



# Family Nursing & Home Care

## **Standard Operating Procedure Care of Next Infant (CONI) Programme**

March 2023

## Document Profile

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## Introduction

In 1991, the *Back to Sleep Campaign* launched in England and Wales; where the number of infant deaths from sudden unexpected death in infancy (SUDI) reduced by 86%. This campaign was instrumental in saving countless lives. It is still a sad fact that infants are still dying from what in some instances could be preventable deaths. The Child Safeguarding Practice Review Panel (2020) reviewed 568 incidents (2018 to 2019) where 40 involved infants who had died suddenly and unexpectedly, making this one of the largest groups of children notified.

There are two ways of describing the death of an infant:-

### Sudden Unexpected Death in Infancy (SUDI)

SUDI refers to all unexpected deaths up to one year of age at the point of presentation. As such, it is a descriptive term rather than a diagnosis. At the conclusion of an investigation, they will divide into those for which we have a clear diagnosis, including those related to underlying medical causes, accidents and homicides (explained SUDI), and those for which we do not have a diagnosis (SIDS) (Sidebotham and Fleming, 2007).

### Sudden infant death syndrome (SIDS)

The sudden death of an infant less than one year old that apparently occurs during normal sleep, which remains unexplained after a thorough investigation, including a complete autopsy, review of the circumstances of death and the clinical history (Krous et al., 2004). There are some cases in which there is no clear cause of death. Pathologists in the UK often use the term 'unascertained' for such cases, many of which are associated with risk factors such as co-sleeping and bed sharing that might have contributed to the death.

The Lullaby Trust provides comprehensive support with its 'Safer Sleep' campaign providing accessible information to both professionals and the public. Which makes a difference and FNHC Health Visitors and HCS Midwifery Services routinely give this advice to all parents. Where in 2020 and in line with the advice from the Safeguarding Practice Panel Review, a Safer Sleep Tool Kit is included in FNHC Health Visiting Templates to enable tailoring of safer sleep advice to every parent, where this "prevent and protect model" is an identified proactive step that makes a difference.

Where parents to be have however lost a baby to SUDI, the Care of Next Infant (CONI) programme is a programme set up by the Lullaby Trust to provide additional care and support to families who have experienced a Sudden Unexpected Death in Infancy (SUDI) \*\*also known as Sudden Infant Death Syndrome (SIDS).

The CONI programme provides specialist advice, information and support to health professionals who, in turn, support bereaved families with the baby who is born next to help them enjoy the first year of their baby's life with the added reassurance of knowing their baby is healthy, gaining weight and has access to swift medical treatment as required.

For those families affected by loss, the priority of care is through a targeted support programme, dependant on need and over a period of approximately six months to a year post the birth of their next child. Where Health visitors have a duty of care to support families who have had a previous sudden infant death, or have a baby under 1 year who has suffered a Brief Resolved Unexplained Event (BRUE).

The programme remains supported by The Lullaby Trust and is run in by Family Nursing and Home Care, in partnership and supported by Health and Community Services. The programme can be extended to support a wider group of families who may have special reason to be anxious about their baby.

They may, for example:

- be close relatives of a baby that has suffered a sudden infant death
- have lost a baby to causes other than sudden infant death
- have a baby who has experienced a BRUE

The following standard operating procedure provides support and guidance to practitioners in offering additional care through the CONI programme. Where response to families is systematic, organised, and timely and is a recognised compassionate way of supporting families to care for their next baby.

Midwives, GP's, Nursery Nurses, Emergency Department Staff, Paediatricians and Paediatric Nurses all have a remit in supporting the programme as children identified may require support within their clinical areas and there are signed agreements within the paper work for CONI which recognises the need for their service input.

## SOP 1 CONI Programme Key Principles

### **Purpose**

This SOP outlines the key principles of the CONI Programme.

### **Scope**

Practitioners who may be involved in supporting the programme directly or indirectly.

### **Core Requirements**

Identification of families who may be at the highest risk is crucial as this programme enables targeted support and advice.

A history of SIDS in a family identifies a particularly vulnerable group of families with whom health visitors have the skills needed to work effectively. The ability to professionally 'befriend' the family, to listen to the parents' concerns, empathise with them, develop strategies to help them, liaise with relevant agencies and identify causes for concern, are core skills. These are fundamental to helping build a trusting but effective therapeutic relationship between the health visitor and the parents. The CONI programme offers additional resources to help the health visitor hold effective dialogue and monitor the general health of the infant.

CONI recognises the link economic disadvantage and risk of SUDI.

Families enrolled on the CONI programme may have the following in common and these are risk factors to SUDI for the next baby:

- maternal smoking in pregnancy
- Unemployment 5 times higher
- 50% more mothers single & unsupported
- Double proportion low birth weight babies
- 50% more babies born preterm
- 40% parity 4 or more
- Almost half as many babies breastfed

Factors associated with increased risk of perinatal mental illnesses include:

- history of mental illness
- family history of mental illness
- psychological disturbance during
- pregnancy (e.g. anxiety or depression)
- lone parent or poor couple relationship
- low levels of social support

- recent adverse or stressful life events
- socio-economic disadvantage
- teenage parenthood
- early emotional trauma/childhood

As an infant death has such an impact on a parents' mental health they are then anxious and fearful. It is important that they are given the opportunity to express their concerns and feelings and develop confidence with their next baby during the first 6 months when the risk of SUDI is greatest.

## SOP 2 CONI Programme Support for Parents

### **Purpose**

This SOP outlines the support available on the CONI Programme.

### **Scope**

Practitioners who may be involved in supporting the programme directly or indirectly.

### **Core Requirements**

The help parents receive can be as much or as little as they like. Parents can choose from:

#### Symptom diary

The diary allows parents to note changes in their baby's health, appearance and behaviour, which they can discuss with their Health Visitor.

#### Weighing scales

Healthy babies show regular gains in weight, ill babies may fail to gain, or may lose, weight. A weight chart (the Sheffield Weight Chart) can be used to plot the baby's weight changes and those gaining weight either too slowly or too quickly can be seen by a local paediatrician.

#### Movement/apnoea/breathing monitor

Movement monitors detect baby's movements as they breathe. An alarm rings after 20 seconds to alert parents if breathing movements stop. A very small number of babies may have problems with their breathing, but most will be entirely normal. Although monitors do not prevent sudden infant death, anxious parents report that they are reassured by using the monitor, particularly at night.

#### Mattress Monitor

Parents if they can afford them can buy their own mattress monitors or at times then FNHC can access charitable support from other on island charities to help parents purchase a mattress monitor if they wish to do so.

#### Basic Life Support (BLS) training

BLS training is offered to all parents, preferably before the baby is born or before the family leave the hospital. Those who choose to take a movement monitor home



must complete BLS training (Appendix 1). Further training can be accessed via St Johns Ambulance Services.

### Room thermometer

It is important that babies do not become too hot or cold. A simple room thermometer tells parents the temperature in the room.

### Baby Check

Baby Check is a book/App designed to help parents decide whether they should take their baby to the doctor. It contains 19 simple checks which test for symptoms or signs of illness. Each check has a score and the total score indicates how unwell the baby is likely to be.

### Paediatricians

Paediatricians can talk with and advise parents after the death of their baby and during a subsequent pregnancy. After a new baby is born, they can offer routine checks or examine the baby if the parents are concerned. At times an agreement can be signed with a paediatrician for a child to have swifter access to paediatric care if required, (which needs to be agreed on a case by case basis) as described below.

### Baby Passport

Can be used to fast-track babies through (adult) Emergency Departments to the paediatrician.

### General Practitioners

Can offer advice and support, particularly during any illness in the baby.

### Midwives

Can ensure that parents are offered CONI during subsequent pregnancies and can help parents as they begin to use the support programme after their new baby is born.

### The Lullaby Trust (National CONI coordinators)

Support and advise the local coordinators and provide training and information to the local CONI coordinators.

## SOP 3 CONI Enrolment Pathway

### **Purpose**

This SOP outlines the CONI Programme Enrolment Pathway.

### **Scope**

Practitioners who may be involved in supporting the programme directly or indirectly.

### **Core Requirements**

#### **Ante Natal Pathway**

- Mother books for antenatal care.
- Midwife refers to the local co-ordinator by email via [Enquiries@FNHC.org.ie](mailto:Enquiries@FNHC.org.ie) by 24 weeks gestation.
- Local co-ordinator liaises with midwife / family health visitor and arrangement made to meet parents ante-natally at a time either suited to parental choice or 2 months before the Estimated Date of Delivery (EDD)
- CONI resources and equipment are introduced ante-natally wherever this is possible.
- Arrangements made for Basic Life Support training for any family members who will care for the baby regularly. Local training is available from St Johns Ambulance Service or can be arranged via the hospital BLS training team
- Enrolment is to be completed online by own Health Visitor and copy to local co-ordinator. Written consent is not required as no identifying data is required (Appendix 1).
- Notification of enrolment to the CONI programme should be made to the paediatric department, Emergency Department, and GP (local co-ordinator or HV must document this process as completed) that a baby is on the CONI Programme on the EMIS template (CONI enrolment).
- Families may benefit from the support of CONI but can decline to share their anonymous information or decline the programme completely. In either case advise local CONI co-ordinator and complete the Notification of non-participation form (Appendix 1).

#### **Health Visitor/Post Natal Pathway**

- Parents meet health visitor ante-natally or post-natally to discuss a pathway of additional support and introduce CONI programme
- Parent led process and parents may opt for a bespoke programme
- Contact local CONI co-ordinator via [Enquiries@FNHC.org.ie](mailto:Enquiries@FNHC.org.ie)

- CONI resources and equipment introduced by the health visitor with support from local co-ordinator
- Arrangements made for BLS training locally for family members who will care for the baby regularly
- Written consent is not required but verbal consent is compulsory to enrol and shared anonymously with the Lullaby Trust on the form supplied in the registration link. There are no identifying factors
- You can complete online and submit or download the enrolment forms, take to the family and then complete the online form after the visit
- CONI family resources are partly available to download (excluding growth charts, thermometers and some leaflets, which must be obtained via your local co-ordinator)
- Notification must be made to the paediatric department, Emergency Department, and family GP to inform that a baby is on the CONI programme; this should be completed by the CONI co-ordinator unless otherwise arranged

## SOP 4 Roles and Responsibilities

### **Purpose**

This SOP outlines the roles and responsibilities of the health professionals working with the CONI Programme.

### **Scope**

Practitioners who are involved in supporting the programme directly or indirectly.

### **Core Requirements**

#### CONI Paediatrician

The local CONI Paediatrician provides medical advice and support to the professionals supporting families on the CONI Programme (in conjunction with the General Practitioner and Consultant Paediatrician). This may include seeing the family in the antenatal period on request of the local CONI co-ordinator, to give the parents the opportunity to discuss the findings concerning their previous child's death and the care of their future child. Meeting with parents after the baby is born and where possible at the anniversary of the previous baby's death.

#### Local CONI co-ordinator

The Local CONI Co-ordinator will be a named and suitably qualified practitioner within FNHC Child and Family Division.

#### Health Visitor

- Discuss each case with the referrer/CONI co-ordinator if further information is required
- Meet the family to discuss and initiate the CONI Programme
- Register the family with the Lullaby Trust online and complete the Lullaby Trust CONI Programme Registration (enrolment) form (Appendix 1)
- Local Co-ordinator to inform any professionals who are involved that this family are on the CONI Programme
- Promote breastfeeding as numerous studies have supported the protective effects of breastfeeding, with one overview report concluding that breastfeeding reduces the incidence of SIDS by approximately half

- Have a discussion about smoking cessation with parents who smoke, as the risk of SIDS is greatly increased if either parent smokes during pregnancy or after the baby is born. Refer to local smoking cessation services as part of the CONI package of support
- Provide Sheffield Weight Charts- The advice is that all babies on the scheme should have their weights recorded on the Sheffield Weight Chart at regular intervals, a minimum of weekly
- Act as a resource to the family Health Visitor/0-19 Practitioner, G.P. and other professionals working with the family
- Signpost families to other resources available; for example bereavement support via the Lullaby Trust's free listening and befriender service, also Winston's Wishes for children's bereavement support
- Refer to appropriate services for anxiety for example Perinatal Mental Health, midwife or GP
- Provide Movement/Mattress monitors, supplied by the co-ordinator
- The CONI co-ordinator will ensure that the manufacturer guidelines are adhered to, and following each loan period/episode of care the monitors will be serviced by their return to SCBU for a check by the medical engineering team. Monitors should be serviced a minimum of annually
- Note that not all families will need a monitor
- Movement monitors should not be used after 6 months of age as the sensor leads could become a safety hazard
- Signpost parents to the Lullaby Trust Baby Check App
- All families should be signposted to the British Red Cross or St John's Ambulance YouTube video, and/or Lullaby Trust basic life support leaflet
- Place an alert on EMIS and request **TrakCare** alert
- Update is via reading the literature on The Lullaby Trust and any updates via email
- Ensure that families who not wish to go on the CONI programme have their needs assessed and additional support arranged as required such as Universal Partnership Plus/MESCH visiting. Reinforce advice on safer sleep using Lullaby Trust leaflets (Appendix 1)

- Draw up a plan of home visits and/or clinic contacts to meet the parents' needs whilst they are on the CONI programme. Document the plan in personal child health record (PCHR) (red book) so parents are partners in this
- Ascertain parental commitment to accessing clinic to have their baby weighed, and the baby weights are recorded on to Sheffield Weight Charts where used
- Promote bonding and attachment with baby
- Ensure that the CONI documentation is completed at contacts and any deviation from the normal is acted upon by referring to GP/Paediatrician and reasons explained to the family
- Encourage parents to continue with the symptom diary (optional) to record their baby's health, which they can then discuss with their Health Visitor
- Calculate when the family should complete the CONI Programme and arrange to meet with them when the baby is 6 months old or two months beyond the age at death of the previous baby, or the last BRUE event. The time period should be flexible as some families may choose to end the programme earlier than calculated, and some may wish to continue a little longer (this may be up to the baby being aged 12 months). Complete the evaluation form (Appendix 1) and submit to the Lullaby Trust electronically

## Glossary of Terms

**Sudden Unexpected Death in Infancy (SUDI)** SUDI refers to all unexpected deaths up to one year of age at the point of presentation. As such, it is a descriptive term rather than a diagnosis. At the conclusion of an investigation, they will divide into those for which we have a clear diagnosis, including those related to underlying medical causes, accidents and homicides (explained SUDI), and those for which we do not have a diagnosis (SIDS) (Sidebotham and Fleming, 2007). The medical term used to describe the sudden and unexpected death of a baby that is initially unexplained.

### **Sudden Infant Death Syndrome (SIDS)**

The sudden and unexpected death of an infant less than 1 year of age, with the onset of the fatal episode apparently occurring during sleep that remains unexplained after a thorough investigation including performance of a complete autopsy and a review of the circumstances of death and clinical history.

### **Brief Resolved Unexplained Event (BRUE)**

An event lasting less than 1 minute in an infant less than 1 year of age that is associated with at least one of the following: cyanosis or pallor; absent, decreased, or irregular breathing; marked change in muscle tone (hypertonia or hypotonia); altered level of responsiveness. Baby must otherwise be well-appearing and back to baseline health at the time of presentation. The diagnosis of a BRUE can only be made when there is no explanation for a qualifying event after an appropriate history and physical examination.

## References

Lullaby Trust (2017) *Target SUDI Together: Research Priorities in Sudden Unexpected Death in Infancy*. Available at: [Target-SUDI-Together-July-2017.pdf \(lullabytrust.org.uk\)](https://lullabytrust.org.uk/target-sudi-together-july-2017.pdf). Last accessed 28<sup>th</sup> February 2022

Lullaby Trust (2020) *Care of Next Infant (CONI)*. Available at: [new-CONI-leaflet-2020-FINAL.pdf \(lullabytrust.org.uk\)](https://lullabytrust.org.uk/new-CONI-leaflet-2020-FINAL.pdf). Last accessed 28<sup>th</sup> February 2022

Child Safeguarding Practice Review Panel (2020) *Child Safeguarding Practice Review Panel: Annual Report 2020*. Available at: [The Child Safeguarding Annual Report 2020 \(publishing.service.gov.uk\)](https://publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/944447/The-Child-Safeguarding-Annual-Report-2020.pdf). Accessed 30<sup>th</sup> June 2022

Tieder JS et al (2016) *Brief resolved unexplained events (formerly apparent life-threatening events) and evaluation of lower-risk infants*. *Paediatrics* 2016 May; 137:e20160590



## Appendix 1 Resources

### CONI Programme Enrolment Form

<https://www.lullabytrust.org.uk/professionals/care-of-next-infant/coni-programme-registration-form>

### CONI Programme notification of non-participation form

<https://www.lullabytrust.org.uk/professionals/care-of-next-infant/information-for-coni-coordinators/>

### CONI Programme Feedback Form (participants)

[CONI Feedback Form - The Lullaby Trust](#)

### CONI Programme Support Materials

The following can be directly downloaded from the Lullaby Trust Website

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

- Alarm record (optional)
- CONI leaflet
- Information for GP Records
- Paediatric Passport
- Baby Check App
- Safer Sleep Information for both full term and premature infants.
- Bereavement Support Helpline

The following are provided by the local CONI co-ordinator:

- Symptom diary
- Weight chart
- Safer sleep easy read card (foreign language versions can be downloaded)
- Room thermometer
- Bereavement support leaflet
- Product guide
- Apnoea Alarm
- Mattress Monitor

BLS training

St Johns Ambulance <https://www.youtube.com/watch?v=avYRvVHAvfM>; cartoon  
song version <https://www.youtube.com/watch?v=Gc1kR8ZQxQ4>;

BLISS [https://www.youtube.com/watch?v=0nx-6\\_EaADA](https://www.youtube.com/watch?v=0nx-6_EaADA) (by a mother)

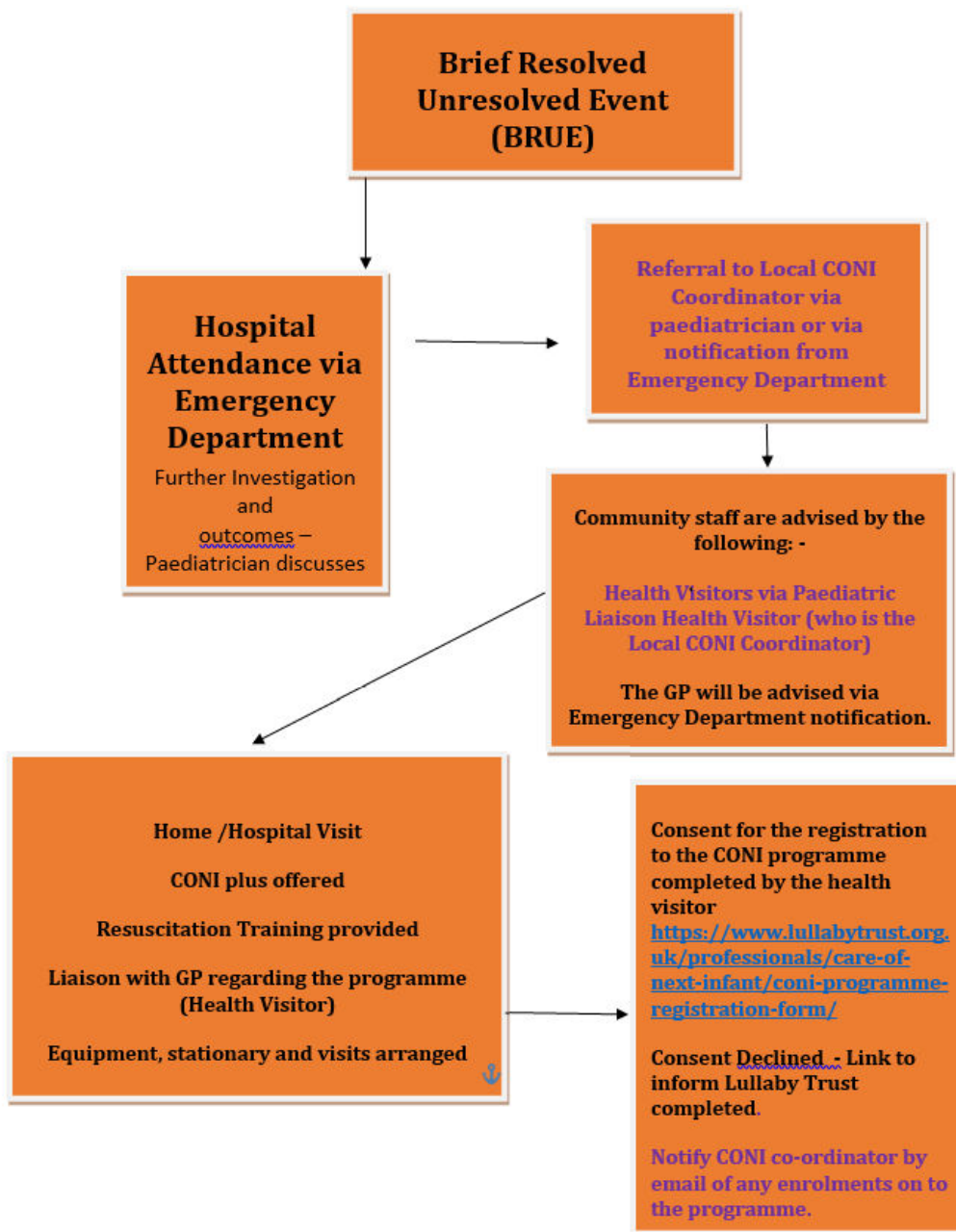
Information for healthcare professionals:

<https://www.lullabytrust.org.uk/professionals/care-of-next-infant/>

## Appendix 2 BRUE Enrolment Pathway

### BRUE Enrolment Pathway

Information in Purple involves the CONI Coordinator



## **BRUE – Brief Resolved Unexplained Event Pathway**

### **Lower Risk Babies**

Emergency Department Guidelines are as follows:-

- Greater than 60 days
- Gestational age greater than 32 weeks
- Only one event
- No cardio pulmonary resuscitation
- No features in the history of concern (including child abuse, family history of sudden unexplained death, toxic exposures)
- No physical examination findings (bruising, cardiac murmurs, organomegaly)

Management:

- Share information with primary care staff regarding attendance (HV/GP)  
Consider pertussis swab/ECG
- Information sharing will be via the paediatric liaison health visitor
- Brief monitoring in the department /admission for observation to the children's ward for monitoring.

A lower risk BRUE is unlikely to represent a presentation of a severe underlying disorder and is unlikely to recur. Infants who have had a lower risk BRUE may be discharged safely if their parents feel reassured and capable of caring for their infant at home. It should be acknowledged with the family, that these events are highly anxiety provoking and parents often feel that their child has nearly died. Parents should be reassured, and safer sleep advice should be revisited by the staff/health visitor.

When discharged, it is recommended that these infants have early medical follow up with GP or paediatrician if this has been arranged. In practice, many infants with a lower risk BRUE are admitted to the hospital ward for observation and paediatric opinion and later discharged to the health visitor. It is unlikely that CONI will be necessary in this instance.

### **Higher Risk Babies**

If the infant does not meet all of these criteria, the BRUE is considered high-risk, and more likely represents an underlying medical condition that will need further follow up by a paediatrician. Patients with a higher risk BRUE may still have a benign cause for their symptoms and should be admitted for observation, cardiorespiratory monitoring and paediatric review.

Consideration of additional support via CONI should be considered on a case by case basis and practitioners can identify the use of CONI to support parents.

## **Other families**

The CONI programme can be extended to families whose babies may be at increased risk of SUDI or who have reason to be anxious about their child these may include:-

### **Sudden Unexplained Infant Death**

Parents whose babies suffer a Sudden Unexplained Infant Death episode need further investigation, but for as many as quarter of such events no cause will be found. The fears that these parents have for their child's subsequent safety are similar to those expressed by parents with a sibling born following a SIDS, namely that the child will suddenly die, that they are frightened of the responsibility of parenthood and that professionals will not understand their anxieties. These babies are known to be at increased risk of dying.

### **Close relatives**

Parents who are close relatives of a SIDS baby i.e. one of the parents has had a sibling die or a niece or nephew die with a recorded cause of death of SIDS. Their babies are not at increased risk due to the family history. Parents may however, be very anxious, depending on the closeness of their relationship to the baby that died or because the new baby is premature etc. It may be appropriate to offer CONI when counselling cannot allay these fears.

### **Other baby deaths**

Parents of babies born following a post-perinatal death from causes other than SUDI occurring after discharge from the neonatal or postnatal unit. Parents of SIDS/SUDI are additionally vulnerable need extra support because no cause of death can be given. However, any parent whose child dies may experience feelings of guilt, inadequacy and failure. Where anxiety persists, CONI may provide appropriate help.

Local protocol allows the inclusion of parents made anxious for reasons other than the above. Reasons for inclusivity should be discussed with the team lead/co-ordinator and clearly recorded.

## Appendix 3 SIDS/SUDI Enrolment Pathway

**Previous SIDS/SUDI Enrolment Pathway**  
Information in Purple involves the CONI Coordinator

