# CARE OF THE NEXT INFANT (CONI) – GUIDELINE

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Date EQIA completed: 27/06/16

Documents to be read alongside this policy:
- MP02 – Management of Medical Devices
- MD01 – Consent to Examination or Treatment
- BCUHB Infant Safer Sleeping Guidance

Purpose of Issue/Description of current changes:
No longer delivering CONI plus

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<th>First operational:</th>
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**PROPRIETARY INFORMATION**

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1 Introduction

This policy is to provide midwives, health visitors, paediatricians, paediatric nurses, Neonatal Nurses, GP’s and other relevant health professionals with the framework for the process to identify and enrol parents and families for the CONI (Care of Next Infant) programme.

The CONI programme is a national programme that was established in 1988 by the Foundation for the Study of Infant Death (FSID), to work in partnership with the NHS to provide support for parents who have lost a child through sudden infant death syndrome (SIDS) and are planning to, or have a new baby.

Definitions

“Sudden infant death syndrome (SIDS) is defined as the sudden unexpected death of an infant less than one year of age … that remains unexplained after a thorough investigation, including performance of a complete autopsy and review of the circumstances of death and the clinical history.” (2004) “Cot Death” is also a term commonly used to describe a sudden and unexpected infant death that is initially unexplained. The equivalent medical term is “sudden unexpected death in infancy (SUDI)”. Some sudden and unexpected infant deaths can be explained by a thorough post-mortem examination. However Cot deaths that remain unexplained after a post-mortem examination are usually registered as sudden infant death syndrome (SIDS). Sometimes other terms like, sudden unexpected death in infancy (SUDI) or unascertained may be used (2006).

2. Scope

This policy applies to all professionals involved in The Care of the Next Infant (CONI) and clients who fit the criteria of the CONI programme.
It is indiscriminate of different groups e.g. race, gender, ethnicity, disability, language, religion and beliefs.

3. Aim

To ensure that there is good communication between Midwives, CONI Coordinators, Health Visitors, Paediatricians, Paediatric Nurses, Neonatal Nurses and General Practitioners.

To ensure that parents/families with personal history of cot death are identified at the appropriate time in order for them to access the CONI programme, so that they can receive appropriate and structured support.
4. Objectives

To guide the actions of professionals in terms of their responsibility to the client, and the actions they should take following identification of parent who has previously suffered the loss of a cot death.

To ensure that every parent and family is offered CONI support service, relevant to geographical area.

To ensure parents and families receive adequate coordinated support and emotional support following a previous infants cot death and during subsequent pregnancy and delivery to help alleviate their fears through support and education.

5. Target population of CONI Programme

Eligibility

History of either parent experiencing the loss of a child through Sudden Infant Death Syndrome (SIDS).

6. Practice Recommendations

Parents/families should be offered the opportunity to participate fully or partially in the CONI programme during subsequent pregnancies and until the child is at least six months old or two months after the age at which the previous SIDS occurred. Anniversaries of the previous baby’s birth and death are important and may affect when the support is withdrawn.

Parents should be informed about the support available and choose what is required with advice of the local designated health professional.

**CONI programme includes one or more of these interventions.**

- Negotiated contact between family and Health Visitor as required.
- Provision of Apnoea monitor/ mattress- Apnoea monitor before 6 months & Apnoea mattress after 6 months.
- Resuscitation training for parents.
- Sheffield weight chart and weekly weighing
- Room thermometer
- Symptom diaries
- Infants progress review by Paediatrician
- Paediatric CONI passport supplied.
Referral Process

- Referral by all health professionals who have contact with children and families.

7. Responsibility of Key Staff

Midwives (Hospital & Community)

The midwife identifies an antenatal parent with a history of previous SIDS, whilst completing Notification of Pregnancy form.

The midwife refers the pregnant mother for CONI Scheme by sending a completed referral form to the local coordinator.

The Midwife provides the pregnant mother with extra support during pregnancy and post-natal period for 10 - 28 days after the birth of the baby.

The midwife notifies the Health Visitor of the birth of the baby.

Health Visitors

Family Health Visitor to inform CONI Coordinator of the birth of the baby.

After the baby is born the care of the baby and the family lies with the primary health care team, with the family’s Health Visitor taking on the role of Key Worker. The HV will discuss any parental concerns as well as offering support, advice and reassurance.

The Health Visitor liaises with the local coordinator regarding resources required (i.e. stationary, equipment and faulty equipment).

Paediatrician

Involvement of a Consultant Paediatrician is essential in the antenatal & post natal period.

A Paediatrician completes the neonatal examination before discharge home and discusses any concerns with relevant professionals and makes referrals/follow up as necessary.

The Consultant Paediatrician will be in contact with the General Practitioner for each family involved in the programme.
Local Coordinators

Local CONI coordinators will be responsible for/or facilitation of:-

- Liaison with the National CONI Coordinator and for the local administration of CONI.
- Organising and providing the CONI programme.

  This can include meeting with the family to discuss the programme in detail and to ensure that the midwife, Health Visitors, GP and Paediatrician are informed about the parent’s admission onto the programme. (See Appendix letters sent out)

- Supporting professional training regarding CONI.
- Making contact with the mother at around 32 weeks (2 months prior to Expected Date of Delivery) (EDD) following confirmation of continuation of pregnancy with midwife/Health Visitor. Families also to have the option of contact in early pregnancy for anxious parents, especially to address concerns regarding the previous SIDS.
- Carrying out a home visit jointly if required with the family Health Visitor to:
  
  a) Provide the appropriate equipment ......
  b) Teach parents how to use equipment.....
  c) Advise parents how to seek help in an emergency ...

  An apnoea alarm can be left with the parents before the baby is born so that they have plenty of time to familiarise themselves with how it works.

- Notifying the designated Paediatrician about new referral.
- Informing the General Practitioner of new referral to the CONI Scheme.
- Arranging resuscitation training for parent/family during the antenatal period at the home. This should be undertaken on a separate occasion to the home interview.

- Obtaining parental consent for the information gathered on the CONI programme to be sent for analysis to Lullaby Trust London following discharge from the programme. If consent is declined, records will be held locally with the child’s health records.
- Evaluate parent’s experience of CONI service at the end of the programme.

Accident & Emergency/ Paediatric Ward/Special Care Baby Unit
• To access the relevant CONI pack for local training/update purposes
• To be aware of the CONI “passport”
• To be aware of the named lead Paediatrician for CONI

Senior Nurse Manager:

• To supervise Local Coordinator/Health Visitor involvement and continuity
• To ensure that local Coordinators/staff have the opportunity to access update/training.

8. Documentation Requirements:

Good standard of record keeping as per NMC 2009 Record Keeping guidance for Nursing & Midwifery Council Guidance.

Contract and plan of care to be recorded in Health Visiting documents/records by Health Visitor and in Personal Child Health Record (PCHR red book).

Coordinator to keep own record until infant discharged from programme and then to be kept in Health Visitors records.

Symptoms Diary, Weight Chart etc to be sent to the CONI National Coordinator at the Lullaby Trust London after Discharge from CONI Programme (with parental consent) for research purposes.

Paediatric “PASSPORT” CONI to be placed in the child’s Personal Child Health Record (RED BOOK) and to remove at the end of the programme.

CONI GP Checklist to be kept with the clients notes in surgery.

9. Education/training

CONI Coordinators to attend one day initial training followed by annual regional meetings.

CONI Coordinators to update colleagues as new information becomes available.

CONI resource pack to be sent out to relevant departments/General Practitioners and updated as required.

10. Apnoea Monitors:

Graseby monitors to be used only for CONI referrals.
To be checked after each client by Electro Biomechanical Engineering Department

To be serviced regularly by EBME as requested.

Any fault to be checked by EBME

11. Audit

Evaluate the CONI programmes across North Wales annually by collating local figures which will be carried out by CONI Coordinators. The Lullaby Trust will undertake Audit to evaluate effectiveness of the CONI programme.

12. Equality Impact Assessment

BCUHB values and respects the individual through providing equal opportunities for active involvement within the scope of the Health Board’s needs and resources. The Health Board will aim to ensure that its equal opportunity policy guides all its dealings with clients considered in this guideline.

This policy has undergone the process of Quality Impact Assessment and appears to be compliant with the current information available. Continuing monitoring of this will be undertaken to ensure it remains compliant.

13. References:
Lullaby Trust SIDS Facts and Figures. August 2015
Participation of disadvantaged parents in child care research.
Child Care Health Dev 31(5):581-7
In: “Completed Research” From FSID website accessed 4th August 2008

Sudden infant death syndrome and unclassified sudden infant deaths: a definitional and diagnostic approach.

IN: Factfile 2. Research background to the Reduce the Risk of Cot Death advice by the Foundation for the Study of Infant Deaths
From FSID website accessed 4th August 2008:
Nursing and Midwifery Council (NMC) (2004). Guidelines for records and record keeping
NMC, London

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Members of the Working Group:

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<td>Fiona Brown</td>
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Health Visitors & local CONI coordinators

Consultation has taken place with:

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<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Date Consulted</th>
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Appendix 1 – CONI Referral form Midwife

CONI – CARE OF THE NEXT INFANT

Please notify the coni co-ordinator of all women booking for antenatal care who have suffered a sudden infant death (SIDS) or whose partner has suffered a SIDS.

Mother’s name ……………………………………………………………………………………………………

Address ……………………………………………………………………………………………………………

…………………………………………………………………………………………………………………………

Post code …………………………………………………………...

Telephone number …………………………………………

EDD …………………………………………………………………

Booked for Delivery at ………………………………………………………………………………………

Name of Mother’s GP ………………………………………………………………………………………

Address …………………………………………………………………………………………………………………

…………………………………………………………………………………………………………………………

Reason for referral, with details if known:

A) Mother’s previous SIDS …………………………………………………………………………

…………………………………………………………………………………………………………………………

B) Partner’s previous SIDS …………………………………………………………………………………

…………………………………………………………………………………………………………………………

C) Other information ………………………………………………………………………………………

…………………………………………………………………………………………………………………………

Name of midwife making the referral ……………………………………………………………

Date ………………………………………………………………………

PLEASE FORWARD TO LOCAL CONI CO-ORDINATOR (add name and address)
Appendix 2 - Notification to Client

Date

Dear

Your midwife has referred you to the CONI programme. I would like to meet with you in the next two weeks if possible to outline the CONI programme. If you decide to enrol on the programme you will be contacted again later in your pregnancy around (32 weeks) to arrange a home visit from myself and your family Health Visitor. This will be to discuss the documentation and the equipment etc and the help and support it can offer you.

If at any time you wish to discuss the programme or do not wish to continue on it, please contact me at the above address or phone number.

I look forward to meeting you soon.

Yours Sincerely

Health Visitor CONI Co coordinator.
Appendix 3 - Notification to Health Visitor

Date

Dear

I have been informed by the midwife that ………………………

Name ………………………
Address ………………………
……………………
……………………
Tel ………………………
GP ………………………
EDD ………………………

Would like to be referred to CONI Programme.

A joint visit is necessary with the family Health Visitor approximately two months before the birth is expected.

Please could you contact me to arrange a convenient time for us to visit the family.
It is also important that you inform the CONI Coordinator on receipt of the birth notification.

Yours Sincerely

Health Visitor CONI Coordinator
Appendix 4 – CONI letter Notification to Paediatrician of Families Inclusion on the CONI Programme

Date

Dear Br Barnard

I am writing to inform you that
Name……………………………………
Address………………………………
……………………………………
……………………………………
……………………………………
Tel   …………………………………
DOB …………………………………
GP……………………………………

Would like to be referred to the CONI Programme.
EDD………………    DOB………………

Previous SIDS    Yes /No

I would be grateful if you could ensure that this information is passed on to your colleagues.

Yours Sincerely

Health Visitor

CONI Coordinator
Appendix 5 – CONI letter to GP

Notification to General Practitioner of Clients inclusion on to CONI Programme

Date

Dear Dr

I am writing to inform you that ..........................................................
..........................................................................................
..........................................................................................
..........................................................................................

Has been included on to the CONI Programme.

EDD................. DOB................

I would be grateful if you could ensure this information is passed on to your colleagues so that it can be flagged up in your surgery.

Previous SIDS Yes/No

Yours Sincerely

Health Visitor

CONI Coordinator
Appendix 6 – CONI letter discharge from Programme

Notification of Discharge from CONI Programme to Colleagues

Date

Dear Colleague

I am writing to inform you that:

Name ................................
Address ................................
Tel ......................................
GP ......................................
DOB ....................................

Has now been discharged from the CONI programme

Yours Sincerely

Health Visitor

CONI Coordinator
Appendix 7 – CONI Letter Parent/family declaration form.

Conformation that CONI Programme explained to Parents

Date

Dear Parents

I confirm that the CONI Coordinator has explained the CONI scheme

Monitors
Resuscitation
CONI pack
Signature
Print Name
Address

Health Visitor

CONI Coordinator

Return Address: ........................................................................
........................................................................
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## EQUIPMENT LOAN FORM

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<thead>
<tr>
<th>Name:</th>
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<tbody>
<tr>
<td>Date of Birth:</td>
</tr>
<tr>
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</tr>
<tr>
<td>Address:</td>
</tr>
<tr>
<td>Tel No:</td>
</tr>
<tr>
<td>School:</td>
</tr>
<tr>
<td>Equipment Details:</td>
</tr>
<tr>
<td>Equipment Serial Number:</td>
</tr>
<tr>
<td>Service Due</td>
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I undertake to return this **NHS equipment** to the above address when it is no longer medically required, or if I move out of the area so that it can be reissued for the benefit of another child.

Any equipment in need of servicing should be returned to the above address.

Signed:................................................................. Date:.................................