

# Gathering feedback from families and carers when a child or young person dies

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A resource to help support professionals in  
their work with bereaved families and carers



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# FOREWORD

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As a professional who cares for children it's hard to know where to begin when asking families/carers about their experiences when their child died. Professionally I needed affirmation from families/carers that they wanted us to ask them about their experience, overwhelmingly the families who responded to the survey SANDs along with other third sector organisations working in this area told us that they did want us to do this. I needed to know 'what mattered most' in these circumstances, families/carers generously told us. I don't think these conversations or requests for feedback via surveys will ever be comfortable given the nature of this work, but what I do believe is that we've taken a step forward. We've asked families what matters and as a result gathered a suite of questions for professionals to use more confidently than if they were starting this work from scratch. I think this work forms part of maturing processes of listening and working with families/carers, I hope you'll use it in your practice of supporting families/carers and share your experiences of the difference you make through listening to families/carers.

*Kath Evans, Director of Children's Nursing, Barts Health, and former Experience of Care Lead for Maternity, Infants, Children and Young People, NHS England*

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We all have an obligation to review the care that we provide and gather feedback from those who receive our care. Bereavement care is no different. However, in the absence of a validated tool, we appreciate how difficult it could be for local services to develop a set of questions that could cover the range and breadth of circumstances that bereaved families and carers could face.

Given the sensitivity of the subject matter and the difference of views it was clear that we would have to consult widely and seek consensus where possible. It was also clear that a single one-size-fits-all tool would not be possible. As such we have developed this guidance and a suite of questions that can be tailored to individual

circumstance. We do, however, suggest that local services include a sub-set of core questions that can enable some comparative insights into the bereavement care provided.

We greatly appreciate the input, expertise and patience of all the professionals and family members who have supported this work. We hope that in time it will help colleagues both within London and nationally review and improve their bereavement care.

*Tracy Parr, Director of Transformation, Children & Young People's Programme, Healthy London Partnership*

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I am delighted that Sands have been able to contribute to this important project. Our survey of bereaved parents, supported by organisations working with bereaved families who have experienced the death of a child between birth and 18 years old, illustrated how important it is that families are offered the opportunity to provide feedback about their care should they wish to. Whilst nearly all bereaved parents believed they should be offered the opportunity to provide feedback about their experience of care, all families are different when it comes to how and when they would feel able to do this.

Services need to be flexible in their approach to ensure bereaved families are able to provide feedback in a way and at a time that is right for them. This toolkit provides a template for services to establish a feedback mechanism which is both flexible and sensitive to the needs of bereaved families.

All healthcare professionals want to ensure that they can provide the best possible care to families when they need it most, and we hope that this toolkit will help services to develop based on the feedback of bereaved parents.

*Kate Mulley, Director of Research, Education and Policy, Sands*

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# INTRODUCTION

## 98% OF BEREAVED FAMILIES SURVEYED FELT THAT THEY SHOULD BE OFFERED THE OPPORTUNITY TO PROVIDE FEEDBACK ON THEIR CARE FOLLOWING THE DEATH OF THEIR CHILD

There is a statutory requirement for ALL child deaths to be reviewed by those providing care for them to determine whether anything could have been done differently to improve the care of children in the future. This aligns with a national initiative, [Learning from Deaths](#), which looks to ensure that learning from deaths is routinely captured and acted upon. The experience of bereaved families and carers is an important component of this work and that of the Child Death Overview Panels (CDOPs) tasked with reviewing child deaths.

Many parents and carers who have experienced bereavement want to offer feedback to ensure lessons are learned and good practice is shared. This can be instrumental to inform improvements in care. However, seeking out these experiences in bereavement care can feel difficult. Until recently there have been no nationally validated measures to capture the experience of women, families and carers following the death of a baby or child. However, in June 2017, NHS England, in partnership with the London Clinical Networks and Sands (the Stillbirth and Neonatal Death Charity) published [Gathering feedback from families following the death of their baby: A resource to support professionals in maternity care](#). This resource summarised the views of 437 parents who had tragically experienced the loss of a baby, in regard to their preferences for being surveyed about their own bereavement care. It also provided guidance to professionals about how to collect feedback, and provided a tool to support with this task - the [Maternity Bereavement Experience Measure \(MBEM\)](#).

Following the success of the MBEM, NHS England commissioned the Healthy London Partnership and Sands to undertake a similar project to ask families/carers about the acceptability of developing a measure to capture their experience following the death of their child up to the age of 18. In 2018 Sands in collaboration with a range of other voluntary sector partners sort input from families on this

subject. 382 families who had experienced the loss of a child responded and offered their views on this work. They included families whose children had died following, or as a result of, a range of circumstances including pre-term birth, sudden unexpected death in infancy (SUDI), sudden illness, following a long term condition, trauma and suicide.

The survey received responses from families at a range of time points following their child's death. 21% of those who responded had experienced the death of their child within the previous 12 months, 30% between 1-3 years after the death, 15% between 3-5 years after the death, and 33% more than 5 years after the death. Importantly, 98% of bereaved families who responded to this call for input on the development of an experience measure felt that they should be offered the opportunity to provide feedback on their care following the death of their child.

The Healthy London Partnership drew on the outputs of this work, and the invaluable work of a number of publications that had been co-developed with bereaved families<sup>1</sup>, to produce this resource. [Gathering feedback from families and carers when a child dies](#) seeks to set out the key principles of good bereavement care and provide a tool to support the collection of feedback from parents and carers – the Childhood Bereavement Experience Measure (CBEM). This resource is intended to support all healthcare systems, but especially those who do not have an existing mechanism for collecting feedback from bereaved families and carers.

We are grateful to all of the parents, families and healthcare professionals who have taken the time to contribute to this work. We hope that everyone in local bereavement support teams, clinical teams, patient experience teams, patient advice and liaison services, third sector organisations, and charities find this resource useful in driving forward local improvement in bereavement care.

<sup>1</sup> [Learning from deaths](#) Guidance for NHS trusts on working with bereaved families and carers, [Information for families following a bereavement](#), and [When a child dies: A guide for parents and carers](#) were published to provide guidance for families and NHS staff on the care that should be provided to and received by families following the death of a child.



## ABOUT THIS RESOURCE

### THIS RESOURCE IS DESIGNED TO ACT AS A GUIDE FOR THOSE PROFESSIONALS COLLECTING FEEDBACK LOCALLY ON THE BEREAVEMENT CARE OF FAMILIES AND CARERS FOLLOWING THE LOSS OF A CHILD

Along with providing the best healthcare outcomes to patients, the NHS is dedicated to providing the best experience of healthcare too. The collection of a person's views about their own care, such as Patient-Reported Experience Measures, are incredibly important tools in aiding relevant professionals understand the individual experience of care, either during and/or after the period where care is provided. They can often provide important insights into the care provided that are not apparent from the review of a patient's clinical outcomes. This information can be used to make tangible improvements to the care provided for others.

This resource sets out the key principles of good bereavement care, and provides a tool to support the collection of feedback from parents and carers – the Childhood Bereavement Experience Measure (see Appendix 3). It has not sought to redefine bereavement care, rather consolidate the principles and themes outlined within existing published literature, much of which has been co-developed with bereaved families. It is designed for use by bereavement support staff, key workers<sup>2</sup> and all professionals involved in the care of bereaved families following the death of a child. *It will also be of use to bereaved families, carers, local providers and commissioners. It is not designed to be a one-size-fits-all tool that can be used for all families without adaptation, but rather a bank of questions that can be used to tailor an appropriate questionnaire to a family's circumstance.* This resource outlines a number of considerations that should be taken into account before seeking to collect information from bereaved families.

The resource was informed by a survey of 382 bereaved families, as well as published literature and expertise from parents and bereavement professionals across England. The voluntary survey, led by Sands, followed a similar approach to that adopted for the MBEM. It was distributed widely through a number of bereavement support channels. The

inclusion criteria were deliberately broad to reflect the wide range of experiences and opinions (a parent that had experienced the death of their child between birth and 18 years of age). Two-thirds of the respondents had experienced the death of their child within the previous five years, and over 50% within the previous three years. The survey linked participants to appropriate support services, given the possibility that its completion could bring up difficult memories of their experiences.

The CBEM itself is designed to support the gathering of insight directly from families (and if applicable, carers) about their bereavement care following the death of their child, either by a conversation, interview, electronic questionnaire, or using a hard copy document. This resource also provides practical guidance as to how the information collected should be used to drive local improvements to bereavement care, and signposts to relevant information and national organisations whose aims are to support bereaved families and carers, and professionals that work with them. As such, this resource is designed to act as a guide for those professionals collecting feedback locally on the bereavement care of families and carers following the loss of a child.

However, for local healthcare providers that have well-established and effective systems and processes for collecting feedback, it is not expected that this resource, nor the CBEM, will replace those local systems. It is hoped that relevant sections may be considered for inclusion within those existing systems, and that this resource will be considered during any review of those systems.

This resource has been tested with bereaved families and bereavement support staff to ensure that it effectively and sensitively captures the experiences of bereaved parents and carers.

<sup>2</sup> The responsibilities and competencies of the Key Worker are outlined in Appendix 5 of the *Child Death Review: Statutory and Operational Guidance (England)*



## CONSIDERATIONS WHEN COLLECTING FEEDBACK

THERE IS NO RIGHT OR BEST TIME, FORMAT OR METHOD FOR COLLECTING FEEDBACK FROM BEREAVED FAMILIES. SUCH CONSIDERATIONS SHOULD BE TAILORED TO THE PREFERENCES OF THE INDIVIDUAL FAMILY AND / OR CARER

Each death is a unique event and therefore the preferences of the family (and if applicable carers) as to if, how and when they would feel most comfortable in providing feedback on their bereavement care will vary widely. As such, it is important that the family's choices and preferences are central to the collection of any feedback on their bereavement care.

Professionals collecting feedback should be mindful that families wishing to provide feedback will feel comfortable doing so at different times. They will have a preference regarding who they would feel most comfortable providing that feedback to and in what format. They will also have a preference as to how long they wish to spend reflecting on their own bereavement care.

From the feedback of the 400 families surveyed by Sands, 22% responded to say that they would have felt comfortable taking up to 15 minutes to provide feedback, whereas 30% and 34% respectively would have felt comfortable taking 15-30 or over 30 minutes.

It would therefore be difficult to implement a single tool that can accommodate the preferences of all families, or that could capture the necessary information on all circumstances, without being too long and onerous to complete. As such, the Childhood Bereavement Experience Measure has been designed as a template that can be used, adapted and tailored to individual circumstances for the collection of information from families and carers for children from post maternity care to 18 years. If a baby died on a maternity ward, it may be more appropriate to use the [Maternity Bereavement Experience Measure](#).

**The bank of questions within the Childhood Bereavement Experience Measure should be used as a guide for collecting feedback from bereaved families following the death of their child. They should be tailored to the individual circumstance as not all questions will be applicable to all families**



## WHEN SHOULD FEEDBACK BE COLLECTED?

Feedback should only be collected if and when a family and / or carer(s) feel comfortable in providing feedback. Some families may not wish to provide feedback, and in such cases, their wishes should be respected and they should not be made to feel uncomfortable, or pressurised into responding. Some families may wish to provide feedback shortly after the death of their child, whilst others may wish to wait several months, or even years before doing so.

From the survey of **400 bereaved families** carried out by the charity Sands, **24% would have felt comfortable providing feedback 3-6 months** following their child's death, **28% between 6-12 months**, and **24% after 12 months**. Only **4%** of those surveyed would have **felt comfortable providing feedback in the period shortly after their child's death**, and **16% within the first 3 months**. This is consistent with the experiences of many bereavement leads across the UK who have indicated that the majority of their feedback questionnaires have historically been completed within the 3-6 or 6-12 month windows following the child's death.

Feedback can also be provided on more than one occasion. For instance, if a family provided feedback on their bereavement experience in the months following their child's death, they may wish to supplement that feedback at a later point, such as following the conclusion of the formal review of their child's death, or at a later point. They should be supported to provide feedback at a time and frequency that suits them. 44% of families would have preferred to provide feedback after the completion of all processes, enquiries and procedures, but the same proportion would have preferred the opportunity to feedback both before and after those processes had concluded.

It should be noted that whilst the formal review process for a child's death can take up to and even beyond eighteen months in certain circumstances, bereavement care should not be time limited and therefore may continue beyond this. As such, bereavement experience may be captured even after any formal review process has concluded.



## WHO SHOULD COLLECT FEEDBACK?

Feedback on a family or carer's bereavement experience should be collected by someone that they feel comfortable with. This would ideally be a professional known to them, who may have been involved in either their own bereavement care or the care of their child.

**63% of those bereaved families who responded to the survey felt that it was highly appropriate, or appropriate for a professional involved in the processes surrounding the death of their child to collect feedback on their bereavement care.**

Any professional collecting feedback from families should have received appropriate training. It may be appropriate for the local Bereavement Nurse Specialist or the professional acting as the 'Key Worker' to the family to take on this responsibility. However, in some circumstances, the family or carer may not feel comfortable providing feedback to those directly involved in their own bereavement care, especially if they have had a negative interaction. Feedback should be offered through a number of routes and the family, if willing to provide feedback, should be supported to use the method that makes them feel the most comfortable.





## HOW MANY QUESTIONS SHOULD A QUESTIONNAIRE OF THE CARE OF BEREAVED FAMILIES / CARERS INCLUDE?

**It is recommended that any questionnaire of the care of bereaved families and carers contains no more than 20 questions and is reviewed by the local legal and complaints teams or Patient Advice and Liaison Service (PALS) before use**

When testing the CBEM, the most common theme from the feedback received was that the 40+ questions contained within the CBEM was considered to be too onerous and perhaps distressing for any bereaved family or carer to complete. Careful consideration was given when developing the CBEM to ensure that all of the key themes of bereavement care were included. However, there must be a balance between including questions of a granularity that will enable the identification of local quality improvements, and what can reasonably be expected from those being asked to complete it. The CBEM has therefore been developed as a bank of questions that can be drawn from depending upon the individual circumstances of the bereaved family or carer. Not all questions will be relevant to all scenarios and careful thought should be given to the number of questions asked. It is therefore advised that the CBEM is not shared with bereaved families and carers in its entirety.

If the family or carer wish to provide feedback shortly after the death of their child, it may not be possible for them to respond to the questions regarding the learning culture of the organisation as the child death review process may not have concluded. There may be a number of scenarios where there may be value in asking additional questions that are not included within the CBEM. These could include scenarios where a child has died with learning disabilities, abroad, or outside the hospital setting, or as a result of a suicide. Any questions used as part of a questionnaire for bereaved families should be crafted in plain and simple language and be designed to meet a reading age of 12 years old. It is the recommendation of many of the bereavement professionals across England that have fed into this resource that any questionnaire contains no more than 20 questions and is reviewed by the local legal and complaints teams or Patient Advice and Liaison Service (PALS) before use.



## HOW SHOULD FEEDBACK BE COLLECTED?

There is no right or best way of collecting feedback from bereaved families and carers. **74% and 72% of those families** surveyed confirmed that they **would have felt comfortable providing feedback online or via a paper form**. **53% would have felt comfortable** providing feedback in a **face-to-face setting**, such as a structured interview, whilst only **25% would have felt comfortable** providing feedback **over the telephone**.

Where the questionnaire is completed in a face-to-face setting, bereavement leads have outlined that many families in practice have preferred to answer the questionnaire in stages over a number of interactions. This may provide a wider perspective over time and limit the potential distress to the family and / or carer. It should be recognised that when a family or carer is surveyed, especially if it is many months after the death of their child, they may not have a complete recollection of the events and the provision of their care. There may be some questions that they are unable to answer or would need some support in answering. If the questionnaire is sent in a hard copy to a family or carer to complete without the support of a healthcare professional, it is recommended that it is limited to less than 20 questions.



## USING THE FEEDBACK TO DRIVE IMPROVEMENTS

Local systems will have their own established processes in place for gathering and acting upon feedback on the care of all the services that they provide. As part of those processes, bereaved families and carers also need sensitively developed opportunities to provide feedback on the bereavement care that they receive, this Childhood Bereavement Experience Measure offers a framework for insight to be gathered in a flexible, family centred way.

Once collected, feedback should be collated to determine whether any themes can be identified. This feedback should be considered alongside any other clinical information at

the Child Death Review Meeting (if received by this point), and the Child Death Overview Panel meeting, and, as appropriate, at relevant local governance groups. Where learning is identified, this should be embedded locally and included within local training and education. Importantly, instances of high quality care should be recognised and celebrated. Families should be informed of any changes to the systems of care resulting from the review of their child's death or as a result of the feedback provided by families and carers on the bereavement care that they received.



## IDEAL BEREAVEMENT CARE WOULD INCLUDE:

### 1. END OF LIFE / PALLIATIVE CARE

- Respect the family's privacy and wishes at the time of their child's death
- Provide opportunities for the family to view, have contact, and make memories with their child (where appropriate)
- Inform families about the post mortem process
- Provide support around any decisions requiring consent
- Provide practical information in relation to the registration of a death, the collection of a death certificate, personal belongings, medical and other records

### 2. COMPASSIONATE CARE

- Treat bereaved families with compassion, dignity, respect, kindness, and sympathy
- Ensure that information collected is treated confidentially
- Look out for signs of isolation and encourage families to invite friends to attend meetings and seek support

### 3. SUPPORTIVE ENVIRONMENT

- Consider appropriate venues and forums for proposed meetings and interactions and give families a choice
- Provide support to families when decisions are required to be made within short timeframes
- Provide families with time and space to process information and do not pressurise them to make decisions or engage with services

#### 4. COMPASSIONATE COMMUNICATIONS

- Staff should properly introduce themselves
- Ensure communications are:
  - in plain, understandable language (free of jargon) with clarification of any technical terms, phrases, acronyms, processes, procedures, and organisations
- Clear, concise and provided in an easily digestible format
- Person centred, sensitive, sincere and appropriate in tone with sensitive headings
- Transparent, open and honest
- Accessible in the language of choice

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#### 5. PERSONALISED CARE

- Ensure those providing care are trained
- Listen to bereaved families and take their views on board
- Respect the values, culture, faith and beliefs of the family
- Ensure that support is provided to the wider family, including siblings and friends
- Check death certificate for accuracy before providing to a family

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#### 6. BEREAVEMENT SUPPORT

- Provide bereavement support in the aftermath of a child's death and for as long as is required
- Ensure that suitable and appropriate bereavement support is accessible in a timely fashion and when required
- Signpost bereaved families to sources of high quality advice and support services including: aftercare; chaplaincy; counselling; independent advocacy; legal; local charities, helplines, and family liaison service

#### 7. CHILD DEATH REVIEW PROCESS

- Help families understand the child death review process - which organisation will lead, which professionals will input, and the timescales involved
- Ensure that bereaved families have a dedicated and named support officer, a 'key worker'
- Treat bereaved families as equal partners throughout the child death review process
- Ensure timely, responsive contact, information and support from the key worker
- Ensure bereaved families are represented and / or supported at key meetings
- Ensure bereaved families know how to support and contribute towards any investigation(s) into their child's death (where applicable)
- Ensure bereaved families understand how to appeal any decision

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#### 8. LEARNING CULTURE

- Support bereaved families to provide feedback about the care of their child and their own bereavement care (if they wish to do so)
- Outline ways to raise concerns and welcome challenge positively
- Provide bereaved families opportunities to evaluate any recommendations or action plans developed to improve services following the review of their child's death
- Provide bereaved families opportunities to contribute to, shape and support local guidance, systems, processes, tools or staff training
- Inform bereaved families of any changes to the systems of care resulting from the review of their child's death



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- Bliss
- Bodie Hodges Foundation
- Care for the Family – Bereaved Parent Support
- Child Bereavement UK
- The Compassionate Friends
- Great Ormond Street Children's Hospital NHS Foundation Trust
- The Lullaby Trust
- National Bereavement Alliance
- SUDC UK
- TAMBA Bereavement Support Group
- Winston's Wish



## GUIDANCE & INFORMATION

### BELOW IS A LIST OF USEFUL GUIDANCE AND INFORMATION:

- *Coping with bereavement* (NHS UK)
- *Information for families following a bereavement* (NHS England)
- *Learning from Deaths in the NHS* (NHS Improvement)
- *Learning from deaths: Guidance for NHS trusts on working with bereaved families and carers* (National Quality Board)
- *Maternity Bereavement Experience Measure: Gathering feedback from families following the death of their baby: A resource to support professionals in maternity care* (NHS England)
- *When a child dies: A guide for parents and carers* (NHS England)
- *Child Death Review* (Healthy London Partnership)
- *Child Death Review: Statutory and Operational Guidance* (England)
- *Bereavement: A Practical Guide for NHS Managers* (The Institute of Healthcare Management)



# NATIONAL ORGANISATIONS

Below are a list of national organisations that provide advice, guidance and support to bereaved families and carers, as well as professionals.

## 2 WISH UPON A STAR

Provides a professional counselling service for suddenly bereaved families, as well as support to individuals who witness the sudden and traumatic death of a child or young adult and support and training for staff

01443 853125

[www.2wishuponastar.org](http://www.2wishuponastar.org)  
[help@2wishuponastar.org](mailto:help@2wishuponastar.org)

## A CHILD OF MINE

A Child of Mine is a registered charity that educate on the needs and experiences of bereaved parents which helps to improve the care they give in the future

01785 283434

[www.achildofmine.org.uk](http://www.achildofmine.org.uk)  
[hello@achildofmine.org.uk](mailto:hello@achildofmine.org.uk)

## AT A LOSS.ORG

AtaLoss.org is a charitable movement of people across the UK who are passionate about enabling the bereaved to receive the support that they need - in easing the pain together

[www.ataloss.org](http://www.ataloss.org)

## BLISS

Bliss champion the right for every baby born premature or sick to receive the best care by supporting families, campaigning for change and supporting professionals, and enabling life-changing research

020 7378 1122

[www.bliss.org.uk](http://www.bliss.org.uk)  
[ask@bliss.org.uk](mailto:ask@bliss.org.uk)

## BODIE HODGES FOUNDATION

A Foundation supporting bereaved families which provides a safe space where families can retreat to and spend time together after the death of their child

[www.bodiehodesfoundation.co.uk](http://www.bodiehodesfoundation.co.uk)  
[nick.hodges@bodiehodesfoundation.co.uk](mailto:nick.hodges@bodiehodesfoundation.co.uk)

## CARE FOR THE FAMILY - BEREAVED PARENT SUPPORT

Care for the Family is a national charity which aims to promote strong family life and to help those who face family difficulties

029 2081 0800

[www.cff.org.uk/bps](http://www.cff.org.uk/bps)  
[mail@cff.org.uk](mailto:mail@cff.org.uk)

## CHILD BEREAVEMENT UK

Child Bereavement UK supports families and educates professionals both when a baby or child of any age dies or is dying, and when a child is facing bereavement.

0800 02 888 40

[www.childbereavementuk.org](http://www.childbereavementuk.org)  
[support@childbereavementuk.org](mailto:support@childbereavementuk.org)

## CHILD DEATH HELPLINE

The Child Death Helpline aims to provide a quality freephone service to anyone affected by the death of a child of any age, not only at times of crisis but also for ongoing needs of callers over their lifetime

0800 282 986 / 0808 8006019

[www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)  
[contact@childdeathhelpline.org](mailto:contact@childdeathhelpline.org)

**THE CHILDHOOD BEREAVEMENT NETWORK**

The Childhood Bereavement Network (CBN) is the hub for those working with bereaved children, young people and their families across the UK

020 7843 6309

[www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)  
[cbn@ncb.org.uk](mailto:cbn@ncb.org.uk)

**THE COMPASSIONATE FRIENDS**

A charitable organisation of bereaved parents, siblings and grandparents dedicated to the support and care of other similarly bereaved family members who have suffered the death of a child or children of any age and from any cause

0345 123 2304

[www.tcf.org.uk](http://www.tcf.org.uk)  
[info@tcf.org.uk](mailto:info@tcf.org.uk)

**CRUSE (BEREAVEMENT CARE)**

Cruse offers face-to-face, telephone, email and website support for bereaved people in England, Wales and Northern Ireland. It has a youth website dedicated to young people ([www.hopeagain.org.uk](http://www.hopeagain.org.uk)).

0808 808 1677

[www.cruse.org.uk](http://www.cruse.org.uk)  
[info@cruse.org.uk](mailto:info@cruse.org.uk)

**THE GOOD GRIEF TRUST**

Exists to help all those suffering grief in the UK. They aim to find the bereaved, acknowledge their grief and provide reassurance, a virtual hand of friendship and ongoing support

[www.thegoodgrieftrust.org](http://www.thegoodgrieftrust.org)  
[hello@thegoodgrieftrust.org](mailto:hello@thegoodgrieftrust.org)

**GRIEF ENCOUNTER**

Support bereaved children and their families to help alleviate the pain caused by the death of someone close. Their services are free, funded through the generosity of their supporters

0808 802 0111

[www.griefencounter.org.uk](http://www.griefencounter.org.uk)  
[contact@griefencounter.org.uk](mailto:contact@griefencounter.org.uk)

**INQUEST**

INQUEST provides expertise on state related deaths and their investigation to bereaved people, lawyers, advice and support agencies, the media and parliamentarians

020 7263 1111

[www.inquest.org.uk](http://www.inquest.org.uk)  
[inquest@inquest.org.uk](mailto:inquest@inquest.org.uk)

**THE LULLABY TRUST**

Aim to reduce the number deaths from Sudden Infant Death Syndrome and support bereaved families who experience the sudden loss of a baby or young child

0808 802 6868

[www.lullabytrust.org.uk](http://www.lullabytrust.org.uk)  
[support@lullabytrust.org.uk](mailto:support@lullabytrust.org.uk)

**NATIONAL BEREAVEMENT ALLIANCE**

The Alliance raises awareness of and promotes access to bereavement support and collaborates strategically to provide a collective voice representing the needs of bereaved people and those supporting them.

[nationalbereavementalliance.org.uk](http://nationalbereavementalliance.org.uk)

**SANDS (STILLBIRTH AND NEONATAL DEATH SOCIETY)**

Sands works to support anyone affected by the death of a baby; improve the care bereaved parents receive; and reduce the number of babies who die through supporting and funding research.

0808 164 3332

[www.sands.org.uk](http://www.sands.org.uk)  
[helpline@sands.org.uk](mailto:helpline@sands.org.uk)

**SUDC UK**

A charity dedicated to increasing awareness and understanding of Sudden Unexplained Death in Childhood (SUDC). It also funds research to better understand and prevent these tragedies

[sudc.org.uk](http://sudc.org.uk)

**WINSTON'S WISH**

A charity which supports bereaved children, their families and the professionals who support them

08088 020 021

[www.winstonswish.org](http://www.winstonswish.org)

[ask@winstonswish.org](mailto:ask@winstonswish.org)

**SUPPORT AFTER SUICIDE PARTNERSHIP**

A special interest group of the National Suicide Prevention Alliance who focuses on supporting those bereaved or affected by suicide

[www.supportaftersuicide.org.uk](http://www.supportaftersuicide.org.uk)

The NHS UK website provides a tool to help find local bereavement support services

[www.nhs.uk/Service-Search/Bereavement%20support/LocationSearch/314](http://www.nhs.uk/Service-Search/Bereavement%20support/LocationSearch/314)

**TAMBA BEREAVEMENT SUPPORT GROUP**

Tamba have an on-line facility to provide virtual peer to peer support to all parents and carers who have lost from a multiple birth whether it is during or after pregnancy

[www.tamba.org.uk/bereavement-support-team@tamba.org.uk](http://www.tamba.org.uk/bereavement-support-team@tamba.org.uk)



### How best to request feedback on bereavement care – a survey of bereaved parents

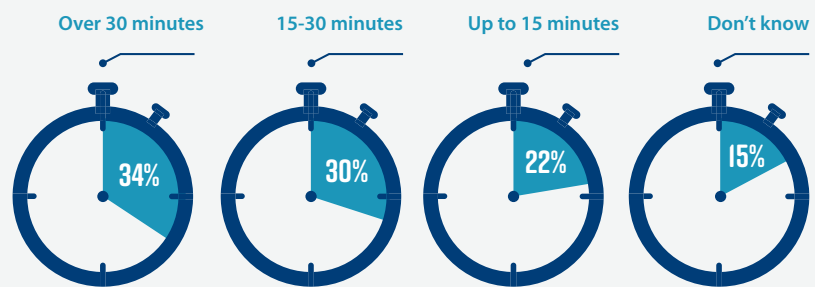


In 2018, Healthy London Partnership and NHS England commissioned Sands to survey bereaved parents whose children had died between 0-18 years of age. Parents were asked if and how they would have liked to have provided feedback on their bereavement care. Over 400 responses have been received and this infographic outlines the key findings.

# 98%

of bereaved parents felt that they should be offered the opportunity to provide feedback.

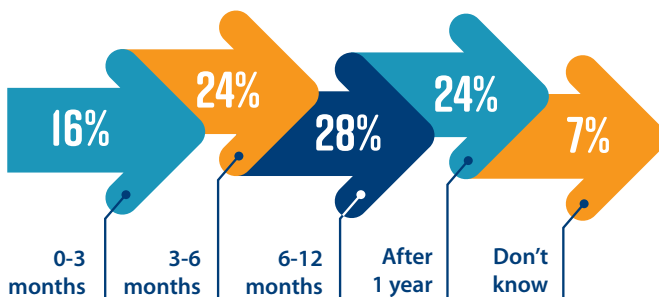
The amount of time bereaved parents would be comfortable spending on providing feedback:



*I feel people deal with grief differently and there is no specific time to be asked this. It would probably be good to ask people to complete a form when the time is right for them than applying any kind of pressure.*

**Bereaved parent**

The length of time following the death of their child that bereaved parents stated they would be comfortable being asked for feedback:



*Be aware that things change from hour to hour in the early days and continue to fluctuate for many years. We may be able to deal with stuff on one day but totally unable the next. That doesn't mean we are disinterested or unreliable.*

**Bereaved parent**

The percentage of bereaved parents who would feel comfortable\* providing feedback in this format:



\*This includes both "comfortable" and "very comfortable" responses.

What works for some families will not be appropriate for others – services should be as flexible as they can with how and when they ask bereaved families for feedback.

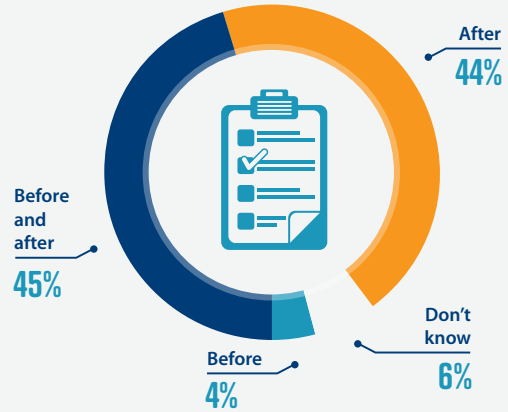
**Bereaved parents would like to provide feedback about:**

**61%** The support and care provided both immediately after and following on from the death of their child.

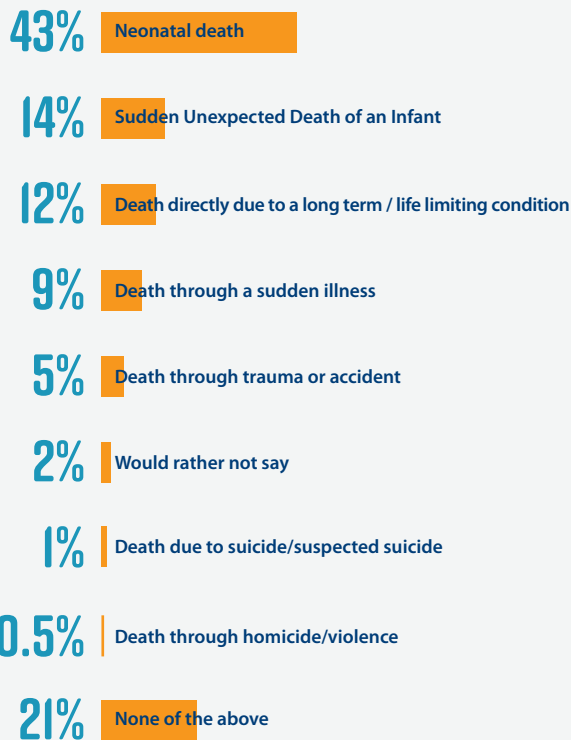
**35%** Ongoing support following on from the death of their child.

**4%** The immediate care and support provided, straight after the death of their child.

**Bereaved families were asked whether they thought feedback should be requested before or after the completion of all processes, enquiries and procedures:**



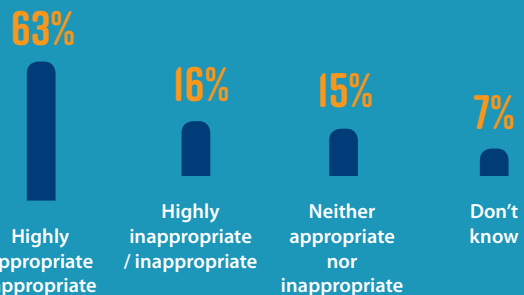
**Experiences of the bereaved parents who completed this survey\*.**



\*Data collected March-April 2018.

“The medical professionals collecting feedback may contact lots of families, but for each family this is a major part of their life and it shouldn't be treated as a standard process.”  
Bereaved parent

**How appropriate would it have been for someone involved in any of the processes surrounding the death of your child to have asked for this feedback?**



Sands Bereavement Support App



sands.org.uk

## APPENDIX 2:

### COVERING LETTER TO ACCOMPANY CHILDHOOD BEREAVEMENT EXPERIENCE MEASURE

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**In instances where families or carers have indicated that they would prefer to complete a hard or electronic version of the questionnaire, the below could be used as the basis for a covering letter or statement:**

---

#### *Trust/organisation details*

Dear (name)

We are very sorry your child has died and appreciate this is a difficult time for you.

The following questionnaire is a way for the NHS to capture feedback about the care you received after the death of your child.

We will use your answers and comments to continually improve care for bereaved parents.

We have worked with bereaved families to develop these questions. This is to help ensure we are asking about what matters most to families and that we do this as sensitively as possible. We have included some open ended questions where you can freely express your thoughts and feelings. A member of staff can be with you to fill out these questions, if you wish, or you can post it back to us.

If you would like to speak to someone about these questions please contact:

*(insert local contact details)*

If you would like to speak to someone outside this organisation please contact the Child Death Helpline on 0800 282 986 / 0808 800 6019 or at [www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)

We appreciate how painful it may be considering the answers to these questions. We are very grateful for your thoughts which will help us improve care for families. We are very sorry for any distress that may be caused by responding to our letter.

Kindest regards,

*(Organisation)*

## APPENDIX 3:

### CHILDHOOD BEREAVEMENT EXPERIENCE MEASURE - FAMILY AND CARER FEEDBACK QUESTIONNAIRE

**The feedback that you provide may lead to improvements to the care for other bereaved families and carers in your area in the future**

We are very sorry your child has died, and we appreciate that this is an extremely difficult time for you.

This questionnaire is for families and carers of children (up until the age of 18) who have died. It allows you to provide any feedback about your experiences that you feel comfortable sharing. You do not have to complete it if you do not wish to do so. If you do, we will use your answers and comments to continually improve care for bereaved families and carers.

We appreciate that there may seem like a lot of questions. You do not have to complete all of the sections, or provide comments in every section, some of which may not be relevant to your circumstance or experience. Please take as long as you need to complete the form, there is no timeline by when you need to complete it by. You may have interacted with a variety of organisations and professionals prior to and following the death of your child. If there were differences in the quality of the care that you received, please feel free to expand upon this, or add any other comments that you may have, to the free-text comments boxes.

You can discuss your answers directly with, or separately return the form to anyone involved in your bereavement care. If you do not feel comfortable sharing this form directly with the professionals involved in your own care, then you can send it to your regional Child Death Overview Panel who are responsible for reviewing your child's death and making sure that any learning identified is acted upon. Details are available at: [www.londonscb.gov.uk/local-child-death-contacts](http://www.londonscb.gov.uk/local-child-death-contacts) [NB this section should be updated dependent upon local processes. If the local CDOP is not best placed to receive these completed forms in the first instance then please amend this section]

*[NB Please tailor this questionnaire to the experiences of the bereaved family and / or carer. It is recommended that up to 20 questions are used. In instances where more than one child has died, the questions relating to 'your child' should be changed to 'your children']*

**What is your relationship to the child who died?**

.....

**How long ago did your child die (months)?** This will help bereavement staff understand when may be an appropriate time to ask bereaved families to complete this questionnaire in future.

.....

**SECTION 1:****LAST MOMENTS SHARED / PALLIATIVE CARE**

This section covers questions that focus on the period leading up to and immediately after your child's death.

*[NB Not all of these questions will be appropriate for all families and / or carers].*

<b>To what extent do you feel:</b>	Strongly agree	Agree	Neither agree / disagree	Disagree	Strongly disagree	Not applicable
1.1. That your child was treated with care and respect?						
1.2. That your privacy was respected at the time of your child's death?						
1.3. That your wishes were respected around the care of your child before and after their death?						
1.4. You had opportunities to see, have contact with and (where appropriate) make memories with your child after they had died?						
1.5. Informed about the hospital and coroners post mortem process?						
1.6. Supported to understand and be involved in any decisions, including those requiring your consent? <i>[NB To make this question more specific the following could be added: the donation of tissues and organs or the holding of a post mortem examination]</i>						

<b>Were you provided with:</b>	Yes	No
1.7. Information about your child's belongings and records? <i>[NB To make this question more specific the following could be added: guidance to help you register your child's death; collect their death certificate; personal belongings; and access their medical and/or other records]</i>		

**Comments**

If you wish to add any comments about your answers above, please use this box to do so:

The following sections include questions that cover your experiences up until the point that you completed this questionnaire.

## SECTION 2:

### COMPASSIONATE CARE

To what extent do you feel:	Strongly agree	Agree	Neither agree / disagree	Disagree	Strongly disagree	Not applicable
2.1. That you were treated with compassion, dignity, respect, kindness, and sympathy?						
2.2. That any information that you shared with any professionals has been treated confidentially?						
2.3. Supported and encouraged by professionals to invite friends, family members or an advocate to join you at relevant appointments or meetings?						

#### Comments

*If you wish to add any comments about your answers above, please use this box to do so:*

## SECTION 3:

### SUPPORTIVE ENVIRONMENT

To what extent do you feel:	Strongly agree	Agree	Neither agree / disagree	Disagree	Strongly disagree	Not applicable
3.1. That your privacy was considered and respected throughout?						
3.2. That you were offered a choice about the setting (hospital, home, GP surgery etc) and forum (face-to-face, telephone) of proposed meetings and interactions?						
3.3. That any meeting rooms were set up to make you feel comfortable?						
3.4. That you received the support and available information you needed if decisions had to be made quickly?						
3.5. You were given time and space to process information and were not pressurised to engage with services when you did not feel up to doing so?						

#### Comments

*If you wish to add any comments about your answers above, please use this box to do so:*

**SECTION 4:**

## COMPASSIONATE COMMUNICATIONS

To what extent do you feel that communications were:	Strongly agree	Agree	Neither agree / disagree	Disagree	Strongly disagree	Not applicable
4.1. In plain, understandable language (free of jargon), that helped you understand what was being explained to you?						
4.2. Clear, concise and in a helpful format?						
4.3. Appropriate and relevant to your circumstances?						
4.4. Sensitive and sincere?						
4.5. In your own / preferred language?						
4.6. Open, honest and truthful?						
4.7. From professionals who properly introduced themselves (gave you their name and job title) and let you know how you could contact them (where applicable)?						

**Comments**

*If you wish to add any comments about your answers above, please use this box to do so:*

**SECTION 5:**

## PERSONALISED CARE

To what extent do you feel:	Strongly agree	Agree	Neither agree / disagree	Disagree	Strongly disagree	Not applicable
5.1. Confidence in the team caring for you and your family?						
5.2. That those caring for you listened and took on board what you had to say?						
5.3. That you were supported to make decisions that were right for you?						
5.4. That your values, culture, faith and beliefs were respected?						
5.5. That appropriate care and support was provided to your family – siblings, grandparents and friends (where applicable)?						

**Comments**

*If you wish to add any comments about your answers above, please use this box to do so:*

**SECTION 6:**

## BEREAVEMENT CARE AND SUPPORT

Were you:	Yes	No	Not applicable
6.1. Offered bereavement care and support following your child's death?			
6.2. If you were offered bereavement care and support, were you able to access it at times convenient to you?			
6.3. If you were offered bereavement care and support, do you feel that it was suitable for you?			
6.4. Made aware of local support services that were applicable to your circumstances? <i>[NB To make this question more specific the following could be added: aftercare; chaplaincy; counselling; independent advocacy; legal; local charities; helplines and family liaison services such as the Patient Advice and Liaison Service (PALS)]</i>			
6.6. What bereavement care were you offered? <i>It would help the staff reviewing your care if you could outline what bereavement care you were offered below. If you wish to add any other comments about your answers above, please use this box to do so:</i>			

**SECTION 7:**

## CHILD DEATH REVIEW PROCESS

Were you:	Yes	No
7.1. Informed that there was a process for reviewing your child's death and how it would run?		
7.2. Provided with a named support officer, known as a 'key worker', to act as a single point of contact with you throughout the process of reviewing your child's death?		

To what extent do you feel:	Strongly agree	Agree	Neither agree / disagree	Disagree	Strongly disagree	Not applicable
7.3. You were prepared for and supported throughout the child death review process?						
7.4. Your input into the process of reviewing your child's death was considered equal to that of the professionals caring for your child?						
7.5. You received information and support from your key worker in a timely manner without having to chase them?						
7.6. You were represented and / or supported at key meetings by the key worker?						
7.7. You were provided information about how to raise any concerns or complaints about the review into your child's death, or appeal any decision taken by those reviewing your child's death? <i>[NB In circumstances where concerns, complaints or appeals had been lodged by the family, there may be value in asking a question about whether the family felt that the concern, complaint or appeal had been received positively and handled professionally]</i>						



If there was an investigation into your child's death, to what extent do you feel:	Strongly agree	Agree	Neither agree / disagree	Disagree	Strongly disagree	Not applicable
7.8. Informed, involved and that your views mattered in the process? <i>[NB If there was a joint agency response, coroner's investigation, or serious incident investigation, such opportunities would include the setting of the terms of reference of the investigating panels and commenting on draft investigation reports]</i>						

### Comments

If you wish to add any comments about your answers above, please use this box to do so:

## SECTION 8:

### LEARNING CULTURE

To what extent do you feel:	Strongly agree	Agree	Neither agree / disagree	Disagree	Strongly disagree	Not applicable
8.1. Supported to provide feedback about the care of your child and your own bereavement care (if you wished to do so)?						
8.2. That any feedback you provided was welcomed by those caring for you?						
8.3. Confident that any feedback that you provide(d) will be used to make changes?						
8.4. That you had opportunities to feed into any plans to improve your local services (if you wished to do so)? <i>[NB This could include evaluating any recommendations or action plans as a result of the review of your child's death, or help shape any local support, guidance, or staff training to improve the future care for families]</i>						
8.5. That you were provided information about how to raise concerns or complaints about your own care? <i>[NB In circumstances where complaints had been lodged by the family, there may be value in asking a question about whether the family felt that the complaint had been received positively and handled professionally by the relevant local service?]</i>						
8.6. That you were informed of any changes made as a result of the feedback that you provided?						

### Comments

If you wish to add any comments about your answers above, please use this box to do so:

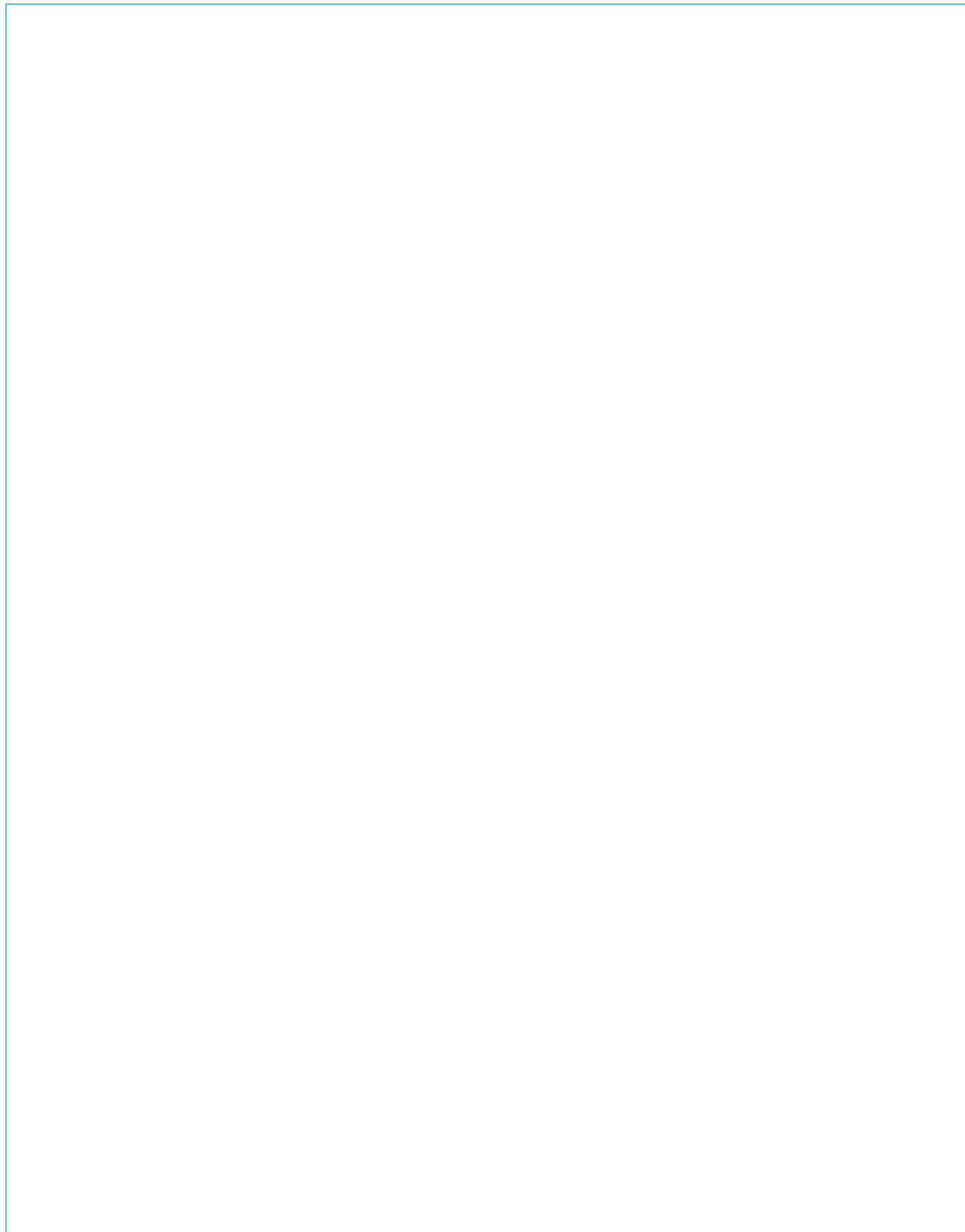
**SECTION 9:**

## OTHER COMMENTS

**Please use this space to include any other comments that you may wish to add that you have not included above.**

*As part of this process we will be feeding back any comments that you have about the team caring for you. If you feel that you received particularly good or sub-optimal care from any particular doctor, nurse, police, key worker, social worker, midwife, health visitor, palliative care team, chaplaincy, or pastoral support team, please feel free to include any comments below.*

**Comments**



**We greatly appreciate the time that you have taken to share your thoughts and experiences with us.  
Thank you**

