Child Death
Overview Panel
Southwest Peninsula

Child Death Response & Review Service
Southwest Peninsula

Second Annual Public Report
April 2023 - March 2024

Foreword

Year 2023-2024

A Child Death Overview Panel's primary function is to review the deaths of all children ordinarily resident in our geographical area. A robust review process enables us to identify learning and make recommendations to reduce the risk of future deaths to our Partners and the wider audience on a national level through the National Child Mortality Database.

This second annual public report brings together the themes and trends identified through the Child Death Review Process to our regional South West Peninsula Child Death Overview Panel (CDOPs) over the past year.

In identifying patterns across groups of child deaths we have the opportunity to work towards highlighting to our partners preventative action to reduce avoidable child deaths in the Peninsula. Even where deaths of children are sadly unavoidable, themes and trends from those reviews afford us the opportunity to highlight required improvement in service provision across our region.

CDOP recognise that the engagement of professionals, parents and carers into this unique process in England is paramount to ensuring the CDOP fulfil its functions.
A good Child Death Review should ensure families voices are heard to enable the final review to be as robust as possible.

This past year of reviews have highlighted several themes that we will focus on within this report. These include:

- The lack of consistency in bereavement care across the region is a theme within many of the reviews, a subject that our Joint Agency Response Nursing team are particularly passionate about.
- Palliative care provision in our region and the importance of bringing together voices of families and professionals in relation to choices relating to end of life care.
- The themes and trends identified in relation to safe sleeping and the impact poor housing has on families particularly those in temporary accommodation.
- Our desire is that this report influences thinking and practice in a way that enables us to act to protect children from avoidable deaths and improve service provision across our region for our families.

> "The death of a child is profoundly traumatic for any family. As a service we seek to walk alongside those affected, offering support and guidance throughout the review process. We can never make things 'right' but we can ensure questions are asked, questions are answered and lessons are learnt. This way we can help prevent future child deaths and ensure the gift given to us, that of hearing the voice of the child and bereaved family, is central to all that we do"
>
> **Mo Cleland, Service Manager CDOP**

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Introduction

The Child Death Review Process applies to all infants, children and young people under the age of 18 years. The purpose of the process is to try to ascertain why children die and put in place interventions to protect other children and prevent future deaths wherever possible.

In 2018 the Government Department responsible for the Child Death Review process moved from the Department of Education to the Department of Health and Social Care; and the statutory responsibility to deliver the process moved from Safeguarding Children Partnership Boards to 'The Partners'. The Partners are Local Authorities and Integrated Care Boards.

Statutory Guidance was published in 2018 ensuring the process is robust and standardised throughout England: Child death review: statutory and operational guidance (England) - GOV.UK (www.gov.uk)

Underpinned by Working Together Chapter 6:

Working together to safeguard children - GOV.UK (www.gov.uk)

The Child Death Overview Panel is a collaborative, multi-agency approach, working to ensure that any learning from the death of a child is captured, disseminated and implemented across the many organisations who have involvement in the health, wellbeing and safety of children, not just locally but across the country. To do this, we review information including reports and investigations that have been compiled around the death of a child, and bring together these reports to see if there are any trends or themes which help us to identify interventions that might reduce the risk of a child dying in the future. Although our role is to be analytical, we are all very aware that behind the reports that we review is a tragic loss, one which has impacted family, friends, communities and often the health and care professionals involved also.

The Southwest Peninsula CDOP covers the Local Authority areas of Cornwall & Isles of Scilly, Devon, Plymouth and Torbay.

The collation and sharing of all learning from Child Death Reviews and the CDOP is managed by the National Child Mortality Database (NCMD) which has been operational since 1st April 2019.

The NCMD gathers information on all children who die across England with the aim to learn lessons that could lead to changes to reduce child mortality.

The Mission of CDOP

The prevention of accidents involving children

The understanding of patterns of childhood death

Improvement in interagency practice in this very sensitive area

Education of the public and of professionals working with children

Membership

The Southwest Peninsula Child Death Overview Panel (SWP CDOP) aim to meet 11 times per year with the majority of meetings dedicated to specific thematic topics, for example; neonatal deaths, sudden unexpected deaths of infants, road traffic incidents or suicide.

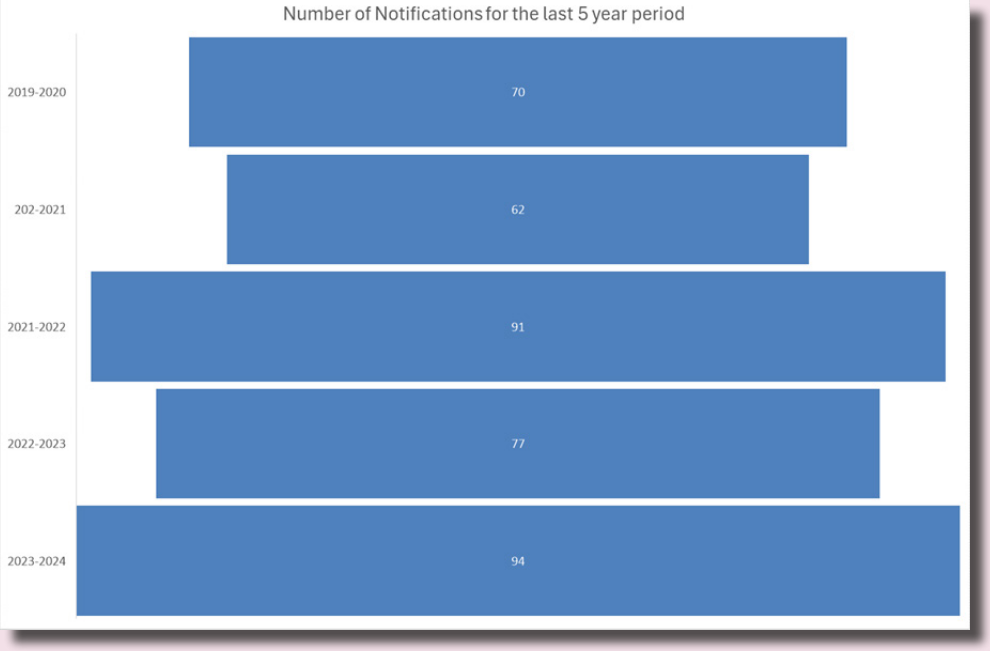
Themed meetings assist in identifying themes and support greater learning.

SWP CDOP comprises of senior representatives from key partner agencies who together have expertise in a wide range of services regarding children's health and wellbeing.
The membership of Child Death Overview Panels are made up of (but not limited to):

- Chair of the Panel – Director of Public Health
- Designated Doctor for CDOP
- Child Death Review & Response Service Manager
- Designated/Named Nurse for Safeguarding Children
- Safeguarding Children's Partnerships
- Police
- Obstetrics
- Midwifery
- Public Health Nursing
- Paediatrics
- Neonatology
- Social Care
- Paramedics/Transport Services
- Education

Other senior professionals are invited on a case by case basis.

Notification of Child Deaths to SWP CDOP - Annual Comparison



There were 94 deaths of children resident within the Southwest Peninsula notified in the year 2023/2024. A small number of additional deaths were notified to SWP CDOP of children not normally resident here.

In accordance with the Office for National Statistics and the NHS Digital guidance relating to the publication of births and death statistics, when a count is equal to or less than 5 (including zero), data must be suppressed. As such, data for this group cannot be reported separately.

Legislation allows for CDR partners to review the deaths of non-resident children within the CDR partners' area of responsibility.

The Statutory guidance states that a; *"pragmatic approach Child Death Review should be taken to such deaths, entailing discussion between the CDOP team in the area where the child is resident and that team in the area where the child died. The primary responsibility for panel discussion should lie with the CDOP where the child has died. However, consideration should also be given to where the most learning can take place."*

Due to the Southwest Peninsula's unique geography, with an expansive coastline and its increase in population size during the holiday seasons SWP CDOP additionally reviews the deaths of some non-resident children, who die within the Southwest Peninsula area, if there is local learning to be identified.

Even though a small number of non-resident children's cases are reviewed each year the SWP CDOP understands the importance of these reviews and the learning that may be gained. The decision to review the case of a non-resident child is made on a case by case basis.

Where the decision is made not to review the case the learning from the resident CDOP is always requested and shared with our Partners.

South West Peninsula Child Death Overview Panel Activity

The amount of cases reviewed by CDOPs in any one year will not match the number of notifications of deaths in the same year. The reviewed deaths may be a mix of deaths from several previous years. This is a consequence of CDOP being the ‘final discussion’ around the death of a child and therefore we are required to wait until all organisations’ investigations and reviews including coronial inquests are complete before a case can be presented to Panel.

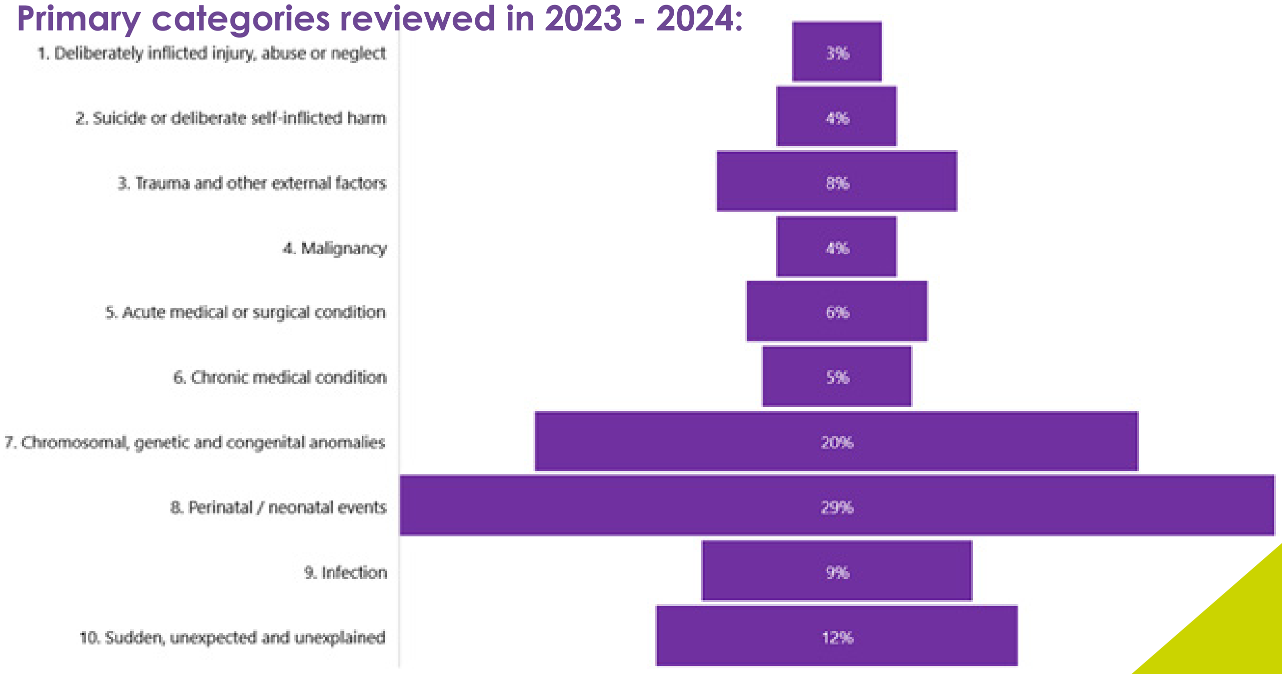
The number of deaths reviewed by SWP April 2023 - March 2024:

Total number of cases reviewed:

91

Across England CDOPs are asked to categorise reviewed cases to ensure consistent data collection; information on categorization can be found in the Child death analysis form. The category system is hierarchal with the uppermost ticked category recorded as the primary category.

Primary categories reviewed in 2023 - 2024:



Modifiable Factors Identified

One of the key functions of the Child Death Overview Panels is to decide whether a child death is modifiable. Deliberation over cases has demonstrated to the Panel that whilst in some cases it is relatively clear whether the death was modifiable or not, in many cases the decision is not clear cut. The Panel works to the national definition as shown below, but beyond this there are no other nationally directed tests or approaches that would support the reaching of a decision.

The national definition is as follows: A death should be categorised as modifiable if: The panel have identified one or more factors, in any domain, which may have contributed to the death of the child and which, by means of locally or nationally achievable interventions, could be modified to reduce the risk of future child deaths.

Determining modifiability is not about determining whether the death of the case being reviewed was preventable but whether there was a reasonable probability that if the factor in question was modified, by achievable methods, the risk of future child deaths would be reduced.

The SWP CDOP strive to develop a consistent approach to ascertaining modifiability in child death.

% of cases with modifiable factors (South West Peninsula)

40%

% of cases with modifiable factors (England)

43%

Most Frequent Modifiable Factors Identified

Sleep environment / unsafe sleeping arrangements

Access to appropriate services

Initiation of treatment / identification of illness

Treatment plan issues

Overcrowded living conditions / unsafe living environment

Exposure to cigarette smoke during pregnancy and beyond

Communication within or between agencies or between professionals and families

Issues with following guideline / pathway or policy

Focus on Bereavement Care

This year our Panel Members have reviewed a number of cases that have highlighted the lack of adequate bereavement support available to families. Parents and carers and professionals have voiced their concerns around the lack of easily accessible emotional and psychological support for families, particularly for those families whose children die unexpectedly.

Although we see grief as a natural response, losing a child is an unnatural event, a traumatic experience and a tragedy. Parents and carers sometimes describe the loss of a child as taking a physical as well as a mental toll. The continued lack of accessible bereavement support in our region will undoubtedly have long term effects on parents, carers, siblings and the wider family members, putting pressure on other services in the future.

> Parental feedback during the CDRP has been that bereavement support shouldn't be dependent on the way that a child has died. Parents have expressed the sudden nature of some deaths means that that they have no way of preparing or ensuring support is in place for them. Families have expressed they feel charities can be a postcode lottery and would not have given them support immediately when they really need it.
>
> **Verbal feedback from Parents during the CDRP to JAR Nursing Service**

Recommendations of our Partners have been focused around highlighting the importance of accessible bereavement support for all in our region.

1. Disparities are evident in our region for bereavement support after a child's death and access to counselling and support. No matter how a bereavement occurred there should be an equitable access to service for all.
2. Robust support for children and young people who are bereaved in any circumstance is paramount.
3. More than one family may require a bereavement room; access to bereavement rooms can be essential for families in their bereavement journey. Families may want to stay with their babies for a few days and this should be considered when planning wards and units in our region.

CDOP ask our partners: Are you assured that bereavement support is equitable and available across our region?

Focus on Palliative Care

"People who are approaching the end of their life are entitled to high-quality care, wherever they're being cared for"[1]

CDOP have identified from reviews that children receiving palliative care have a lack of choice around their preferred location of end of life care.

When a child is dying it is vital to offer children and their families choice and control around what matters to them most. In some instances families of children on a palliative care pathway may wish for their child to die at home, a place they are familiar and comfortable with.

Ambitions for Palliative and End of Life Care: A national framework for local action 2021-20262 insists that *"Palliative and end of life care must be a priority. The quality and accessibility of this care will affect all of us and it must be made consistently better for all of us."*

One family have voiced their thoughts and feelings around why this choice remains crucial and the profound effect that lack of choice has on families in our region. They have kindly agreed to let us publish their statement on the matter.

> The news that families may not currently have the option for a child to die at home in Devon left me deeply distressed. Denying this choice infringes on a human right and hampers the invaluable support palliative care teams offer during such a sacred moment in a family's life. If Xan had died in hospital or hospice due to a lack of funding or support for home care, it would have altered the grieving process, potentially leading to trauma and mental health issues for the family.
>
> As a mother whose child has died, it feels unbearable to me for any parent to have to face the news that having your child die at home is no longer an option. Not only are you having to face the death of your child, but you're having to now fight for the right to choose where your child dies. Where is the empathy? Where is the respect for human ethics? Xan's death will remain with us, but thanks to the exceptional team supporting us, there is a profound peace in our hearts, affirming that death is not something to fear or turn away from. The deep respect between our family and the palliative team resulted in a good death, emphasising the importance of getting it right in that one chance.
>
> **Mother of Xan (11 years and 9 months)**

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[1] What end of life care involves - NHS (www.nhs.uk)

Ongoing Work by our Partners

NHS Devon Integrated Care Board (ICB) has led on a small working group which has been reviewing the palliative and end of life care provision available in Devon through 2023/24.

A scoping exercise has confirmed the following gaps in service provision:

- There is no commissioned access to dedicated End of Life Care to support a child to die at home out of hours. This is provided on an ad hoc and good will basis by community nurses.
- Children living in Plymouth and Torbay do not have access to in hours specialist palliative care nursing team. Nursing is provided by non-specialist community nurses.
- There is no commissioned access to dedicated medical or pharmacy specialists to support End of Life care to support a child to die at home out of hours. This is provided on an ad hoc basis by hospice medic, and acute paediatric medics.
- There is no access to specialist palliative care psychology for children or staff to access psychological support when dealing with palliative and End of Life Care.

A case was presented to NHS Devon for investment in a Devon only model. The ICB asked for the case to be reviewed and consider a Devon wide model which also takes into account wider regional links and opportunities with neighbouring ICBs and NHSE.

NHS Devon is keen to learn from the Starling Service a new children's end of life care at home pilot service that is currently being run by University Hospitals Bristol & Western NHS Foundation Trust and Children's Hospice South West to children in Bristol and if it could be adapted for a local model. NHSE hope to extrapolate learning and expertise on how the Starling Service can be scaled up and is likely to report in spring 2025.

The South West Children's Palliative Care Strategic Network developed a paper and report which was submitted to the South West Quality Group & Regional Quality Assurance Group (May 2024). Both gave support for this to be high priority for action to be taken forward. As well as recognising it as a risk at a regional level. South West Children and Young People Transformation Programme is currently carrying out a regional finance scoping exercise on current paediatric palliative care spend which will complement the previous mapping piece on current service provision and enable common opportunities for collaboration and investment.

Devon locality is not currently able to offer consistent and equitable End of Life Care for children to die at home. Current mitigations to address service gaps include the community nursing teams, Children's Hospice South West and acute paediatric teams working closely together to provide bespoke packages of support within their current capacity for individual children and families who require End of Life Care.

We have also been working with our adult hospice colleagues to provide home care for young people over 16 years of age.

Lisa Pullen
RN Child, MSc Palliative care
Operational, Clinical and Professional Lead for the Community Children's Nursing Pathway
www.childrenandfamilyhealthdevon.nhs.uk

Other concerns and themes identified from CDOP linked to palliative care

Child Death Review Meetings should hear the voice of the family / child through their Keyworker. A Keyworker should be appointed to families to ensure they have an opportunity to engage in the Child Death Review Process.

Cases where hospice were involved had positive feedback from parents on their experience.

Value of Advanced Care Plans (ACP) and benefit of early and ongoing discussions with families.

Continued concerns that families in rural areas who are in poverty do and will find accessing services, particularly tertiary services, more and more difficult.

Focus on Temporary Accommodation

Unsuitable housing for families in temporary accommodation is known to put children at risk. Having the ability to sleep your baby safely should be available to all families regardless of where they live or position they find themselves in.

Reviews this year have highlighted a theme whereby in some circumstances families living in temporary accommodation have not been afforded the ability to safely care for their children, for example not having access to or space for a safe and suitable sleeping space. Temporary accommodation provided in some circumstances has been inadequate for these vulnerable families.

Recommendations to our Partners

NCMD data shows 55 homeless children (42 of which were under 1 year old) have died in temporary accommodation since 2019.

Recently the risks of temporary housing for children has reached the headlines in Amnesty's hard hitting video campaign[1].

CDOP recommend Local Authorities ensure the temporary accommodation allocated to a family is suitable for their needs, especially in relation to breast feeding parents and those with children under 1 year old. If not already implemented Local Authorities should consider implementing steps for families with children going into temporary accommodation.

All households with children in temporary accommodation under 5 years of age are offered travel cots and/or bed guards.

Request that hotels / bed and breakfasts used for temporary accommodation of families not only provide a travel cot but the cot is erected in the room ready for use.

All households in temporary accommodation with a child / children under 24 months of age are issued 'safe sleeping for emergency situations' Lullaby Trust guide.

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[1] https://www.youtube.com/watch?v=bu-N8uv4jn8

Key Learning & Recommendations from Child Deaths

Self-Harm and Suicide

- Education about the dangers of aerosol misuse should be included in the PSHE curriculum
- Suicide Prevention Training/Mental Health First Aid should be expanded to all staff working within schools including non-teaching staff

A focus on self-harm and suicide is to be considered for the 2024-2025 CDOP public report.

Road Traffic Safety

- Local Authorities should ensure roads outside all schools in their area are safe with regards to their layout and speed restrictions.
- CDOP recommendation that crossing points are reviewed to ensure they do not coincide with speed cushions. The impact of speed cushions on the severity of injuries in children needs to be considered and incorporated into safe road design.
- Previous regulation 28s, (issued by coroners in response to concerns highlighted during an inquest), to prevent future deaths in England have highlighted the lack of school crossing patrols as a risk. Schools should take into account highlighted risks and recommendations from Highways where there is no crossing patrol available.
- Education about road traffic safety delivered by schools should include discussions around using phones while walking. This is particularly important to those children who are transitioning to walking to school on their own.
- CDOP are aware of Safer School Street Scheme[1] which may be a consideration for local authorities to take part in/put in place.

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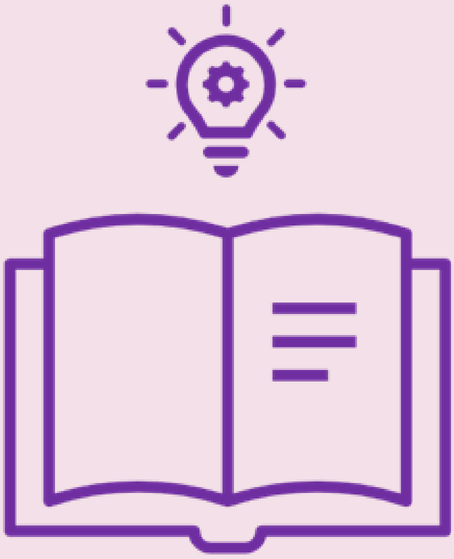
[1] Safer School Street scheme | PLYMOUTH.GOV.UK

Infection prevention

- Screening of Group B Streptococcus (GBS, group B Strep or Strep B) in pregnancy may be beneficial to identifying infants at risk of developing Group B Strep infection.
- There is value in educating parents during pregnancy with regards to the symptoms of sepsis rather than after birth as parents have a lot to take in with several leaflets handed over on several subjects. Important messages may be missed during this time.
- Antenatal Health Visiting face to face contact for parents and carers would be beneficial to understanding the volume of information passed to parents by way of leaflets.
- Agencies need to ensure that families with children with profound disabilities feel empowered to seek support urgently, particularly following procedures that may have a high infection risk.

Communication within and between Agencies

- Trusts should have a guideline or toolkit on how to assess pregnant (or potentially pregnant) women/people who attend Emergency Departments or other acute areas including how to assess for pregnancy related conditions or obstetric complications (including preterm labour) and how to refer to the obstetric/midwifery team.
- In cases where there is an extended period of fetal bradycardia (low heartrate) prior to delivery the neonatal team should be notified immediately to the potential that the infant may be born in poor condition.
- Trusts should be aware that although babies born alive under 22 weeks gestation do not meet the criteria for a Child Death Review Meeting by way of the Perinatal Mortality Review Tool[1], the Trust where the baby died should still conduct a CDRM and provide an Analysis form for the Child Death Review Process (4.1.3). Trusts can liaise with their local CDOP to ask for advice if unsure. CDRMs can be conducted in a way that is proportionate to the death i.e. through a mortality meeting or similar case discussion with a group of other cases if appropriate.



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[1] Perinatal Mortality Review Tool | PMRT | NPEU (ox.ac.uk)

Working with our Partners

Safe sleeping whilst away from home

With our extensive coastline and picturesque villages, it is no surprise that Devon and Cornwall are popular destinations for tourism. Our counties experience the second highest influx of visitors in England (behind London).

Reviews of deaths of both resident and non-resident children revealed that families who are staying away from home may be out of their usual safe sleep routine.

Two identified needs:

- Encouraging visitors or those away from home to know their location
- Encouraging visitors or those away from home to remember Safe Sleeping advice in an unknown environment

In response to this, in collaboration with the Lullaby Trust a staying away from home poster has been produced[1].

Staying away from home?

the lullaby trust

Following a safer sleep routine for EVERY sleep, day and night will reduce the risk of sudden infant death syndrome (SIDS). It is important that even when you are not at home you continue to follow safer sleep advice.

✓ Place your baby on their BACK for every sleep

✗ Keep them SMOKE FREE DAY AND NIGHT

✓ In a CLEAR, FIRM and FLAT, SEPARATE SLEEP SPACE

✓ Keep the room between 16-20°C so they don't get too HOT

USING A TRAVEL COT

If you're using a travel cot:

- Use a cot with a rigid frame and base
- The mattress should be firm, flat and have a waterproof cover
- Avoid adding any extra padding under your baby
- Place the cot away from radiators and direct sunlight
- Keep out of reach of blind cords and other hazards

CO-SLEEPING

Whether you choose to co-sleep or it is unplanned, there are some key risks you should avoid. It is dangerous to fall asleep with your baby if:

- They were premature or weighed under 2.5kg or 5½ lbs when they were born
- Or if you or your partner:
  - Have recently drunk any alcohol
  - Smoked
  - Taken drugs or medication that make you drowsy or less aware

If you are bedsharing with your baby consider any risks before every sleep, as they are constantly changing.

It's OK for your baby to fall asleep in a car seat when travelling, but they should be taken out as soon as you get to your destination, and placed onto a **firm, flat surface to sleep**

WHAT3WORDS

The What3Words App is useful when you are staying away from home. It can help you describe your exact location in an emergency. Download the app as soon as you arrive **https://what3words.com/**

Registered Charity Number: 262191
Company registration number: 01000824
Produced in collaboration with South West CDOP

Alongside the poster, the South West Peninsula CDOP have produced a toolkit for businesses who provide accommodation for visitors, including those in emergency accommodation.

Our Partners should ensure this information is disseminated through their appropriate channels.

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[1] https://www.lullabytrust.org.uk/product/emergency-situations-poster/

Working with Families

The Joint Agency Response Nursing Service for the South West Peninsula is the team of Nurse Practitioners, referred to as JAR Nurses, who provide ongoing support, advice and liaison for families who have experienced a child's unexpected, or unexplained death. Our response covers children up to their 18th birthday.

The JAR Nurse act as a keyworker for the bereaved family to keep them fully informed of the Child Death Review Process (CDRP) and signpost to local bereavement services.

Continued support for families in the weeks following the death of a child will focus on signposting families to appropriate services to meet individual needs. This will be different for each family.

Quotes from our families

> “ I'm not sure I will ever be able to thank you enough for how you have held us up and supported us with such tenderness over the last few months. ”

Mother to 17 year old

> “ The JAR nurse was everything you would have wanted her to be in the meeting putting forward your thoughts and questions on your behalf. ”

Mother to 17 year old

> “ You say all the right things at the right time and I feel so much calmer after talking to you, thank you. ”

Mother to 1 month old

> “ Thanks for your support. I would like to say it was very helpful that you have been there for me, it's really great that such support is available, and also it is good to know there is someone out there who realises how hard the circumstances are, not everyone realises. ”

Mother to 17 year old

Closing Remarks

The Child Death Review process supports both families and professionals to feedback on processes that are currently available or where there is felt to be a gap, in order that when a child dies, the voice of the family and child remain heard. The feedback we receive from families allows us to improve services on a local level, but is also collated at a national level through the National Child Mortality Database. The research and data collected is helping to direct national strategies which put children and families at the heart of improvements.

Locally, Southwest Peninsula CDOP have focused on some emerging themes from the Child Death Reviews undertaken. We see a recurrent theme of parents being “out of their normal routine”, including being rehoused into temporary accommodation, staying with family members, or on holiday. We know that there is an increased risk of harm to children in these periods whilst family members/carers adapt to the new environment. We are delighted to have been able to work with The Lullaby Trust to produce the “Staying Away from Home” poster included in the report. This highlights some potential risks of a new environment to parents and will enable any risks to be mitigated as much as possible.

We also continue to work with the necessary partners to ensure that bereavement support is available and equitable for all families who have sadly lost a child, irrespective of age, cause of death or postcode. Sadly, many families continue to highlight this need, and it is something we are striving to ensure is in place.

We send a heartfelt thank you to the parents who have contributed to the learning from each Child Death Review. This information will be used to improve local public health messaging and added to the information that is gathered nationally in an effort to prevent future deaths.

Dr Helen Channer
Consultant Pediatrician & Designated Doctor for Child Death Overview Panel
South West Peninsula Child Death Response & Review Team

Produced by Child Death Response & Review Team

Livewell
Southwest