The HLP CDOP Programme - Bereavement Resource Guide for CDOPs

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Acknowledgements

This guide would not exist without the drive, commitment and expertise of the London CDOP system. Many have contributed to this resource and have shared examples of best practice and illuminated issues and assets that will help the London CDOP system achieve a uniform high quality interface with the bereaved and ensure they are getting the support they need. In particular the authors would like to thank.

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About the Healthy London Partnership

Healthy London Partnership formed in April 2015. It has been working across health and social care, and with the Greater London Authority, Public Health England, NHS England, London’s councils, clinical commissioning groups, and Health Education England. We have
united to amplify the efforts of a growing community of people and organisations that believe it is possible to achieve a healthier, more livable global city by 2020.

The NHS cannot achieve this goal alone and is working with partner organisations to ensure improvements are made through the London Health Board and the London Health and Care Devolution Programme. Partners involved include 32 Clinical Commissioning Groups, NHS England (London), Public Health England, London Councils, Health Education England, the Greater London Authority and the Mayor of London. The London Health and Care Collaboration Agreement, endorsed by Government, provides a blueprint for partnership working to help make London a healthier city where health and care services meet the needs of individual Londoners.

Our work is organised into transformational focus areas. All partners pooled funding to undertake transformational change across London, through clinical and enabler programmes. Each programme aims to solve a different health and care challenge faced by the capital. All aim to make prevention of ill health and care more consistent across the city.

**About the Healthy London Partnership CDOP Programme**

From September 2016 the Health London Partnership has been running a support programme for London CDOPs.

With a multi-agency steering group including subject matter experts from the CDOP system, Police, Metropolitan Police, Local authorities and Public Health England the Steering Group has provided focussed steer and constructive challenge to the programme and ensured that there has been a clear accountability underpinning the work.

Through themed workshops, seminars, and themed reviews it aims to enable the London CDOP system to meet the challenges of legislation and strengthen CDOPs ability to prevent the avoidable deaths of children in London. To date themes addressed have included Asthma Deaths, Suicide, service mapping and the need for a shared approach to case management, standards, definitions and Minimum Data Set for London.
Introduction by Professor Russell Viner London Partnership

The death of a child is a devastating event to parents, carers, siblings and those around them. The recent Royal College of Paediatrics and Child Health report [1] State of Child Health (RCPCH Feb 2017) noted that:

- There were there were 2,517 deaths among infants in England and Wales in 2014.
- Most deaths during childhood occur during the first year of life, particularly the first month of life.
- Infant mortality rates across all UK countries have declined markedly over the past 40 years. However, progress has slowed over the past 20 years, particularly compared to other European nations.
- Conditions related to preterm birth are the most common causes of death in infancy.
- Socioeconomic status is strongly associated with infant mortality, with increasing risk associated with higher levels of maternal deprivation.

The UK ranks 15th out of 19 Western European countries on infant (under one year of age) mortality and has one of the highest rates for children and young people in Western Europe. Given this background the need to provide adequate bereavement support is both a moral and service imperative.

The London CDOP system has a key role in assuring the support offer for the bereaved is sensitive to their need and that delivery is uniformly excellent across London. This guide is a practical resource aimed at supporting this crucial work.

The guide is divided into three sections:

**Part One** is aimed at supporting CDOP Processes including: information on how CDOPs can include families in the review process, communication of findings with families, checklists, and standardised letter, a feedback summary, recommendations on supporting families around receiving the Post Mortem Report and includes a best practice pathway shared with the HLP CDOP Programme by Lewisham CDOP.

**Part Two** focusses on how Local CDOPs can ensure that their areas are providing a high quality bereavement service and links to both standards and experience measures.

**Part Three** focusses on resources and information that London CDOPs can use themselves or signpost the bereaved towards.

We strongly encourage the use of this guide and the resources within to support the crucial work that you do and hope you find it helpful. As ever any and all feedback on the guide and the HLP CDOP programme is deeply appreciated.

Professor Russell Viner Clinical Director Healthy London Partnership

PART ONE: The role of CDOPs, Processes for engagement with the Bereaved, capture of experience and resources

This guide is presented in “DRAFT for CONSULTATION format” as we are seeking your help and advice in refining and improving this basic draft. We are hoping that you will find it helpful and that given its draft status you will find useful content and resources that will help you support the bereaved you are working with. We really need your help in refining this DRAFT. Please send your feedback on this resource by close of play on Thursday 27th July 2017.

Please send any suggestions for edits or additions to: Daniel.Devitt@nhs.net

A note on this Guide

This guide is designed to support you in the work that you do.

It comes about as a response to repeated requests from CDOP partners for a consolidated resource to help them deliver high quality bereavement support. Through face to face conversations, feedback received at the HLP CDOP programme workshops and direct requests for specific resources or assistance.

The consultation period for the HLP Bereavement Resource Guide for London CDOPs is running from the 29th June to the 27th July 2017. If you wish to submit any comments, suggestions or queries please email them to daniel.devitt@nhs.net

The Role of CDOPs in Supporting Bereaved Families

It is important to acknowledge that CDOPs do not in themselves provide bereavement support, excepting in their sensitive and supportive role throughout the review process and their interaction with the bereaved.

They do however have a clear role in ensuring that the bereaved receive the care support and clarity they need. CDOPS through their recommendations and day to day operations should be active in calling for the provision of local bereavement services and be active in encouraging the commissioning of and ultimately use of both statutory and third sector bereavement specialist services by the bereaved.

This guide has been developed as a resource to support the best practice delivery of one of the key areas of CDOP work, the support and assistance of the bereaved. Drawing from national and Local London practice and driven by the outputs of the Mapping workshops of June 2017 they are an attempt to encourage and guide a shared delivery of high quality information and support for those who have been bereaved.

It aims to provide the London CDOP system with key tools and related resources to help support the delivery of a uniformly high quality information and bereavement support offer.

We encourage London CDOPs to use the templates and methodology from the guide to help eliminate some of the unwarranted variation that we all know has an impact on our ability to serve the needs of those facing bereavement
“I” Statements on the Bereaved Point of View

The voice of the bereaved is an essential component to the work we do. The bereaved can share with us much necessary and important information that can when reviewed alongside the input of professionals give us clear and powerful insight into why a child or young person has died. Arrangements at home, local service practices and issues, family history and details of siblings can give us crucial information identifying potential deficits in care, insights for future care, preventative interventions and a deep understanding of the needs.

Through understanding these needs we can frame a service offer that is clear, flexible, robust and above all humane, supporting those who have been bereaved in the best possible way.

“I statements” are a simple and powerful method to understand the needs of the people we work for.

1) I need you to understand that this is unique and terrible for me, and I am stuck in the middle of many complex and confusing processes and need many different types of support and advice.
2) I need you to understand that this is the worst possible event and you need to bear with me as I go through this and help me through this.
3) I want to tell my story once and for you to share this with those who need to know.
4) I need the professionals involved with the review of the death of my child to talk to each other and work as a team.
5) I need to a single point of contact that I can go to if I have questions at any time
6) I need to be kept informed about the next steps for the review and the likely timescales this might take
7) I need to know about the review of the death of my child and both who is doing this and why?
8) I need to have help to access bereavement support and services when I need and at the times I need, reflecting that my needs will change over time, and sometimes I will need more support and other times less
9) I need you to help me understand what has happened, clearly and in a language and a style that meets my needs and I can I can meet phone or email a professional when I need to ask more questions or discuss the options.

The death of a child is the worst experience a parent or carer can face and we must do all we can to ensure we are not making matters worse and where possible we help and support the bereaved.

Initial Contact

Colleagues have taken great pains to tell us through the programme workshops that they wish they were in a position to do the job of contacting and initiating the support of the bereaved far better than they often can.
A key aspect of the work of CDOPs is the contact they have with the bereaved, including requests from the child’s family for updates on the review of the death of their child. There is a need for a clear and concise summary of the CDOP review and ideally a record of the recommendations and lessons learned that can be shared with other organisations contributing to the review.

Clearly the variation in the nature and circumstances in which children die, the complexity of the events leading up to death and the potentially large number of other processes involved (Investigations by the Police and Coroner, Pathology, Mortality and Morbidity meetings etc.) would make a one size fits all approach impossible to use and ineffective.

That being said there are a few helpful things we can do to enhance the quality of the information and support provided to the bereaved – and the professionals working with them.

Drawing upon many impressive examples from across London and the feedback of colleagues throughout the many HLP CDOP workshops we are pleased to share a best practice model letter for usage in London CDOPs. See Appendix XXX

It aims to set out a clear and concise description of the CDOP process and the support offer for the bereaved. It captures and supports several key areas for CDOP works already being delivered across London including:

- A focus on the needs of the bereaved for information and support and clarity on the role of CDOPs
- A focus on a single point of contact for the bereaved and the recognition that their access and support needs are both important and unique
- A focus on enabling the voice of the bereaved to be heard and include in the review
- A focus on providing progress updates and a summary of the CDOP review

**The HLP CDOP Review Summary**

A key aspect of the work of CDOPs is the contact they have with the bereaved in the form of day to day progress reports, queries and requests for updates on the review of the death of their child. There is a need for a clear and concise summary of the CDOP review and ideally a record of the recommendations and lessons learned that can be shared with the system.

Clearly the complexity of circumstances and the potentially wide range of processes involved (Police, Coronial, Pathology, Mortality and Morbidity meetings etc.) would make a one size fits all approach impossible to use and ineffective.

That being said there are a few helpful things we can do to enhance the quality of the information summary and support provided to the bereaved – and the professionals working with them.

Please see Appendix A for a basic summary report for sharing with the professionals involved in the case and also Appendix XXX a summary report for the bereaved themselves.

The forms encourages CDOPs to capture details of their progress and details of their interface with the bereaved and allows them to share a summary version of the final CDOP
Panel discussion deliberations and recommendations with both the bereaved and the local system.

- The information in the summaries should be clear concise and readily understood with appropriate levels of information to give a summary of a specific case, but not so exhaustive or detailed that a lay audience would not be able to interpret them nor so broad that they become a significant burden on the CDOP that provides them.
- The Duty of Candour on all health service providers is an explicit responsibility and a formalised and standardised method of feeding back to the bereaved and local system will aid in the delivery of this obligation.
- There is a need to be sensitive with all parties both those bereaved and service providers, balancing the need to share recommendations and lessons learned with the necessary tact and courtesy we should afford each other.
- It is crucial that the CDOP feeds back information on the review to the professionals who have been involved in it. Many services are reliant on feedback such as this to address service development opportunities and improve the quality improvement and learning environment they operate. A password protected version of the HLP CDOP Programme Summary form provides a useful tool to close the information gap with involved services.
- Recommendations and Lessons learned should be framed so that they address systems or services and avoid identification of individuals at fault. If such individual factors are identified they would be represented in either Coronial, professional of Police proceedings, and the CDOP focus is not concerned with investigation of conduct or intent but more generally to review system level activities.
- CDOPs should try to ensure that families are supported through these processes, though they are not necessarily required to provide that support themselves, but can in their assurance function ensure that appropriate support is locally available and must be clear and supportive in their dealings with the bereaved.

Involving the Bereaved

There are many examples from the CDOP system of innovative and supportive practice with regards to Bereavement support. The Lewisham CDOP have kindly shared an example of good practice that lays out their approach to the how they both support the bereaved and seek to include the voice of the bereaved in their panel processes.

Lewisham Child Death Overview Panel: Summary for London CDOPs on the Bereavement support offered to parents when a child has died

- **First letter** sent in order to: let parents know about CDOP process; gain implicit consent for information sharing; includes Bereavement resource details (See attached). This letter includes the offer of contact to the CDOP chair via our CDOP
Parental feedback tells us that many parents are not able to read leaflets in the first weeks after the ‘earthquake’ of a child dying. So we plan to send a 2nd letter 3 months after the death which focuses mainly on bereavement support. We will share when we have a draft.

3-4 weeks before we plan to review the case at CDOP, a 3rd letter is sent to tell the parents that the review is coming up and invite them again to make contact if they wish to discuss anything in relation to their child that they think may assist the panel in the review or that they want the panel to be aware of. This letter also includes bereavement resources.

Parents that do make contact sometimes want a telephone conversation, sometimes just email contact and sometimes face to face. Face to face meetings are usually conducted at Kaleidoscope—a children’s centre in Lewisham but we will go to the home if parents are not able to come out. This meeting is always conducted with at least 2 people, usually the CDOP Chair and CDOP nurse though if parents have specific medical questions, the 2nd person may be the designated paediatrician. The meeting is written up and a summary sent to parents for checking and then a final summary will be sent to parents and a copy made available to CDOP in advance of the review.

Note that CDOPs have a significantly different discussion when there is input from parents and in our view, a richer insight into the life and death of that particular child.

The Lewisham CDOP has found real value in engaging with the bereaved and has championed the inclusion of the bereaved voice in the VCDOP Panel.

First letter to the Bereaved from Lewisham CDOP

Lewisham Safeguarding Children Board
Lewisham Safeguarding Children Board
Child Death Overview Panel
Kaleidoscope
3rd Floor
32 Rushey Green,
London SE6 4JF
0203 0492088
Email: pauline.cross@lewisham.gcsx.gov.uk
lh.childdeath@nhs.net
February 2017

Dear Ms
I have been told of the very sad death of your son/daughter name. I hope you and your family will accept my deepest sympathy.

The death of a child is always particularly sad. If we examine the circumstances of every death of a child or young person we can better understand why these tragedies happen, and improve local services if they are shown to have problems. We hope that by doing this we will be helping the individual child’s family understand why they died, but also that we can help other children and families in the future. From 2008 the law in England changed and now requires that we review every child death in this way.

The review is done by a panel called the Child Death Overview Panel and includes doctors, other health specialists and child care professionals. Over the next weeks and months, the panel will be asking health professionals for information about name from their medical records. This information will be used to help us understand why name died, and improve our services for all children and their families. I am the chair of this panel, please contact me should you wish to discuss the process in more detail, or if you have any objection to our collecting information to inform the review. If I am unable to answer the phone when you call please leave a message and I will respond as soon as possible. My contact details are given above. I also include a leaflet with more information, which I hope you will find helpful.

I can reassure you that all the information we gather will be treated with the deepest respect and in strictest confidence. None of our findings, recommendations or reports will name or identify your child or family.

Yours sincerely,

Pauline Cross
Child Death Overview Panel Chair
Consultant Midwife/Public Health Strategist

Cc Dr

Follow up Letter to the Bereaved from Lewisham CDOP
As I explained in my earlier letter, all deaths of children and young people under 18 are reviewed by a Child Death Overview Panel which includes doctors, other health specialists and child care professionals. The panel has gathered information about child name from the health services, children’s services and other services who were involved before his/her death. This information will be discussed by Panel members who will make any recommendations necessary to improve how services are provided for children and families in future.

I am now writing to you to see if you have any information or views that you think would help us to understand child’s death better. I am also concerned to hear about the services provided to him/her and your family both before and after his/her death. You can either write to me, e-mail or contact me by telephone, or, if you prefer, we can arrange to meet face to face. My contact details are given above. If I am unable to answer your call please leave a message and I will respond as soon as possible.

I know how difficult it must be to deal with this information, but please feel free to contact me should you wish to discuss anything. I also include a leaflet with more information, which I hope you will find helpful.

All the information we gather will be treated with the deepest respect and in strictest confidence. None of the panel’s findings, recommendations or reports will name your child or family.

Yours sincerely,

Pauline Cross
Child Death Overview Panel Chair

Consultant Midwife/Public Health Strategist

Cc: GP details here
Part Two High Quality Bereavement Support for CDOPs

In November 2016 the revised SUDI guidelines underscored the need for high quality bereavement support.

“Providing support and care to the bereaved family from the earliest possible stage is a core component of the joint agency response and runs through all stages of the response. The parent(s), who are usually the first to discover their infant has unexpectedly died, will be extremely distressed and shocked. At all times consideration should be given to the family’s wishes and beliefs, and how these can be accommodated within any statutory requirements.”

The SUDI guidelines go on to note that the work of The Lullaby Trust, that when a family experiences bereavement “their overwhelming need is to find out why their infant has died, and they would like the investigation to be as thorough as possible.”

Families are supportive to a robust and rigorous process of investigation and review. They want to know what has happened to their child, and a key area of the support offer from CDOPs focuses on their need “to be told what is happening, what has been found so far and what will happen next.”

Given that CDOPs do not provide bereavement support themselves - though a few CDOPs in England, including Wandsworth CDOP ² have recruited officers with a specific remit for bereavement support – the bulk of the contribution of CDOPs to bereavement support lies in the on-going interface they have with the bereaved from their initial contact and the on-going information and support they offer by signposting to local or national services and organisations delivering bereavement support.

See also Appendix D for resources for professionals

Key Stages and Processes Where Support May Be Required

Each death of a child or initiates a potentially complex and long process of reviews that can involve multiple agencies over significant lengths of time and given the issues of deaths overseas or even out of borough on-going need for support and advocacy on behalf of the bereaved.

<table>
<thead>
<tr>
<th>Linked processes</th>
<th>Multi Agency working arrangements and partners</th>
</tr>
</thead>
<tbody>
<tr>
<td>Serious Incident Investigation</td>
<td>Local Acute or Community Trust investigation, potentially feeding into NHS</td>
</tr>
</tbody>
</table>

There are many points in the processes above where supportive communication with the bereaved can be of benefit. Clearly as bereavement is a unique and individual experience and the needs of the bereaved will vary a one size fits all approach would not work but a minimum offer could usefully address two key areas Navigation/Explanation of the different processes and Post Mortems.

**Navigation/Explanation of the different processes:**

CDOPS are the local professionals tasked with the review of all child deaths and as such usually complete their reviews towards if not precisely at the end of the many different processes that are involved.

This allows them a unique and privileged position to support the bereaved with an overview or summary of the different processes and indeed the CDOP Panel findings, and importantly the recommendations.

CDOPs should also seek to engage with the bereaved to ensure that their input and experience is captured within the review process as they will have useful insights to share which will be of significant benefit to the quality of the review conducted on services and the circumstances of their children’s death.

**Post Mortems**

Practices across London varies but there are still many accounts of the bereaved receiving copies of Post Mortem reports with little or no support in interpreting them. Leaving aside
the potential for Post Mortems to arrive through the post unexpected and the potential for distress this might cause they are as technical documents not intended for consumption by a lay audience without support. Many CDOPs in London have over time offered to talk through the reports with the Bereaved.

The RCPATH guidance on Post Mortems is invaluable in supporting this: https://www.rcpath.org/discover-pathology/what-is-pathology/information-about-post-mortems-for-friends-and-relatives-.html

Quality Improvement and Standards:
To assist CDOPs consider the services they are able to deliver and gain broader understanding of the Standard or measures connected to Bereavement care the following section is provided to enhance understanding of the quality systems and methodologies underpinning two key Quality Improvement interventions connected to the bereavement agenda, the Maternity Bereavement Experience Measure and the Bereavement Care Standards. We hope that awareness of these will assist CDOPs in their assurance role and given them confidence in the services they refer the bereaved to, and broaden their understanding of the experience of care measures in the Maternity pathway

The Maternity Bereavement Experience Measure:

Many parents 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.

On the 22nd June 2017 NHS England London Clinical Networks launched the Bereavement experience measure gathering feedback from families when a baby dies.

During the autumn of 2016 Sands (the stillbirth and neonatal death charity) undertook a survey to identify if and how parents wanted to share their experiences after the loss of a baby. Responses were obtained from 437 parents, an overwhelming majority felt that it is appropriate for bereaved parents to feed into bereavement care service improvements and gave their views about the most appropriate way of doing so (Appendix 1). This feedback directly informed the development of this Maternity Bereavement Experience Measure (MBEM) questionnaire and supporting resource, which was created collaboratively by Sands, NHS England and the London Maternity Clinical Network.


The development of a generic Children and Young People Bereavement Experience Measure is now under development and will follow shortly.

Bereavement Care Standards

In 2007, the Bereavement Care Pathways Project: a partnership initiative between Cruse and the Bereavement Services Association was established examining the ‘gap’ experienced by bereaved people between bereavement services in the statutory and voluntary sectors. Grief is a natural process and this project highlighted that support can be
effectively provided in different settings and in a range of ways, to meet diverse needs over time.

It is useful for CDOPs to be aware of the standards and importantly local commissioners assure themselves that the local bereavement offer adheres to the Bereavement Care Standards. The following fundamental principles should be integral to any bereavement service that meets the minimum standard:

- **Confidentiality**: services should respect the confidentiality and privacy of each bereaved person and any information shared by them, with due regard to safeguarding, consent and data protection.
- **Respect**: services should respect the individuality of each bereaved person’s grief and needs, with each person treated with compassion and sensitivity.
- **Equality and Diversity**: services should be non-discriminatory and delivered without prejudice, recognising and responding to personal beliefs and individual situations including (but not exclusive to) age, culture, disability, gender, sexuality, race, religion and spirituality (Equality Act 2010)
- **Quality**: services should ensure that all those delivering support to bereaved people, whether in a paid or voluntary capacity, have the skills, knowledge, training, supervision and support relevant to their role, and that services work to improve what they offer.
- **Safety**: services should have robust processes for recruitment, including appropriate levels of clearance with the Disclosure and Barring Service and on-going staff/volunteer development. There needs to be due regard to safe and ethical practice in order to protect bereaved people and those who work with them. The necessary processes for safeguarding must be in place and accountability evidenced through an audit trail.


**Together for Short Lives Care Pathways**

Together for Short Lives promotes a care pathway approach to children’s palliative care, and has produced three care pathways which relate to different age groups, and a further one specifically focused on making choices surrounding the withdrawal of life-sustaining treatment. Giving families real choice is key to the care pathway approach: a choice of place of care, a choice of place of death, a choice of emotional and bereavement support, and putting the child and family at the center of decision making to produce a care plan that is right for them.

**Together for Short Lives publishes four care pathways:**

- A Neonatal Care Pathway for Babies with Palliative Care Needs (for babies)
- A Core Care Pathway for Children with Life-threatening and Life-limiting Conditions
- Stepping Up (a framework for transition to adult services)
- A Care Pathway to Support Extubation within a Children’s Palliative Care Framework

This standards document sets out the key standards that form the back bone of these four care pathways, for easy reference. It also includes self-assessment audit tools relating to these standards, so you and your colleagues can map how your service currently performs and think about how to develop the areas where the standards may not be fully met. See: [http://www.togetherforshortlives.org.uk/professionals/resources/3687_standards_framework_for_children_s_palliative_care_2015_free](http://www.togetherforshortlives.org.uk/professionals/resources/3687_standards_framework_for_children_s_palliative_care_2015_free)
Appendix A CDOP Initial contact letter

Dear [PARENT'S NAME]

The [INSERT LOCAL NAME] Child Death Overview Panel (CDOP) has been informed of the very sad death of your child, [CHILD’S NAME]. We would like to express our sincere condolences to you and your family at this most difficult time.

The death of a child is always particularly sad. If we examine the circumstances of every death of a child or young person we can better understand why these tragedies happen, and improve local services if they are shown to have problems. We hope that by doing this we will be helping the individual child’s family understand why they died, but also that we can help other children and families in the future.

We are writing to you as the CDOP for the [INSERT AREA HERE] to explain that in line with UK law, which requires the review of all deaths of every child that my CDOP will be conducting this review.

The review is done by a panel called the Child Death Overview Panel and includes doctors, other health specialists and child care professionals. Over the next weeks and months, the panel will be asking health professionals for information about [INSERT CHILD’S NAME] from their medical records. This information will be used to help us understand why [INSERT CHILD’S NAME] died, and improve our services for all children and their families.

I am the chair of the [INSERT LOCAL CDOP NAME]. Please contact me should you wish to discuss the process in more detail, or if you have any objection to our collecting information to inform the review.

Alongside this we are aiming to help support you and your family and provide you with information that may assist you get the bereavement support you might need and updates and information on the review as it is conducted.

Please find enclosed and overleaf details of local bereavement services that may be of help to you.

Please also see NHS Choices bereavement resources: http://www.nhs.uk/Livewell/bereavement/Pages/coping-with-bereavement.aspx
We will be gathering information about your child from the health and local services that may have been involved with your family prior to (CHILD’S NAME)’s death to gain an overview of what has happened and will seek to provide you with a summary of the review.

Sometimes the medical information that is gathered by CDOP reviews is hard to understand. At this time of immense sadness we are aiming to help you as best we can by explaining clearly the processes involved issues we are looking at and what we discover. In reviewing the circumstances of the death of your child we have to remain detached and analytical. This can make the words we use seem cold and impersonal. We apologise for this and wish to stress that in spite of this necessary detachment we never lose sight of the suffering you have been exposed to. Our purpose is to seek to find answers and learn lessons to share with you, the services who work with children and hopefully where we can prevent the deaths of further children.

We will aim to help you gain an understanding into what has occurred. Please feel free to contact us now or at any point in the future, if you would find this helpful.

Please see the enclosed leaflets which explain the review process and please visit https://www.gov.uk/government/publications/child-death-overview-panels-contacts which explains more about the work of CDOPs and our commitments to you.

Please see and also the Duty of Candour: [http://www.cqc.org.uk/sites/default/files/Duty-of-Candour-2016-CQC-joint-branded.pdf] which explains the statutory (legal) duty to be open and honest with patients (or ‘service users’), or wrong that appears to have caused or could lead to significant harm in the future. It applies to all health and social care organisations registered with the regulator, the Care Quality Commission (CQC) in England.

All the information we gather will be treated with the deepest respect and in strictest confidence. None of our findings, recommendations or reports will name or identify your child or family.

The CDOP team would like to hear from you if you have any information or views that you would like us to bear in mind for the review or if I can help with any questions you may have.

Please feel free to call INSERT NUMBER HERE or email XXXXXXXXXX. If I am unable to answer the phone when you call please leave a message and I will respond as soon as possible.

I apologise for sending you this letter at this time, but hope our work will be able to support you and your family at this distressing and difficult time.

Yours sincerely,

Insert sig

CHAIR - Insert local area CHILD DEATH OVERVIEW PANEL
Cc GP LOCAL BEREAVEMENT SERVICES???

Enclosures: CDOP Leaflet – Local or national variant or both and CQC duty of candour

CDOP links
Bereavement,Duty of candour
specific to the age range/mode??? 1e neonatal – SANDS
Cruse/Compassionate friends
SUICIDE - TASC/CALM ETC
SIBLINGS?? – WOULD A CDOP KNOW???
# CDOP Review Summary

**INSTRUCTIONS:** Complete the following table with details of the CDOP Review

<table>
<thead>
<tr>
<th>Child or Young Person’s Name in full</th>
<th>Type here</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Birth (Age of the Child or Young person)</td>
<td>Type here</td>
</tr>
<tr>
<td>Any Siblings</td>
<td>Yes/No</td>
</tr>
<tr>
<td>Address of the Bereaved</td>
<td>&lt;Insert the country, region, district, etc. for the bereaved&gt;</td>
</tr>
<tr>
<td>Place of Death</td>
<td>Type here</td>
</tr>
<tr>
<td>CDOP Reference</td>
<td>Case number</td>
</tr>
<tr>
<td>Reporting period</td>
<td>&lt;Insert the time period covered by the report, e.g. January – June 201&gt;</td>
</tr>
<tr>
<td>Summary compiled by</td>
<td>&lt;Insert the name of the person who prepared this report&gt;</td>
</tr>
<tr>
<td>Date submitted</td>
<td>&lt;Insert date&gt;</td>
</tr>
</tbody>
</table>

**Summary**

**INSTRUCTIONS:** Insert a one paragraph summary of progress during the reporting period that could be shared with the bereaved and involved professional stakeholders.

<Insert text here>

**Activities & Outputs**

**INSTRUCTIONS:** Complete the following table for each activity in the project (see example below). Describe your progress with the activity and the outputs generated. Choose a status for each activity (achieved, in progress, challenges or not started).

**EXAMPLE:** Review of the death of a child following on from a Major Incident

<table>
<thead>
<tr>
<th>Status RAG rated</th>
<th>In progress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective</td>
<td>To determine what sessions can be learnt from the review</td>
</tr>
<tr>
<td>Activity dates</td>
<td>Key dates of the review – ie Rapid Response, CDOP panel meeting, coronial or other key dates</td>
</tr>
<tr>
<td>Please add significant dates and actions to this summary of the case.</td>
<td>Include all details of contact with the bereaved – dates and times and formats</td>
</tr>
<tr>
<td></td>
<td>ie Initial letter</td>
</tr>
</tbody>
</table>
Follow up phone call
Email exchange via SPOC
Face to face meeting to discuss Post Mortem results
Reissuing of bereavement support materials

Review Deliberations and Recommendations summary
INSTRUCTIONS: Complete the following table with the latest results for your key indicators. Focus on description of the areas of care or service delivery considered and any recommendations following on from this if possible, rather than activities and outputs which are already described in the previous section.

| Type here |

Partners & Stakeholders
INSTRUCTIONS: Complete the following table describing your collaboration with each of the relevant partners / stakeholders involved in the review.

The following table summarises our relationship with key partners and stakeholders during the reporting period:

<table>
<thead>
<tr>
<th>Partner / Stakeholder</th>
<th>Relationship update</th>
<th>Lessons Identified and Recommendations framed</th>
<th>Shared with Give name and role of person this has been shared with.</th>
<th>How shared? Email/Newsletter Report/Recommendations letter?</th>
</tr>
</thead>
<tbody>
<tr>
<td>EXAMPLE GP Surgery</td>
<td>Delays to receipt of form Bs</td>
<td>Alignment of medication records between GP, School and Secondary Care records ( see</td>
<td>Dr GP Smith Big Practice High street, London Borough of</td>
<td>Email and phone</td>
</tr>
</tbody>
</table>

GP Surgery | Delays to receipt of form Bs | Alignment of medication records between GP, School and Secondary Care records ( see | Dr GP Smith Big Practice High street, London Borough of | Email and phone |
Challenges & Lessons Learned

INSTRUCTIONS: Complete the table below with challenges that were encountered during the reporting period and the lesson learned. Include any solution that you plan to implement in the next reporting period.

The following table summarises the challenges we have faced during the reporting period and the lessons learned / solutions for each challenge.

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Lessons learned / solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Each Summary should have where possible a lesson identified and an action of what we are going to do about this.</td>
</tr>
</tbody>
</table>

**EXAMPLE**

**Lesson Learned**

It is essential that emergency medication plans are rehearsed and more broadly accessible by school staff. In situ awareness of which pupils have them is essential to ensure their timely use in emergencies.

**Solution**

Pan School awareness raising campaigns – targeted training of staff, pupil life support training

<Insert>  
<Insert>  
<Insert>  
<Insert>
<table>
<thead>
<tr>
<th>Bereavement Experience Discussed with Bereaved?</th>
<th>Who did this and what was the result of the discussion – please capture any feedback from Parents carers and families on this area.</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;Insert&gt;</td>
<td>&lt;Insert&gt;</td>
</tr>
<tr>
<td>&lt;Insert&gt;</td>
<td>&lt;Insert&gt;</td>
</tr>
</tbody>
</table>
**Appendix C CDOP Review Summary for the Bereaved**

**CDOP Review Summary**

**INSTRUCTIONS:** Complete the following table with details of the CDOP Review and arrange of a discussion by phone or face to face of the CDOP Panel review.

<table>
<thead>
<tr>
<th>Child or Young Person’s Name in full</th>
<th>Type here</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Birth (Age of the Child or Young person)</td>
<td>Type here</td>
</tr>
<tr>
<td>Any Siblings</td>
<td>Yes/No</td>
</tr>
<tr>
<td>Address of the Bereaved</td>
<td>Type here</td>
</tr>
<tr>
<td>Place of Death</td>
<td>Type here</td>
</tr>
<tr>
<td>CDOP Reference</td>
<td>Case number</td>
</tr>
<tr>
<td>Reporting period</td>
<td>Type here</td>
</tr>
<tr>
<td>Summary compiled by</td>
<td>Type here</td>
</tr>
<tr>
<td>Date submitted</td>
<td>Type here</td>
</tr>
</tbody>
</table>

**Activity dates**
Please add significant dates and actions to this summary of the case.

<table>
<thead>
<tr>
<th>Activity dates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key dates of the review – i.e. Rapid Response, CDOP panel meeting, coronial or other key dates</td>
</tr>
<tr>
<td>Include all details of contact with the bereaved – dates and times and formats</td>
</tr>
<tr>
<td>Initial letter</td>
</tr>
<tr>
<td>Follow up phone call</td>
</tr>
<tr>
<td>Email exchange via SPOC</td>
</tr>
<tr>
<td>Face to face meeting to discuss Post Mortem results</td>
</tr>
<tr>
<td>Reissuing of bereavement support materials</td>
</tr>
</tbody>
</table>

**Review Deliberations and Recommendations summary**

**INSTRUCTIONS:** Complete the following table with the latest results for your key indicators. Focus on description of the areas of care or service delivery considered and any recommendations following on from this if possible, rather than activities and outputs which are already described in the previous section.
<table>
<thead>
<tr>
<th>Bereavement Experience Discussed with Bereaved?</th>
<th>Who did this and what was the result of the discussion – please capture any feedback from Parents carers and families on this area.</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;Insert&gt;</td>
<td>&lt;Insert&gt;</td>
</tr>
</tbody>
</table>


Appendix D Bereavement Resources for Professionals

This section aims to provide London CDOPs with core resources for their work with the bereaved alongside key guidance and resources for generic CDOP operations.

Core resources and frameworks

Working Together 2015 - DfE: [http://www.workingtogetheronline.co.uk/](http://www.workingtogetheronline.co.uk/) see section 5

London Child Protection Procedures
[http://www.londoncp.co.uk/chapters/unexpected_death.html](http://www.londoncp.co.uk/chapters/unexpected_death.html)

November 2016 SUDI guidelines


Coroners Courts & Processes

Coroners information guide

The coronial process

The Coroners Court Support Service

HEE learning resource on giving evidence in a coroners court
Duty of Candour

Duty of Candour aims to help patients receive accurate, truthful information from health providers.

**Professional resources** including full guidance regulations and related guidance:


**Service User version:**


Never Events

Never events are serious incidents that are entirely preventable as guidance, or safety recommendations providing strong systemic protective barriers, are available at a national level, and should have been implemented by all healthcare providers.

Each never event type has the potential to cause serious patient harm or death. However, serious harm or death is not required to have happened as a result of a specific incident occurrence for that incident to be categorised as a never event.

For more information on the framework see:


Always Events:

Staffs in all clinical settings seek to understand and provide compassionate care to meet the comprehensive needs, values, and preferences of the people they serve. Yet, in the busy world of clinical care, all too often what really matters to patients, service users, and their carers is not understood or adequately addressed.

NHS England, in collaboration with Picker Institute Europe and the Institute for Healthcare Improvement (IHI), is leading an initiative for developing, implementing, and spreading an approach to reliably integrate Always Events® into routine care processes.

Working together, the three organisations developed a programme to pilot and test the Always Events® framework and create a toolkit to support implementation of Always Events® within the NHS in England.

Always Events®, initially conceived in the US by the Picker Institute and now led by the Institute for Healthcare Improvement (IHI), are defined as those aspects of the care experience that should always occur when patients, their family members or other care partners, and service users interact with health care professionals and the health care
IHI’s Always Events® Framework (see Figure 1) provides a strategy to help healthcare providers, in partnership with patients, care partners, and service users, to identify, develop, and achieve reliability in person- and family-centered care delivery processes.

IHI Always Events® Framework holds promise as an approach to accelerate improvement efforts to enhance experiences of care for patients, their family members or other care partners, and service users. Genuine partnerships between patients, service users, care partners, and clinicians are the foundation for co-designing and implementing reliable care processes that hold promise for transforming care experiences. The goal of these processes is an “Always Experience.” The creation of an Always Events® is a practical methodology for achieving this goal.

https://www.england.nhs.uk/ourwork/pe/always-events/

**Serious Incidents Framework**

In broad terms, serious incidents are events in health care where the potential for learning is so great, or the consequences to patients, families and carers, staff or organisations are so significant, that they warrant using additional resources to mount a comprehensive response. Serious incidents can extend beyond incidents which affect patients directly and include incidents which may indirectly impact patient safety or an organisation’s ability to deliver on-going healthcare.


**Bereaved Voices:**
Feedback on the Quality of End of Life Care: Consultation Summary


**Bereaved Voices insight resources**

https://www.england.nhs.uk/ourwork/insight/bereaved-voices/

**Palliative and End of Life Care**

CDOPs will inevitably deal with children and young people who have received either palliative or end of life care. Sometimes this can be in the early stages of life and at other times this can be an older child impacted upon by a Life Limiting Condition.

**NICE Guidance** The main resources, including interactive flow chart for palliative and End of Life care for Children and young people can be accessed here:

https://www.nice.org.uk/guidance/ng61

A specific and useful section is included covering the emotional and psychological needs of parents families carers and the dying child which serves as a reminder of the scope of works that might be required to provide good bereavement support.
Emotional and psychological support and interventions

1.2.22 Be aware that children and young people with life-limiting conditions and their parents or carers may have:

- emotional and psychological distress and crises
- relationship difficulties
- mental health problems.

1.2.23 Be aware that children and young people and their parents or carers may need support, and sometimes expert psychological intervention, to help with distress, coping, and building resilience.

1.2.24 Be aware that children and young people may experience rapid changes in their condition and so might need emergency interventions and urgent access to psychological services.

1.2.25 Be aware of the specific emotional and psychological difficulties that may affect children and young people who have learning difficulties or problems with communication.

1.2.26 Provide information to children and young people and their parents or carers about the emotional and psychological support available and how to access it.

1.2.27 Regularly discuss emotional and psychological wellbeing with children and young people and their parents or carers, particularly at times of change such as:

- when the life-limiting condition is diagnosed
- if their clinical condition deteriorates
- if their personal circumstances change
- if there are changes to their nursery care, school or college arrangements, or their employment
- if there are changes to their clinical care, for example if their care changes focus from treating the condition to end of life care.

See https://www.nice.org.uk/guidance/NG61/chapter/Recommendations#emotional-and-psychological-support-and-interventions

Perinatal Palliative Care

In 2017 Together for Short Lives released the new perinatal pathway for babies with palliative care needs which compliments existing materials for supporting parents and carers and is an essential resource to understand the needs of families facing early palliative care.
Cultural competency guide for Palliative care

Post Mortems

RCPATH: Information about post mortems for the bereaved

Human Tissue Authority:

https://www.hta.gov.uk/sites/default/files/Post-mortem_examination__your_choices_about_organs_and_tissue_FINAL_v3_0.pdf

Advice on Postmortems for the bereaved on obtaining post mortem results
https://bereavementadvice.org/topics/death-certificate-and-coroners-inquest/obtaining-post-mortem-results

Child Mortality Indicators and data sets:
https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/childhoodinfantandperinatalmortalityinenglandandwales/previousReleases

RCPCH State of Child Health Report 2017

Public Health England Resources:
Post Incident Pathways

Following on from the recent atrocities in Manchester and at London Bridge HLP has generated a resource to provide support pathways for staff across the NHS system. These have drawn heavily on the work undertaken in Manchester following the incident in May, and on London’s experts across the NHS, public health and from leading voluntary sector organisations.

The pathways aim to help services and communities respond to the needs of those people who are experiencing distress following these attacks and further major incident or atrocities. It describes the range of difficulties that may be experienced by people who are affected and the responses from services and the wider community that are most likely to be helpful. The resource can be found via the link below. https://www.healthylondon.org/mental-health/pathways


Child Death Helpline

Support advice and resources for bereaved parents or professionals:
http://childdeathhelpline.org.uk/

Traumatic Bereavement

Whilst all deaths of children are tragedies there are certain types of death that whilst thankfully rare are a significantly more traumatic due to their often sudden and violent nature. To support CDOPs support the bereaved through this a short list of of links to national resources that cover the

Victim Support

Support after Murder and Manslaughter

Independent Advisory Panel on Death in Custody

Inquest: advice to bereaved people on contentious deaths

AfterTrauma: dedicated to helping survivors of traumatic injury and their carers
Resources for Supporting bereaved parents and carers

There are many different resources available to support those who need to understand how best to interact with and support bereaved families carers and siblings. A small selection of these is detailed below.


The Compassionate Friends [https://www.tcf.org.uk/](https://www.tcf.org.uk/) are a third sector organisation specialising in the support and care of the bereaved. They have a very useful selection of leaflets for professionals that can be accessed here: [https://www.tcf.org.uk/content/resources/?cat=5](https://www.tcf.org.uk/content/resources/?cat=5)

Additionally the TCF website has a section entitled Your Loss which details an array of different materials approaches and fact sheets detailing many of the key areas of bereaved experiences including:

- Grieving parents
- Newly bereaved
- Grieving for an adult child
- Grieving for a baby
- Grieving for a disabled child
- Childless parents
- Bereaved by murder or manslaughter
- Bereaved by suicide
- Bereaved by addiction
- Grandparents
- Siblings
- Single parents
- Step-parents
- Our surviving children
- Our child’s friends
- Prolonged and Intense Grief

Faith or Non Faith Sensitive materials to support those impacted upon by the death of Children and Young People

In a diverse and multicultural environment it is essential that we understand the communities we serve and many times over the course of the HLP CDOP programme we have been informed of faith based resources that have been of use to London’s CDOP community. Below is a brief list of resources that are available to support parents carers and families of any or no faith. They are included here as a possible resource to be shared with the bereaved, but also as a prompt to CDOP personnel to develop who may wish to develop a more nuanced understanding of different faiths attitudes, principles and practices with regards to the death of a child.
It is also important to recognise the significant proportion of the country that does not identify as having a faith and that their needs must be represented just as fully and as with this in mind Agnostic/atheist resources are included here.

See also the guidance for working with faith communities in major emergencies:


<table>
<thead>
<tr>
<th>Faith Group</th>
<th>Organisation</th>
<th>Details of resource</th>
<th>Links</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>CBUK</td>
<td></td>
<td><a href="http://support.childbereavement.org.uk/for_professionals/supporting_families/cultures_and_beliefs">http://support.childbereavement.org.uk/for_professionals/supporting_families/cultures_and_beliefs</a></td>
</tr>
<tr>
<td>Christian Catholic</td>
<td>Rainbows</td>
<td>Website and support resources for catholic – and other children who have been bereaved</td>
<td><a href="http://www.cathchild.org.uk/our-services/rainbows-bereavement-support-gb/">http://www.cathchild.org.uk/our-services/rainbows-bereavement-support-gb/</a></td>
</tr>
<tr>
<td>Islam</td>
<td>Muslim Bereavement support Service</td>
<td>Website with resources and helpline</td>
<td><a href="http://mbss.org.uk/">http://mbss.org.uk/</a></td>
</tr>
<tr>
<td>Islam</td>
<td>Children of Jannah</td>
<td>Website, resources and helpline</td>
<td><a href="https://childrenofjannah.com/about/">https://childrenofjannah.com/about/</a></td>
</tr>
<tr>
<td>Islam</td>
<td>Gardens of Peace</td>
<td>Gardens of Peace is a registered charity operating a cemetery</td>
<td><a href="http://www.gardens-of-peace.org.uk">www.gardens-of-peace.org.uk</a></td>
</tr>
<tr>
<td>Religion</td>
<td>Source/Website</td>
<td>Information</td>
<td>Website/Link</td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Muslims</td>
<td>Muslims in the Greater London area. Their website also offers information and advice about death and burial arrangements according to an Islamic perspective.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Judaism</td>
<td>Jewish Bereavement Counselling Service</td>
<td>Helpline: 0208 951 3881</td>
<td>Email: <a href="mailto:enquiries@jbcs.org.uk">enquiries@jbcs.org.uk</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>The Jewish Bereavement Counselling Service is a national organisation that offers information, advice and specialist bereavement counselling for the Jewish community.</td>
<td></td>
</tr>
<tr>
<td>Non Religious/Agnotion</td>
<td></td>
<td></td>
<td>tbc</td>
</tr>
</tbody>
</table>
For more information on major religious groups see https://en.wikipedia.org/wiki/Major_religious_groups

**LGBT Bereavement Support materials**
http://londonfriend.org.uk/get-support/counselling/

**Bereavement for People with Learning Disabilities**
Increasingly there is recognition in the system that the needs of people with Learning Disability with regards to bereavement have been to date neglected. Most resources focus understandably on the loss of a carer or parent or the end of life needs of the person with Learning disabilities themselves. There are few resources that can be useful in providing parents, or siblings with learning disabilities

Below are three resources that may prove useful to CDOPS in supporting the needs of those with Learning Disabilities that they work with.

**BILD**: http://www.bild.org.uk/resources/ageingwell/endolifecare/

**Dying Matters** http://www.dyingmatters.org/page/people-learning-disabilities

**Health Education England**  https://hee.nhs.uk/sites/default/files/documents/24%20when%20someone%20you%20know%20has%20died%20professionals.pdf

**Bereavement issues in Autism**
www.autism.org.uk/.../9B4951676EAA47579490FF4BE92C85AD.ashx

**Specialist theme or Age, cause specific bereavement resources:**

<table>
<thead>
<tr>
<th>Specialist Theme</th>
<th>Organisation</th>
<th>Details</th>
<th>Links</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finding local support</td>
<td>CRUSE</td>
<td>Searchable database of Bereavement support</td>
<td><a href="https://www.cruse.org.uk/in-your-area">https://www.cruse.org.uk/in-your-area</a></td>
</tr>
<tr>
<td>Finding local support</td>
<td>NHS Choices</td>
<td>Searchable database of Bereavement support</td>
<td><a href="http://www.nhs.uk/Livewell/bereavement/Pages/coping-with-bereavement.aspx">http://www.nhs.uk/Livewell/bereavement/Pages/coping-with-bereavement.aspx</a></td>
</tr>
<tr>
<td><strong>Telephone Support</strong></td>
<td><strong>Child Death Helpline</strong></td>
<td><strong>Resources and support helpline for the bereaved and professionals</strong></td>
<td><strong><a href="http://childdeathhelpline.org.uk">http://childdeathhelpline.org.uk</a></strong></td>
</tr>
<tr>
<td>------------------------</td>
<td>-------------------------</td>
<td>-------------------------------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td><strong>Bereavement support for the Family</strong></td>
<td><strong>Care for The Family</strong></td>
<td><strong>Bereavement support website for parents</strong></td>
<td><strong><a href="https://www.careforthefamily.org.uk/family-life/bereavement-support/bereaved-parent-support">https://www.careforthefamily.org.uk/family-life/bereavement-support/bereaved-parent-support</a></strong></td>
</tr>
<tr>
<td><strong>Bereavement support for the Family</strong></td>
<td><strong>Care for the family</strong></td>
<td><strong>How to help the bereaved – Tips Sheet on how to speak to bereaved parents</strong></td>
<td><strong><a href="https://www.careforthefamily.org.uk/wp-content/uploads/2013/10/How-You-Can-Help-Bereaved-Parents-NEW-2013.pdf">https://www.careforthefamily.org.uk/wp-content/uploads/2013/10/How-You-Can-Help-Bereaved-Parents-NEW-2013.pdf</a></strong></td>
</tr>
<tr>
<td><strong>Bereavement support for the Family</strong></td>
<td><strong>Dying Matters</strong></td>
<td><strong>Web resources for raising awareness of death dying and bereavement issues</strong></td>
<td><strong><a href="http://www.dyingmatters.org/">http://www.dyingmatters.org/</a></strong></td>
</tr>
<tr>
<td><strong>Bereavement support for the Family</strong></td>
<td><strong>A Child Of Mine</strong></td>
<td><strong>Bereavement support services and resources</strong></td>
<td><strong><a href="http://www.achildofmine.org.uk/">http://www.achildofmine.org.uk/</a></strong></td>
</tr>
<tr>
<td><strong>Bereavement support for the Family</strong></td>
<td><strong>The Compassionate Friends (TCF):</strong></td>
<td><strong>A UK-wide organisation where local volunteers provide support to parents who have lost a child, and siblings</strong></td>
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<tr>
<td><strong>Support for Bereaved Children:</strong></td>
<td><strong>Grief Encounter</strong></td>
<td><strong>Bereavement support website for children</strong></td>
<td><strong><a href="https://www.griefencounter.org.uk/">https://www.griefencounter.org.uk/</a></strong></td>
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<tr>
<td><strong>Early Deaths/Still Birth/ Neonatal/Perinatal</strong></td>
<td><strong>Petals</strong></td>
<td><strong>Bereavement Support for those bereaved in pregnancy</strong></td>
<td><strong><a href="http://petalscharity.org/">http://petalscharity.org/</a></strong></td>
</tr>
<tr>
<td><strong>Early Deaths/Still Birth/ Neonatal/Perinatal</strong></td>
<td><strong>Tommys</strong></td>
<td><strong>Bereavement support resource for parents affected by stillbirths</strong></td>
<td><strong><a href="https://www.tommys.org/pregnancy-information/pregnancy-complications/stillbirth">https://www.tommys.org/pregnancy-information/pregnancy-complications/stillbirth</a></strong></td>
</tr>
<tr>
<td><strong>Early Deaths/Still Birth/</strong></td>
<td><strong>SANDS</strong></td>
<td><strong>Web resources, support line and material for both the</strong></td>
<td><strong><a href="https://www.sands.org.uk/support">https://www.sands.org.uk/support</a></strong></td>
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<tr>
<td>Neonatal/Perinatal Bereavement Resource Guide Consultation Draft 1.7</td>
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<td><strong>Early Deaths/Still Birth/Neonatal/Perinatal</strong></td>
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<tr>
<td><strong>The Lullaby Trust</strong></td>
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<tr>
<td>Web resources to support bereaved parents and professionals including the bereavement care network and CONI</td>
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<tr>
<td><a href="https://www.lullabytrust.org.uk/bereavement-support/">https://www.lullabytrust.org.uk/bereavement-support/</a></td>
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<tr>
<td>see also for professionals</td>
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<td>and for bereaved young parents &amp; safer sleeping advice</td>
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<td><a href="https://littlelullaby.org.uk/">https://littlelullaby.org.uk/</a></td>
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<tr>
<td><strong>Bereavement Care Network</strong></td>
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<td>Led by Sands and The Royal College of Midwives (RCM), along with Antenatal Results and Choices (ARC) and Child Bereavement UK, the updated and improved Bereavement Care Network now includes six further partner charities: Bliss, the Miscarriage Association, Multiple Birth Foundation, Tamba, (Twins and Multiple Births Association), Lullaby Trust and the National Maternity Support Foundation.</td>
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<td><strong>Miscarriage Association</strong></td>
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<td>Support for parents who have experienced or anxious about</td>
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<td><a href="https://www.miscarriageassociation.org.uk/">https://www.miscarriageassociation.org.uk/</a></td>
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<tr>
<td>Bereavement Resource Guide</td>
<td>Miscarriage</td>
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<tr>
<td><strong>Early Deaths/Still Birth/Neonatal/Perinatal</strong></td>
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<td>SUDC Foundation – the SUDC UK version of this organisation is currently under review by the Charity Commission awaiting approval as a UK arm of the SUDC Foundation</td>
<td>The Sudden Unexplained Death In Childhood (SUDC) Foundation funds crucial research, raises awareness and provides information and support for families and professionals affected by the tragedy of SUDC.</td>
<td><a href="http://www.sudc.org">www.sudc.org</a> UK website is pending</td>
<td></td>
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</table>
| **Early Palliative** | **BLISS** | Palliative and other support for parents of premature or sick babies | http://www.bliss.org.uk/palliative-care  
http://www.bliss.org.uk/Pages/Category/coping-with-loss |
| **Early Palliative** | Antenatal Results and Choices (ARC) | Support for parents who have to end a pregnancy | http://www.arc-uk.org/for-parents/ending-a-pregnancy/parents-story |
| **Palliative Care for Children and Young People** | **Together for Short Lives** | Support and advice for children with life limiting conditions | http://www.togetherforshortlives.org.uk/  
http://www.togetherforshortlives.org.uk/professionals/care_provision/care_pathways |
| Early Memorialisation | 2 Wish Upon a star | Wales based charity that is seeking to broaden operations in England and campaigns for bereavement suites  
* Bereavement boxes are available for parents at each of these hospitals  
* Immediate bereavement support is available for parents and siblings  
* To provide a professional counseling service for bereaved parents | [http://www.2wishuponastar.org](http://www.2wishuponastar.org) |
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<tr>
<td>Teenagers</td>
<td>Teenage Cancer Trust</td>
<td>Bereavement support for those impacted upon by Teenage cancers</td>
<td><a href="https://www.teenagecancertrust.org/get-help/support-friends-and-family">https://www.teenagecancertrust.org/get-help/support-friends-and-family</a></td>
</tr>
<tr>
<td>Teenagers</td>
<td>Cruse</td>
<td>Web resources focussing on supporting teenagers affected by death</td>
<td><a href="https://www.cruse.org.uk/Children/teenagers-understanding-death">https://www.cruse.org.uk/Children/teenagers-understanding-death</a></td>
</tr>
<tr>
<td>Teenagers</td>
<td>Young Minds</td>
<td>Mental Health support website including bereavement support</td>
<td><a href="https://youngminds.org.uk/find-help/feelings-and-symptoms/death-and-loss/?gclid=CIGLwtT8ydQCFAa87QodzGlBJg">https://youngminds.org.uk/find-help/feelings-and-symptoms/death-and-loss/?gclid=CIGLwtT8ydQCFAa87QodzGlBJg</a></td>
</tr>
<tr>
<td>Support for bereaved children</td>
<td>The Compassionate</td>
<td>A UK-wide organisation where local volunteers</td>
<td><a href="https://www.tcf.org.uk/content/ftb-bereaved-by-suicide/">https://www.tcf.org.uk/content/ftb-bereaved-by-suicide/</a></td>
</tr>
<tr>
<td>Support for bereaved children</td>
<td>Winston’s Wish</td>
<td>A national charity providing support for bereaved children, including those bereaved through suicide.</td>
<td><a href="http://www.winstonswish.org.uk">www.winstonswish.org.uk</a></td>
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<tr>
<td>Deaths by Suicide (Prevention &amp; Support)</td>
<td>PAPYRUS</td>
<td>Prevention of Young Suicide: A UK charity that aims to prevent young suicide.</td>
<td><a href="http://www.papyrus.uk.com">www.papyrus.uk.com</a></td>
</tr>
<tr>
<td>Deaths by Suicide (Prevention &amp; Support)</td>
<td>Samaritans</td>
<td>The Samaritans service supports anyone who needs to talk, including people at risk of suicide.</td>
<td><a href="http://www.samaritans.org">www.samaritans.org</a></td>
</tr>
<tr>
<td>Deaths by Suicide (Prevention &amp; Support)</td>
<td>Grassroots:</td>
<td>A charity that trains individuals and organisations to feel more confident supporting someone at risk of suicide</td>
<td><a href="http://www.prevent-suicide.org.uk">http://www.prevent-suicide.org.uk</a></td>
</tr>
<tr>
<td>Deaths by Suicide (Prevention &amp; Support)</td>
<td>Campaign Against Living Miserably (CALM)</td>
<td>A charity that aims to prevent male suicide in the UK.</td>
<td><a href="http://www.thecalmzone.net">www.thecalmzone.net</a></td>
</tr>
<tr>
<td>Deaths by Suicide</td>
<td>National Prevention of Suicide Alliance</td>
<td>National Coalition of Third sector and other partners focusing on the prevention, intervention and postvention support required by deaths with both professional and the public resources</td>
<td><a href="http://www.nspa.org.uk/">http://www.nspa.org.uk/</a></td>
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<tr>
<td>Deaths by Suicide</td>
<td>National Confidential Inquiry into Suicide and Homicide by People with Mental Illness</td>
<td>National centre for research into deaths by Suicide</td>
<td><a href="http://research.bmh.manchester.ac.uk/cmhs/research/centrefo">http://research.bmh.manchester.ac.uk/cmhs/research/centrefo</a> rsuicideprevention/nci</td>
</tr>
<tr>
<td>Deaths by Suicide</td>
<td>The Alliance of Suicide Prevention Charities TASC</td>
<td>(TASC) is an alliance of the leading charities dealing with suicide prevention and mental health issues. The TASC website is an educational and resource hub.</td>
<td><a href="http://tasc-uk.org/">http://tasc-uk.org/</a></td>
</tr>
<tr>
<td>Deaths by Suicide</td>
<td>Facing the Future:</td>
<td>Support groups for people bereaved by suicide run by Samaritans and Cruse Bereavement Care.</td>
<td><a href="http://www.facingthefuturegroups.org">www.facingthefuturegroups.org</a></td>
</tr>
<tr>
<td>Deaths by Suicide</td>
<td>If U Care Share Foundation</td>
<td>Provide timely practical and emotional support to people touched by a suicide and deliver training on suicide prevention, intervention and postvention.</td>
<td><a href="http://www.ifucasheare.co.uk">www.ifucasheare.co.uk</a></td>
</tr>
</tbody>
</table>
| Deaths by Suicide | Step by Step: | Support for schools affected by an attempted or suspected suicide, provided by Samaritans | http://www.samaritans.org/education/step-by-step
T: 0808 168 2528 E: stepbystep@samaritans.org |
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<tr>
<td>Deaths by Suicide</td>
<td>Suicide Bereavement Network</td>
<td>Membership organisation that provides face-to-face and online support for anyone who is coping with the suicide of someone close.</td>
<td><a href="https://sbnwk.org.uk/">https://sbnwk.org.uk/</a></td>
</tr>
<tr>
<td>Deaths by Suicide</td>
<td>Survivors of Bereavement by Suicide (SOBS)</td>
<td>Support for adults who have been bereaved by suicide</td>
<td><a href="http://www.uk-sobs.org.uk">www.uk-sobs.org.uk</a></td>
</tr>
<tr>
<td>Road Traffic Accidents</td>
<td>Brake</td>
<td>Support for victim and bereaved of road crashes</td>
<td><a href="http://www.brake.org.uk/victim-support/support-guides-for-road-crash-victims">http://www.brake.org.uk/victim-support/support-guides-for-road-crash-victims</a></td>
</tr>
<tr>
<td>Homicide, mass mortality &amp; terrorism</td>
<td>Metropolitan Police</td>
<td>Web resource outlining the support available via Family Liaison Officers</td>
<td><a href="http://212.62.21.14/Site/bereavementfamilyliaison">http://212.62.21.14/Site/bereavementfamilyliaison</a></td>
</tr>
<tr>
<td>Category</td>
<td>Organization</td>
<td>Description</td>
<td>Website</td>
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<tr>
<td>Bereavement Support Group</td>
<td>Surviving the Loss of your World SLOW</td>
<td>Support group for bereaved parents focussing on peer support</td>
<td><a href="http://slowgroup.co.uk/">http://slowgroup.co.uk/</a></td>
</tr>
<tr>
<td>Bereaved Voices</td>
<td>Warwickshire University</td>
<td>Warwick CDOP Training Courses including SUDC</td>
<td><a href="http://www2.warwick.ac.uk/fac/med/study/cpd/cpd/sudc">http://www2.warwick.ac.uk/fac/med/study/cpd/cpd/sudc</a></td>
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<td></td>
<td>Child Bereavement UK</td>
<td>Training and support provider supports families, and educates professionals when a baby or child of any age dies or is dying or when a child is facing bereavement.</td>
<td><a href="https://childbereavementuk.org/">https://childbereavementuk.org/</a></td>
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