

| <b>DOCUMENT CONTROL</b>   |  |
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| <b>Title:</b>   | <b>Care of Next Infant Policy (CONI)</b> |
| <b>Version:</b>   | <b>2</b>                                 |
| <b>Reference Number:</b>  | <b>CL113</b>                             |
| <b>Scope:</b>   |  |
| This policy is aimed at Health Professionals with the intention that it will be followed by CONI trained Health Visitor thereby promoting best practice   |  |
| <b>Purpose:</b>   |  |
| <ul style="list-style-type: none"> <li>• Guides the actions of professionals in terms of expectations, and the actions they should take following identification of parent with previous or family history of Sudden Unexpected Death in Infancy (SUDI).</li> <li>• Ensure that every parent and family is offered the same level of consistent CONI support services.</li> <li>• Promotes a co-ordinated support service for families who have experienced previous incident of SUDI.</li> <li>• Ensures parents and families receive adequate emotional support following a previous infant's SUDI and during subsequent pregnancy, delivery and beyond.</li> </ul> |  |
| <b>Requirement for Policy</b>   |  |
| To offer the CONI programme to identified families requiring support.   |  |
| <b>Keywords:</b>  |  |
| Care of the Next Infant (CONI), Cot death, Sudden Unexpected Death in Infancy (SUDI), Sudden Infant Death Syndrome (SIDS).  |  |
| <b>Supersedes:</b>  |  |
| Version 1   |  |
| <b>Description of Amendment(s):</b>   |  |
| Policy has been revised by representation from Bury, HMR and Trafford Community Services to meet the requirements of Pennine Care NHS Foundation Trust.   |  |
| <b>Owner:</b>   |  |
| <ul style="list-style-type: none"> <li>• Specialist Health Visitor/CONI Co-ordinator, Louise Wileman</li> <li>• Children's Services Locality Lead, Kath Beer</li> </ul>   |  |

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|---|--------------------------------|
| <b>Accountability:</b>  |                                |
| <ul style="list-style-type: none"> <li>• Associate Director of Nursing and Healthcare Professionals</li> <li>• Executive Director Of Nursing, Professional Leadership &amp; Quality Governance</li> </ul>   |                                |
| <b>Individual(s) &amp; group(s) involved in the Development:</b>  |                                |
| <p>This document has been developed in collaboration with the following interested parties:</p> <ul style="list-style-type: none"> <li>• Kath Beer,</li> <li>• Jo Whitnall,</li> <li>• Rachel Sant,</li> <li>• Sarah Mutema.</li> </ul>   |                                |
| <b>Individual(s) &amp; group(s) involved in the Consultation:</b>   |                                |
| <p>The document has been circulated for consultation and comments have been taken into consideration and the document amended accordingly:</p> <ul style="list-style-type: none"> <li>• Senior Management Team, Health Visiting Service, Midwifery Service, Community Paediatrician, G.P's and the Safeguarding Teams in Bury, HMR and Trafford.</li> </ul> |                                |
| <b>Equality Impact Analysis:</b>  |                                |
| <b>Date approved:</b>   | 23 <sup>rd</sup> November 2018 |
| <b>Reference:</b>   | CL113-EIA113                   |
| <b>Freedom of Information Exemption Assessment:</b>   |                                |
| <b>Date approved:</b>   | 25 <sup>th</sup> January 2019  |
| <b>Reference:</b>   | POL2018-90                     |
| <b>Information Governance Assessment:</b>   |                                |
| <b>Date approved:</b>   | 25 <sup>th</sup> January 2019  |
| <b>Reference:</b>   | POL2018-90                     |
| <b>Policy Panel:</b>  |                                |
| <b>Date Presented to Panel:</b>   | 28 <sup>th</sup> January 2019  |
| <b>Presented by:</b>  | Louise Wileman                 |
| <b>Date Approved by Panel:</b>  | 28 <sup>th</sup> January 2019  |
| <b>Policy Management Team tasks:</b>  |                                |
| <b>Date uploaded to Trust's intranet:</b>   | 26 <sup>th</sup> March 2019    |
| <b>Date uploaded to Trust's internet site:</b>  | 26 <sup>th</sup> March 2019    |

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| <b>Review:</b>   |  |
| <b>Next review date:</b>   | January 2022   |
| <b>Responsibility of:</b>  | Specialist Health Visitors                                   |
| <b>Other Trust documentation to which this policy relates (and when appropriate should be read in conjunction with):</b> |  |
| CL122  | Safeguarding Families Policy.                                |
| CO010  | Incident Reporting Management and Investigation Policy       |
| CO016  | Medical Devices Management Policy                            |
| RM001  | Records Management Policy                                    |
| <b>Policy Associated Documents:</b>  |  |
| TAD_CL113_03   | <a href="#">Referral Form for the CONI Programme</a>         |
| <b>Other external documentation/resources to which this policy relates:</b>  |  |
|  | CONI Protocol 2017   |
|  |  |
| <b>CQC Regulations</b>   |  |
| <b>This guideline supports the following CQC regulations:</b>  |  |
| Regulation 9   | Person centred care  |
| Regulation 11  | Need for consent   |
| Regulation 12  | Safe care and treatment                                      |
| Regulation 13  | Safeguarding service users from abuse and improper treatment |
| Regulation 17  | Good governance  |

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## **1. INTRODUCTION**

This policy sets out to provide health professionals with the framework for the process to identify and enrol parents and families for the Care of Next Infant (CONI) programme. The CONI programme is a national programme that was established in 1988 by the Foundation for the Study of Infant Death (FSID).

The programme works in partnership with the National Health Service (NHS) to provide support for parents who have lost a previous child through a Sudden Unexpected Death in Infancy (SUDI) and are planning to or have a new baby.

Sudden Infant Death Syndrome (SIDS), which is also known as 'cot death' remains a significant cause of death in babies over one month of age (The Foundation for the Study of Infant Death, 2016). A child's death is registered as sudden infant death syndrome if post-mortem indicates no specific cause for the death (Levene & Bacon, 2004).

The CONI programme has been extended as CONI PLUS to be available to other families whose babies may be at increased risk of SUDI or who have reason to be anxious about their child.

### **Incidence of Sudden Infant Death Syndrome**

There were 219 unexplained infant deaths in England and Wales in 2016, an increase compared with 2015 (195) but still lower than 2006 (285). (Office for National Statistics 2016)

Unexplained infant mortality rates vary by region and can fluctuate over time. In 2016, the unexplained infant mortality rate was highest in the West Midlands, Yorkshire and The Humber, and North West regions of England, each with 0.45 deaths per 1,000 live births; however, the largest increase was seen in the West Midlands as the unexplained infant mortality rate rose by 21.6% from 2015. The rate in the West Midlands, Yorkshire and The Humber, and North West was statistically significantly higher than London and the South East in 2016.

Whilst most unexplained child deaths are unpredictable, evidence shows that SIDS is associated with a number of risk factors associated with social deprivation and disadvantage. Important factors including poverty, poor housing, over-crowding and smoking are significant public health concerns as they are identified as increasing the risk of SIDS.

This calls for a greater need for preventative and supportive strategies to reduce to risk factors associated with SIDS and promote infants health in disadvantaged families. (DOH 2007)

## **2. RATIONALE**

### **CONI Programme**

The purpose of this organisational policy is to ensure that vulnerable parents/families in Pennine Care NHS Foundation Trust with personal or family history of SUDI are identified in pregnancy so that they receive appropriate and structured support.

The target population is as follows:

- Every family who have experienced a SUDI and also have had, or are expecting a subsequent baby.
- Full or half siblings of an infant who suffered SUDI.

### **CONI Plus Programme**

The CONI Plus Programme is an extension of the CONI programme and offers support to the following target population:

- Parents and families whose babies have died for reasons other than SUDI.
- Following an Apparent Life Threatening Event (ALTE). Consequently they may experience increased anxiety or trauma about a subsequent pregnancy or a new baby.
- Infants born to parent, who have had sibling, niece or nephew die of as a result of SUDI.
- Infants born to parents who have had a previous infant (aged 7 days to 1 year) die as a result of causes other than SUDI following discharge from the neonatal or post-natal unit (this includes infants born at home).

### **Additional Groups**

Consideration will be given to allow the inclusion of parents made anxious for reasons other than 1-4 above.

### **Definition of Apparent Life Threatening Event (ALTE)**

An Apparent Life Threatening Event is a sudden and unexpected event which is frightening to the observer who perceives the baby to be at risk of death, and feels there is a need to take some immediate action. The event has a defined onset and ending and does not lead to death or persistent collapse. A Paediatrician will diagnose ALTE if the baby displays changes in at least two or more of the following: colour, tone, consciousness, movement and breathing. (Lullaby Trust, 2017).

## **3. RESPONSIBILITIES, ACCOUNTABILITIES AND DUTIES**

### **Provider Services**

Provider Services has a responsibility for ensuring the audit process of the policy takes place within Pennine Care NHS Foundation Trust Governance department.

### **Senior Manager/Head of Service**

It is the responsibility of the Senior Manager for dissemination of this Policy.

### **Team Leader**

The Team Leader is responsible for the implementation of this policy.

### **Health Visiting Service, Maternity Services, General Practitioner.**

It is the responsibility of the Health Visitors (H.V) working in partnership with other providers to adhere to the policy to ensure best practice.

#### **4. AUDIENCE**

Parents could self-refer to the programme. Referral can also be made by all health care professionals who have contact with children and families. These include:

##### **The Midwife**

The Midwife will identify a pregnant mother with a history of SUDI, or whose partner has a history of SUDI or where parent meets the local criteria for CONI Plus during antenatal booking. The Midwife will follow National CONI Protocol.

##### **General Practitioner**

The GP will also identify the pregnant mother and refers to local CONI Co-ordinator as per the Protocol.

##### **Health Visitor**

The HV and local CONI Co-ordinator will complete a joint home visit to the parent/family during the ante-natal and/or post-natal periods for an initial family's assessment and to establish a care plan for CONI support. The HV will provide regular contact in partnership with the family to implement the chosen surveillance option(s), to discuss symptom diary, Baby Check (Foundation for the Study of Infant Deaths 2009) and any parental concerns as well as offering support, advice and reassurance. The Health Visitor will discuss concerns about the baby's health and development with the GP and Paediatrician as required. Members of the Health Visiting Team will plot any weight recordings on the Sheffield Weight chart and will monitor the record of the apnoea monitor alarm. The HV will liaise with the local CONI Co-ordinator regarding resources required throughout the programme. (For example; stationery, sensors for the apnoea alarm, faulty equipment). The Lullaby Trust will evaluate the service provision for the family at the end of the programme through a questionnaire.

##### **Paediatrician**

It is appropriate that babies on the CONI Programme are given fast or open access to the paediatric team in line with local arrangements for other vulnerable babies.

##### **Local CONI Co-ordinator**

The CONI Co-ordinator's function is to administer the support programme. This includes interviewing the parents to explain the support in detail, briefing the named HV, Midwife and General Practitioner, arranging training in resuscitation for parents, organising the distribution of stationery and equipment as well as training staff in the CONI Programme. While the care of the family remains with the primary health care team, the Co-ordinator is available for advice and support. The Co-ordinator will ensure all relevant staff are aware of the programme and how to refer families.

##### **North West Ambulance Service**

The North West Ambulance Service will flag the address of a child registered on the CONI programme once a referral has been made by the CONI Coordinator.

## **5. INTRODUCTION OF CONI PROGRAMME**

The local CONI Co-ordinator will visit families at home to explain the programme in detail. The optimal time for this is about 2 months before the expected date of delivery. Appropriate methods of support should be discussed and selected and consent obtained for the information to be shared with the CONI team.

### **Practice recommendations for CONI**

Parents/families should be offered the opportunity to participate fully or partially in the CONI programme during subsequent pregnancies and / or until the child is at least six months old or two months after the age at which the previous SUDI occurred or ALTE occurred. Parents must be informed about the support available and choose what is required with the advice of the local CONI Co-ordinator.

CONI Programme includes one or more of these interventions. The care of the family remains with the named Health Visitor, General Practitioner, Midwife and Paediatrician and the family can choose from the following:

#### **Regular contact in the home – with a named Health Visitor**

CONI families have consistently rated the H.V visits as an essential component of the support. They identify listening and commitment to regular contact for an agreed time, as the key essential elements of the help provided by the named H.V.

#### **Symptom Diaries – completed by parents and discussed with the named Health Visitor**

Symptom Diaries allow parents to express anxiety about illness identify changes and facilitate health education. They also serve to emphasise to parents the importance of being observant of their children and seeking advice if their child appears unwell.

#### **Baby Check**

The Baby Check booklet or App can be used in conjunction with the symptom diary or independently to assess signs and symptoms of illness in a young baby.

#### **Weight Charts**

All babies on the scheme should have their weights recorded on the Sheffield Weight Chart at regular agreed intervals.

#### **Room Thermometers**

To be used to monitor the air temperature in the room in which the baby sleeps. The temperature should be kept within the recommended range of 16-20 C or bedding and clothing adjusted appropriately.

#### **Movement (apnoea) monitor**

Used to monitor movement in sleep, the monitor can reassure parents that a crisis has not occurred and, with professional help, gradually re-build confidence. The monitors alarm after a pre-set period of no movement and can audibly register each movement detected.

## **Resuscitation Training**

All parents must receive signposting to resuscitation guidelines.

## **Neonatal Investigations**

Families should be advised in the antenatal period (as per National protocol) that their baby should be examined by a paediatrician before discharge from the maternity unit. Further investigations should be guided by the outcome of the review of the sibling's death.

## **Open or fast access to Paediatrician**

It is appropriate that babies on the CONI programme are given fast or open access to the paediatric team in line with local arrangements for other vulnerable babies.

## **General Practitioner**

The family doctor needs to be involved throughout all procedures. Information regarding the implementation of CONI should be circulated to all surgeries. The family's GP should be informed when a new baby is enrolled on to the programme and provided with the handbook - Guidelines for Users (Dec 2014). An alert slip is available for paper records and electronic records should be flagged.

## **Health Visitor**

A negotiated schedule of planned home visits and clinic contacts has been shown to be most effective with the family until the CONI baby passes the age at which the sibling died. A named HV caring for a baby on the programme should be supplied with the handbook - Guidelines for Users (Dec 2014).

## **Visit at 6-7 months and feedback from parents**

Where possible the local CONI Co-ordinator or named HV should visit the family at or towards the end of the planned programme. This is to discuss the withdrawal of the extra support and to offer the feedback questionnaire. Return of equipment arrangements can also be discussed at this time to arrange for cleaning and maintenance/PAT testing.

## **Lullaby Trust support to parents**

Parents can be put in contact with an Lullaby Trust befriender at any time following their baby's death and contact can continue for as long as the bereaved parents wish. This support may be by telephone, letter or e-mail. The Lullaby Trust have a free helpline number 0808 802 6868 and there is a discussion forum and extensive information available at [www.lullabytrust.org.uk](http://www.lullabytrust.org.uk)

## **6. COMPLETION OF THE PROGRAMME**

The duration of the surveillance needs to be flexible to meet individual need. Local practices may vary from the national protocol.

## **7. EVALUATION AND MONITORING**

This policy will be reviewed by the CONI Coordinators every three years or before should there be any changes to the service or evidence arise which necessitates a change to the policy. The CONI programme is being continuously monitored evaluated and improved by the Lullaby Trust following completion of a parent/carer questionnaire at the end of the programme.

## **8. EQUALITY IMPACT ANALYSIS**

As part of its development, this document was analysed to consider / challenge and address any detrimental impact the policy may have on individuals and or groups protected by the Equality Act 2010. This analysis has been undertaken and recorded using the Trust's analysis tool, and appropriate measures will be taken to remove barriers and advance equality of opportunity in the delivery of this policy / procedure

## **9. FREEDOM OF INFORMATION EXEMPTION ASSESSMENT**

Under the Freedom of Information Act (2000) we are obliged to publish our policies on the Trust's website, unless an exemption from disclosure applies. As part of its development, this policy was assessed to establish if it was suitable for publication under this legislation. The assessment aims to establish if disclosure of the policy could cause prejudice or harm to the Trust, or its staff, patients, or partners. This assessment has been undertaken using the Trust's Freedom of Information Exemption Guide, and will be reviewed upon each policy review.

## **10. INFORMATION GOVERNANCE ASSESSMENT**

This Policy has been analysed to ensure it is compliant with relevant information law and standards as in place at the time of approval, and are consistent with the Trust's interpretation and implementation of information governance components such as data protection, confidentiality, consent, information risk, and records management.

Compliance will be reviewed against any changes to legislation / standards or at the next review of this document.

## **11. SAFEGUARDING**

All staff have a responsibility to promote the welfare of any child, young person or vulnerable adult they come into contact with and in cases where there are safeguarding concerns, to act upon them and protect the individual from harm.

Any safeguarding concerns can be identified and acted upon appropriately in line with Greater Manchester procedures and Local Multi-Agency thresholds.

All staff have a responsibility to access safeguarding support and supervision.

## 12. MONITORING

The effective application of this policy / guideline, including adherence to any standards identified within will be subject to monitoring using an appropriate methodology and design, such as clinical audit.

Monitoring will take place on a biannual basis and will be reportable to the Quality Group via the Clinical Effectiveness and Quality Improvement Team.

## 13. REVIEW

This policy will be reviewed three-yearly unless there is a need to do so prior to this; e.g. change in national guidance.

## 14. REFERENCES

Department of Health, 2007. *Implementation plan for reducing health inequalities in infant mortality: a good practice guide*. London: Department of Health. Available from: [https://webarchive.nationalarchives.gov.uk/20130124041845/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_081336.pdf](https://webarchive.nationalarchives.gov.uk/20130124041845/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_081336.pdf) [Accessed 22 January 2019]

Department of Health, 2004. *Standards for better health*. London: Department of Health. Available from: [https://webarchive.nationalarchives.gov.uk/20121206015040/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4086665](https://webarchive.nationalarchives.gov.uk/20121206015040/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4086665) [Accessed 22 January 2019]

Foundation for the Study of Infant Deaths, 2012. *SID Cot death facts and figures*. Available from: <http://www.improvingme.org.uk/media/1134/facts-and-figures-2010-factsheet-1.pdf> [Accessed 22 January 2019]

Greater Manchester Safeguarding Partnership, 2018. *Greater Manchester safeguarding children procedures manual*. Manchester: Greater Manchester Safeguarding Partnership. Available from <http://greatermanchesterscb.proceduresonline.com/> [Accessed 22 January 2019]

Levene ,S & Bacon, CJ, 2004. Sudden unexpected death and covert homicide in infancy. *Archives of Diseases in Childhood*, 89 (5): 443 – 447

Lullaby Trust, 2018. SIDS and SUDC facts and figures. London: The Lullaby Trust. Available from <https://www.lullabytrust.org.uk/wp-content/uploads/Facts-and-Figures-for-2015-released-2017.pdf> [Accessed 22 January 2019]

Lullaby Trust (2017) *Care Of Next Infant – A protocol for a programme of support*. London; The Lullaby Trust.

Lullaby Trust, 2006. *Baby Check is your baby really ill?* London: Lullaby Trust <https://www.lullabytrust.org.uk/wp-content/uploads/baby-check-2015.pdf> [Accessed 22 January 2019]

Lullaby Trust, 2016. *Evidence Base* [online]. London: The Lullaby Trust. Available from: <https://www.lullabytrust.org.uk/research/evidence-base/> [Accessed 22 January 2019]

Office for National Statistics, 2018. *Child mortality in England and Wales: 2016*. London: Office for National Statistics. Available from <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/childhoodinfantandperinatalmortalityinenglandandwales/2016> [Accessed 22 January 2019]

Office for National Statistics, 2018. *Unexplained deaths in infancy England and Wales 2016*. London: Office for National Statistics. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/unexplaineddeathsininfancyenglandandwales/2016> [Accessed 22 January 2019]

Freedom of Information Act 2000

Equality Act 2010