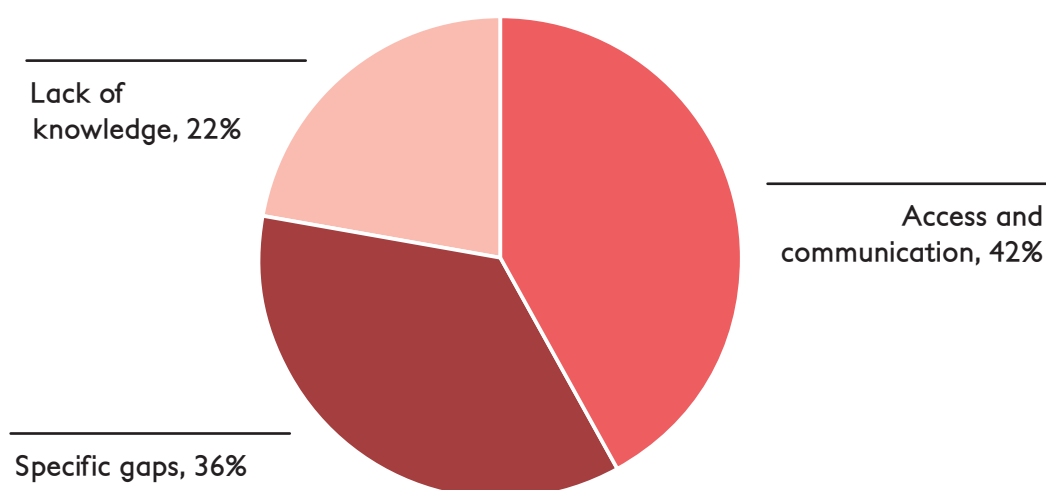


Figure 7: Professionals views of gaps in services for bereaved families.

#### Access and communication – 42%

These responses talked about how services are difficult for families to access for a number of reasons, including that services are difficult to find out about and they are not widely publicised. Some professionals also commented that they themselves did not understand what was available so they felt unable to provide advice or know where to refer families who need help.

I suspect many families feel they are left alone as there is no overarching team taking control of this important aspect of caring for families. (Hospital doctor)

Not many people know about these sorts of services and where to look. (Healthcare support worker)



## Specific gaps – 36%

Other comments explained where respondents perceived specific gaps in care. Some commented that support for siblings – especially younger children – was lacking, some support that is delivered quickly is needed, and some mentioned that longer-term support for families is not available. Others talked about gaps in the continuity of care, for example from the hospital to primary care, waiting times for support, and a lack of specific bereavement support staff.

Support for families who have experienced a sudden death of a family member.  
(Bereavement counsellor)

Lots! Provision is variable and so for some families there is nothing; others receive support from a specialty team but this is time limited. (Hospital nurse)

## Lack of knowledge – 22%

The remainder of respondents stated that they did not know enough about what was available to be able to identify specific gaps.

I imagine many, but I don't know. (Counsellor)

We asked respondents to tell us how child bereavement support services could be improved. Again they were free to answer in any way and 68% offered an answer in two main areas: Coordinated and proactive services; and Publicising services. The remainder of participants' comments detailed how they were unsure how to improve child bereavement support.

## Coordinated and proactive services – 45%

Many professionals thought that services needed to be properly managed, coordinated and accessed via dedicated and trained staff through different channels. Services should proactively reach out to families with tailored, long-term support; and some professionals thought that a single organisation coordinating child bereavement support would improve the current provision.

[A] dedicated team of professionals within LTHT that deals solely with bereavement within hospital (social worker, family care nurse, palliative care consultant, play specialist, psychologist chaplain etc.) to coordinate care within the hospital and be responsible for ensuring liaison between community healthcare / education sector also. (Hospital nurse)

## Publicising services - (33%)

Many respondents talked about how there should be more advertising of the services available and better communication of service provision to both families and professionals in Leeds. Enhanced communication should make it clear what the pathways for accessing help are and enable professionals who have contact with families, such as the primary care team or schools, to quickly signpost or refer them to support.

Clear and up-to-date information to clinicians so we know how best to help/signpost people. (GP)

My main experience is within the palliative care services, especially Martin House and this is held up as a model of best practice in the UK. It is a shame not to use their expertise and advice with respect to service development in Leeds. (Hospital Doctor)

Winston's Wish... offers a helpline but also some one-to-one work and residential weekends. (Charity Worker)

### 3.2.5 Interviews with Healthcare professionals

The following section contains the results of the analysis of qualitative interviews with five health and social care professionals. It is presented in the following four thematic areas: Inexperience; Need for family-centred care; Care continuity and coordination; and Resource constraints.



Figure 8: A thematic map of professional perspective on services for bereaved families.

## Inexperience

GPs explained that they had limited or no experience of child bereavement and because of this, they did not know what services were available to families, and therefore would not be able to refer them to a specific service. One GP, who had experience of child bereavement, had not previously been aware of any services and had found it difficult to identify support for the family. One GP felt that he had been able to support a family through providing parents with explanations of information sent by the hospital, which he perceived helped the family better understand what had happened to their child.

I have never really dealt with a child bereavement so I don't know of any charities so I guess it would be a case of going on the internet and looking when someone came to try and find support services. (GP)

Other participants had more direct experience, a hospital neonatal consultant was able to provide information about the support they offered to families, for example bereavement packs and memory boxes. Another participant gave an overview of the work of the SUDIC team, which she explained has a focus on the public health aspects of child deaths.

We don't have those kind of skills and expertise. [It's] more looking if we can get any public health messages out. (Safeguarding / SUDIC)

## Need for family-centred care

Healthcare staff discussed how they thought support and care after the death of a child should be tailored to meet the needs of individual families. Trained staff should help families to identify their own bereavement support needs and a personalised support package should be assembled.

And it is a very individual process, really, the grieving and bereavement process. I know there are certain phases that everybody goes through, or you expect people to go through. But in terms of their loss, I think sometimes there are different needs depending on whether the young person has gone out on their moped, or whether it was a child that was put to bed on a night. (Safeguarding / SUDIC)

Professionals thought that care and support should proactively reach out to families, rather than expecting families to search for support after their child has died. They also thought that families should be able to decide where they received support, for example in their own home or away from the home, and the channel through which they received support.

Not every family will want the input - they will kind of want to do it [find help] themselves. It is very variable, isn't it. (GP)

Someone that can go out to families – where you might go out to families at set times but then you might be available to go more often for some families...just a support worker essentially. (Neonatal)

The neonatal clinician explained that the support they were able to offer families was fixed and not tailored to each family. Follow-up appointments six weeks after the death are medically focused, rather than bereavement-focused. The SUDIC team were also thought to be able to signpost families to help, but not themselves offer bereavement support. Participants also explained that the services that families need to interact with to fulfil statutory requirements after a death, for example the coroner's office, were not geared towards the needs of the family, rather they were process-led.

**They phone the parents up and ask 'Do you have any concerns about your baby's death?' It's like I have just lost a baby 12 hours ago. (Neonatal)**

## Care continuity and coordination

Professionals talked about family need for care continuity after the death of a child. They thought that care should be coordinated via a single contact person because services are provided by many different organisations and it would be difficult for families to understand how to navigate and access care. They talked about care coordinated via the GP, whilst others thought a bereavement support worker role might be more appropriate. GPs themselves thought that the GP practice should proactively reach out to discuss finding support with families, but that they themselves would not be the most appropriate HCPs to coordinate support.

**I think probably [we should] just be able to provide them with a telephone number they could ring or we could ring to refer them to so that someone would then make contact with them and give them their options, but also so that they could access themselves but also so we could access it to make contact with them and people in that situation don't feel able to make that first [step]. (GP)**

Getting feedback about the ongoing support requirements of families was also important to GPs. They wanted this feedback from others involved in supporting parents so that they could monitor the help they were getting.

**I think it would be useful to have some feedback as to what sort of support [the family] are requiring or needing. Some might just need someone at the end of a phone whereas others might need fairly significant counselling...some feedback I suppose – correspondence. (GP)**

Participants talked about how organisations communicate with each other about families after a child death, for example they talked about how the neonatal unit would inform the GP after the death of a baby. One GP pointed out that different organisations providing bereavement support do not share IT systems, which was a barrier to sharing information.

## Resource constraints

Professionals talked about the constraints to offering support to families. A GP, for example, talked about how a lack of time might prevent some practices offering bereavement visits and that they did not have the expertise to offer counselling. GPs talked about the lack of availability of counselling in primary care, specifically mentioning the long wait to begin therapy. Another participant talked about the constraints on the hospital in providing bereavement support, explaining that hospices and charities are better placed to offer structured and targeted bereavement support for the whole family.

...the extended family support that I think they need that we [the hospital] can't offer so if the baby dies at the hospice the siblings get involved. There is a bereavement sibling group, they do things for grandparents, you know, it is that sort of caring for the wider family that I think is really important, as well as caring for the parents, that we just can't offer. (Neonatal)

Resources in hospital were thought to be improving due to some charity funding, for example they had recently introduced extra facilities for bereaved parents including a quiet room and cold cots, but facilities were still thought not to be ideal for bereaved parents.

It is just from a lack of resources stopping us...yes you can stay with your baby after they have died for days if you want to, but it is certainly better than it was. (Neonatal)

## 4 CONCLUSIONS AND RECOMMENDATIONS

### 4.1 Conclusions

#### Overall conclusions from the families who took part in the research

1. Parent feels they are left to cope on their own. The unexpected death of a child is a traumatic and bewildering experience during which parents are poorly supported in navigating the necessary legal and administrative processes. Parents do not know what to expect and struggle to understand the processes that need to be fulfilled.
2. There is a distinct lack of any co-ordination of support. Parents' emotional and psychological needs are unmet when their child dies unexpectedly and current bereavement services are inadequate. They don't reach out and respond to parent immediate needs, are not tailored, are poorly co-ordinated and counselling that is offered is not skilled to child bereavement. The continuing support in the hours, days and months following a bereavement that is described in the research literature as being important for families was not offered to our participants and professionals suspect this service does not exist in Leeds.
3. In the absence of professional support, families turn to their informal networks for support, which means that those without cohesive informal networks of friends and family will remain unsupported.
4. Bereaved families' needs are under-recognised because systems and processes are focussed on the care of the child, rather than to the care of the bereaved family. This means that when the child dies the care ends.
5. Parents can suffer significant mental and physical impact due to their grief, but they feel that this is not recognised, proactive steps are not taken by professionals and help is only available at crisis point.

## Overall conclusions from professionals who took part in the research

1. Few Leeds professionals perceive child bereavement support to be effective.
2. There is limited joined-up information sharing between professionals in different organisations about the care and support needs of bereaved families.
3. Many healthcare professionals, and especially those in primary care, are unaware of the bereavement services that exist or how effective they are. Those who are aware believe that provision is patchy and available only when certain criteria are fulfilled. Many professionals believe that charities provide the most support to families, but again only when families fulfil specific criteria.
4. Services for bereaved parents do exist but health professionals and families are often unaware of them and cannot easily access them. Healthcare professionals believe they are uncoordinated, poorly communicated and are not proactive.
5. Healthcare professionals believe child bereavement support should be coordinated via the NHS, rather than by charities.

## 4.2 Recommendations

### Recommendations

#### What families need

1. Families need immediate, intensive support to coordinate and liaise with different professionals and services, provide them with information, and act as the family's advocate.
2. Families should receive an automatic referral to this type of support.
3. The care families receive should be family-centred so that it is flexibly tailored to the needs of each individual family, experienced seamlessly and be available for as long as it is needed.
4. Families should have the support of a named person working to join-up services for them, explain and support them through legal processes, and help them identify and access the care services they need.

#### What professionals need

1. Information that is readily available that shows what support is available and how that support can be accessed.
2. A single point of access that they can refer families to – confident that the needs of that family will be met.

## Recommendations for specific stakeholders

**Hospital staff** – should ensure that after the death of a child, families should leave the hospital with a clearly communicated pathway detailing how and when support will be offered. Parents should be given a named contact who will be proactive in coordinating support and bridging the gaps between care providers, including the family's primary care team.

**GP practices** – should make contact with the family as soon as they are informed of the death. Contact should be made by the family's GP to explore the family's on-going care needs, with particular attention to the mental health of the family. GP practices should keep a library of information about the support needs of families after the death of a child and a directory of information that staff can access to help them support families.

**Healthcare commissioners** – should take responsibility for coordinating the recommendations for all stakeholders so that coordinated, family-centred care is available to families after their child dies.

**Schools** – should be aware of the processes that families must undergo and offer specialist support to siblings and friends if the child is of school age when they died.

**The Coroner's team** – need to redesign how they liaise with families so that they communicate in a less process-driven way. They should clearly communicate with families about their role and the timescales involved in investigating the child's death.

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# APPENDIX 1 – Family information sheet

Tell us about your support experiences:

## Elliot's footprint family interview

### About the project

Elliot's Footprint is a charity based in Leeds that helps families through child bereavement by working to improve and extend the services available after the death of a child. Elliot's Footprint has asked Brainbox Research to find out about the services that would help bereaved families. We want to find out more about what support you were offered when your child died and what types of services might have helped you and your family.

### What am I being asked to do?

We would like you to take part in an interview, which will last around one hour. Other members of your family can take part too, if they would like, so that we hear about their experiences and views as well. During the interview we will ask you to talk about the support you and your family had when your child died and any extra support that might have helped you. We know that this will be upsetting and so we will take the interview at your pace and we can take breaks at any time. Fiona will come to interview you. She is very easy to talk to and she will be sensitive to what you have been through. We would like to invite you to talk about your own experiences.

### Will anybody find out what I have said?

With your permission, the discussion will be audio recorded but only members of the research team will hear the recording. Nobody else will be able to find out what you individually have said. We are holding several interviews and the things that people talk about during the interviews will be summarised and included in a report, but no information will be provided that means that anybody could be identified. For example, we may use quotations from the interview in our report for Elliot's footprint but nobody's names will be included.

### Do I have to take part?

No, we hope that you will take part, but you don't have to. We will use what people tell us in interviews to develop recommendations about how services could be designed to better support families and also to design further research with other families, healthcare professionals and support professionals

### What if I change my mind about being interviewed?

That's ok – just tell Fiona that you don't want to talk any more. You don't have to give a reason and she will understand.

### What if I have some questions?

If there's anything you're not sure about, or if you have any questions, you can ask Fiona before the interview or at any time during the interview.

You can also contact Fiona before or after the interview by telephone on 0113 238 0157 or email [fiona@brainboxresearch.com](mailto:fiona@brainboxresearch.com)

Thank you for thinking about taking part.

# APPENDIX 2 – Semi-structured interview schedule

Open: Briefing, general talking about their child, audio recording, informed consent.

## 1. First of all, please tell me a little about you and your family

Who lives here with you? Do you have other relatives living nearby? What about close friends? What do you do on a typical day?

## 2. Please tell me about what happened to your child

Tell me about your child. How old were they when they died? Can you describe what happened? How long ago did this happen? What support did you get when it happened? Professional? Family and friends? Practical and emotional?

## 3. Which professionals did you have contact with at the time?

Doctors? / Nurses? / Your family's GP? Police? The Sudden Unexpected Death in Childhood Team (SUDIC)? Other healthcare people? Volunteers? How did they get in touch with you? What did they do well? What could they have done better? What sort of long-term support were you offered? Was this useful? Why/why not? Looking back, what types of support did you need from these professionals?

## 4. What choices did you have about how your child was cared for after their death?

Holding your child? Choosing clothes? Coming back to the hospital to be with your child? How much were you able to involve other member of your family? Your other children [ask them directly if they are present in the interview]? Close friends? How easy was it for you to express your wishes to healthcare professionals? How much did you feel they listened to you? How well did they guide you through the process? Did they tell you that there were procedures that needed to be followed? How did those procedures impact on you?

## 5. What professional support, if any, were you offered later on?

From which professionals? Healthcare? Counsellors? Guidance teams? Social services? Other support services? What information were you given about support services? Did you use these support services? Why/why not? Were they useful? Why/why not? How long were you offered support for? Was this enough? How could it have been improved? What professional support, if any, did you need?

## 6. Did anybody do or say anything to help your other children?

[only if there are other children in the family]

How much help did you get preparing how you talked to your other children? How much did schools get involved? Were you offered specialist support for your children? Looking back, what support did your family need?

To the brothers and sisters if they are present

## Did anybody do or say anything that helped you?

What help did you need? How easy was it for you to talk about how you felt? And what help you needed? With your parents? With your friends? Teachers? Others?

## 7. How much communication was there between the healthcare team and other support services?

Were bereavement support services contacted on your behalf? Did you feel able to contact them directly? How would you have liked contact to be made? Did you have any contact with the coroner's office? Did anybody help you with this? How could things have been organised better for you?

Anything else we've not yet talked about?

Close: Debrief (including importance of the research), thanks, contact details for Brainbox and for support organisations.

## APPENDIX 3 – Professional questionnaire

We want to find out more about your views on the services offered to bereaved parents and siblings when a child in the family dies. If you want to find out more about the survey or you have any questions you can contact Brainbox Research by emailing [beth@brainboxresearch.com](mailto:beth@brainboxresearch.com)

**1. Which organisation in Leeds, if any, coordinates child bereavement support for families?**

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**2. How should child bereavement services be coordinated? (Please tick one option):**

Via the hospital                      Via GP surgeries                      Via local authorities                      Via charities

Via another organisation (please state) \_\_\_\_\_

**3. How effective or ineffective do you think child bereavement support is for families in Leeds?**

Very ineffective                      Ineffective                      Effective                      Very effective                      Don't know

Please tell us why you think that: \_\_\_\_\_

**4. What gaps are there, if any, in the range of services offered to bereaved parents and families in Leeds?**

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## 5. Do you think these organisations offer the following services to families?

(Please tick ONLY THOSE that you think offer services)

	GP Practices	Hospitals	Charities	Local authority	Other organisations (Please state)
Face-to-face support for parents at home					
Face-to-face support for siblings at home					
Face-to-face support away from the home for parents					
Face-to-face support away from the home for siblings					
Group support for parents					
Group support for siblings					
Written/online information for parents					
Written/online information for siblings					
Telephone support for parents					
Telephone support for siblings					
Practical help for parents					
Support services for other relatives and friends					

## 6. About the child bereavement services you and your organisation offers to parents and families in Leeds (Please tick all that apply)

	I offer this	Others in my organisation offer this	No-one in my organisation offers this	Not sure
Face-to-face support for parents at home				
Face-to-face support for siblings at home				
Face-to-face support away from the home for parents				
Face-to-face support away from the home for siblings				
Group support for parents				
Group support for siblings				
Written/online information for parents				
Written/online information for siblings				
Telephone support for parents				
Telephone support for siblings				
Practical help for parents				
Support services for other relatives and friends				

7 How could child bereavement support in Leeds be improved?

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8. Are you aware of any 'best practice' support offered to bereaved parents and siblings outside Leeds? If so, please tell us about it:

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9. About you

Which type of organisation do you currently work for?

Clinical commissioning group      NHS hospital trust      GP practice      Charity      Local authority

Other (please state) \_\_\_\_\_

What is your job role?

Commissioning health and wellbeing services

GP   Hospital doctor      SUDIC doctor      SUDIC nurse      Nurse

Healthcare assistant      Social worker      Bereavement counsellor      Charity worker

Other (please state) \_\_\_\_\_

**That's the end of the questions. Thank you for helping us.**

If you want to speak to anybody about this survey,

Phone Brainbox Research on **0113 238 0157** or  
Elliot's Footprint by email on **elliotsfootprint@gmail.com** or  
View their website at **www.elliotsfootprint.org**

## APPENDIX 4 – HCP semi-structured interview schedule

Duration: up to 20 minutes.

Open: Briefing, audio recording, informed consent.

1. First of all, can you tell me a little about the team you work in? What is your role in that team? Do other team members work with bereaved families? What are their roles?
2. Have you yourself experienced working with families in this situation?

If yes, can you tell me about that? How well were you able to meet the family's needs? How could the family have been better supported, if at all? What would help you offer effective support?

If no, how able do you think you would be to provide support for a family? Where would you look for help / resources? Which other organisations would you get in touch with? What would help you offer effective support in this situation?

3. How should your organisation provide support to bereaved families after a child dies? What services should be available?
4. How, if at all, should organisations in Leeds work together to support bereaved families? What support should organisations offer to families? Key worker? Help for siblings? Group help? Help in schools? Counselling? Advocacy? Support dealing with the police, the coroner or the registrar?
5. Finally, how should help for families in Leeds be coordinated? Via GP practices? Via hospitals? Via charities? Via another route? Why would this be effective?

Thanks, debrief, contact details.



Rebuilding lives after the  
sudden loss of a child

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