

Care of the Next Infant and Care of the Next Infant Plus

Date	Version
28.11.17	1.0
Purpose	
To identify clear pathway for mothers and infants who are eligible for referral to the Care of the Next Infant (CONI) scheme and the Care of the Next Infant (CONI) Plus scheme. To clearly identify professional roles and processes.	
Who should read this document?	
All individuals involved with children and their families under the age of 2 years, this with include paediatricians, neonatal nurses, midwives, nursing staff and all emergency department staff.	
Key messages	
A scheme to provide additional support for families with a history of infant death in the first 2 years of life. A scheme to provide additional support for families with an infant that has had an apparent life threatening event in the first 6 months of life.	
Accountabilities	
Production	Brigitte Price Care of the next Infant Coordinator Plymouth
Review and approval	Clinical Governance acute Paediatrics and community paediatrics.
Ratification	Director of nursing
Dissemination	Clinical Governance acute Paediatrics and community paediatrics
Compliance	Clinical Governance acute Paediatrics and community paediatrics
Links to other policies and procedures	
Child protection policy	
Version History	
V1	23.04.15
Last Approval	Due for Review
April 2015	April 2020

PHNT is committed to creating a fully inclusive and accessible service.

Making equality and diversity an integral part of the business will enable us to enhance the services we deliver and better meet the needs of patients and staff.

We will treat people with dignity and respect, actively promote equality and diversity, and eliminate all forms of discrimination regardless of (but not limited to) age, disability, gender reassignment, race, religion or belief, sex, sexual orientation, marriage/civil partnership and pregnancy/ maternity.

An electronic version of this document is available on the Trust Documents Network Share Folder (G:\TrustDocuments). Larger text, Braille and Audio versions can be made available upon request.

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1 Introduction

All families with young babies worry about the possibility of cot death. When a family has already suffered this tragedy it is inevitable that the next pregnancy and the next child's life will not only be a time of joy but also anxiety. Experience has suggested that informed professional support during this time can help to alleviate this anxiety and be of value in ensuring appropriate care for the new baby. (Coni Coordinator Manual, 2011)

Despite the fall in numbers following the "back to sleep" Reduce the Risk, campaign in 1991 a total of 3,800 children under five died in the UK in 2013. The UK has one of the highest rates of death for children under five in Western Europe.

Poverty and smoking in pregnancy were two main factors that contributed to the high rate which saw UK child deaths more than double that of Iceland where the rate was the lowest. (The Lancet, 2007).

Five babies die every week from Sudden Infant Death Syndrome (SIDS), it is the leading cause of death for babies between the age of one month and one year. The rate of unexplained death was three times higher among low birth weight babies (less than 2,500g) than babies with a normal birth weight. (Office of National statistics, 2014).

Some of these deaths could be prevented if parents understood how best to sleep their babies safely. This means educating parents not to put babies to sleep on their tummies, not to bed share especially if either parent smokes, takes any medication or has drunk alcohol. To ensure that babies feet are to the bottom of the cot, not to overwrap or swaddle. We now know that one of the biggest risks is putting babies to sleep on sofas and maternal smoking during pregnancy and babies being exposed to second hand cigarette smoke. One of the main roles in the scheme is to support and educate parents in safe sleeping of their babies

2 Purpose, including legal or regulatory background

CONI should be offered to parents expecting a new baby where either parent has previously suffered the sudden unexpected death of a child under the age of 2 years ie the history may come from both parents the mother or the father of the new baby. The programme should also be offered to support families with a surviving child (ren) from a multiple birth where one baby dies unexpectedly.

By 1995 over 4000 babies had been enrolled on to the CONI scheme and centres were requesting that the programme be available to a wider group. So the scheme was extended and CONI plus extends the scheme to include:-

1. Close relatives who had a sudden infant death, ie grandparents, aunts and uncles.
- 2 Other baby deaths, post-perinatal death from causes other than SIDS occurring after discharge from the post natal or neonatal unit.
- 3 Parents, whose babies suffer an "apparently life threatening event."(ALTE). This can then cause fears for the survival of their baby. These babies are known to be at increased risk of mortality. (Gibb and Waite 1998)

It is expected that every local trust will allocate funds to maintain and support their CONI/CONI PLUS programmes. A budget is required to meet recurrent costs which include stationary packs, equipment, servicing of equipment, disposable items for equipment costs to attend regional meetings and co-ordinator training sessions.

3 Definitions

CONI Care of the next infant, A scheme to support parents who have had a death of a child less than 2 years of age in their current or previous relationship.

CONI plus Care of the next infant, A scheme when a death of a child less than 2 has occurred to an extended family member. A baby has an apparent life threatening event under the age of 6 months.

ALTE apparent life threatening event.

SIDS Sudden infant Death Syndrome

4 Duties

Midwife, when the midwife books the mother for antenatal care and takes her obstetric and family history and there is a history of a death in a child less than 2 years of age, a referral will be made to the local conic – coordinator using the referral form (appendix 4). A copy is placed in the medical notes if the woman is happy for it to be there. A copy is then sent to the local conic -coordinator. A teardrop sticker should be on the mother's record to indicate that she has had a death of a baby/child. Mothers are also eligible for the scheme if her partner has had a baby death in another relationship, also if an extended family member grandparent, auntie uncle. The same referral process is used, though the Lullaby Trust classifies extended family as CONI plus. If the midwife has any concerns this can be discussed with the local conic-coordinator.

Obstetrician, if the obstetrician is made aware that the mother is entitled to the scheme then a referral will be made as above if the woman's midwife has not done this.

Conic -coordinator receives the referral and forwards to the relevant conic-coordinator if Devon or Cornwall.

The Conic-coordinator will contact parents and give contact details and arrange a meeting ideally two months before the expected due date. CONI paperwork is completed and resuscitation is arranged. The paediatrician is contacted who cared for the baby who died if appropriate.

Once the baby is born the Conic-coordinator will do a joint visit to the family with the allocated health visitor. Paperwork will be completed and consent signed and sent to the Lullaby Trust. If on discussion with the parents they decide not to consent to share information with the Lullaby Trust then a consent declined is sent to the Lullaby Trust. The family will still be offered the same support as though they had consented.

When a baby is referred following an ALTE the conic –coordinator will meet with the family prior to discharge to discuss the scheme and familiarise the parents with the use of the

apnoea monitor. If the Coni-coordinator is not available identified members in the paediatric community team will meet with the parents.

All support tools are discussed and parents decide what would be helpful for them. The apnoea monitor needs to have been checked and in date by the conic –coordinator who is responsible that supplies of sensors are also provided.

All Coni and Coni plus packs will be ordered via Eproc by the community nursing team as requested by the conic-coordinator.

The conic –coordinator will contact the children’s assessment unit and arrange open access. This will finish when the baby is six months unless the baby has another condition and the named paediatrician wishes for this to be extended.

The conic-cordinator details are given to the parents and health visitor. Depending on the level of complexity of the family or levels of anxiety the conic coordinator may do further contacts and then update the health visitor.

The conic –coordinator will routinely contact the family at 4 months to discuss apnoea monitor use and prepare the family for stopping use by the time the baby is 6 months.

The conic-coordinator will complete a questionnaire sent from the Lullaby Trust between 6-7 months and collect paperwork to be sent to the Lullaby Trust.

Health visitor, attends the initial joint visit and familiarises themselves with the paperwork. The health visitor will see the family weekly to weigh the baby and run through the symptom diary and alarm sheet if being used. The initial visits should happen at home, when discussed with the parent this may change to clinic or be shared with a family health worker as the parents are happy with. Where possible the same scales should be used and all professionals weighing the baby should be confident in plotting on the Sheffield weight chart.

This process is the same for a baby who has had an apparent life threatening event (ALTE) and the health visitor should be informed as soon as possible that a baby has had an ALTE and has been referred to the CONI plus scheme.

The health visitor will pass the general practitioner card to the families general practitioner so that they are aware that the baby is part of CONI or CONI plus. The card requests that the baby will be seen on the day that a parent contacts the surgery.

Health visitors record their contacts on the CONI form C.

Paediatricians/Neonatologists, the paediatrician/neonatologist who cared for the baby who died may have been involved with the family and established a relationship with the parents for that reason they can decide if they would want to be the named paediatrician for the new baby. If there is no previous paediatric consultant or it is not appropriate the named CONI consultant will be allocated . Their role is to provide advice to the conic coordinator or health visitor as required.

Following an ALTE, the paediatrician or neonatologist who admits the baby or is made aware of the baby, should make a referral or ask the nursing staff to make a referral to the Conic-Coordinator using Appendix 5, this should be done as soon as possible so resuscitation can be arranged prior to discharge. The scheme in Plymouth Hospital Trust

area only uses an apnoea alarm suitable for infants under 6 months so the scheme is unable to take referrals for older infants, but liaison and support including the health visitor can be undertaken. However, in this case it is important that resuscitation is still taught and the health visiting services are aware.

All babies on both schemes have open access on the children's assessment unit. Any baby will need to be seen by the paediatric team if there is weight loss that causes a crossing of one channel width in 2 weeks or 2 channels over 8 weeks according the Sheffield weight chart without a medical cause ie diarrhoea and vomiting , upper respiratory tract infection.

General Practitioners.

All general practitioners will be forwarded a notification that the baby is on the scheme. The notification requests that the baby should be seen on the same day that the parent contacts the surgery with a concern. If the general practitioner has any concerns they should contact the service paediatrician at Derriford Hospital.

All professionals

Due to the demographic changes of families who have a Sudden Infant Death there maybe underlying safeguarding concerns. All professionals should liaise with children and family services and follow the Child protection Policy and discuss within child protection supervision as indicated.

All professionals need to provide safe sleep advice, encourage breast feeding and also stop smoking advice during and after the pregnancy.

5	Key elements (determined from guidance, templates, exemplars etc)
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Methods of support.

Regularly weekly contact, with the family's health visitor and fast access to a paediatrician.

Symptom diaries, to assist parents to recognise changes in their babies health and help them to raise concerns to their health visitor at the regular visit. They also create an opportunities for health education.

Baby check booklet, to assess severity of signs and symptoms and assist parents in making decisions regarding seeking medical advice.

Weighing, regular weighing of baby in the home by parents and the weights recorded on to Sheffield Weight Charts.

Weight charts, we advise that all babies on the scheme should have their weights recorded on the Sheffield Weight Charts at regular intervals i.e not less than once per week.

Movement (apnoea) monitoring, provision of an apnoea monitor for parental reassurance for use up to the age of 6 months. In some areas there is apnoea mattress provision for after 6 months but this provision is not available locally.

Room thermometers, parents need to be aware of the room temperature and adjust bedding and clothing appropriately.

Health Education Information, leaflets and the safe sleep card provided by the Lullaby Trust will be discussed with the family in line with other health education provided by midwives and the health visiting service.

Guidelines for User, booklet for health visitors/coni coordinators to provide overview of the scheme.

6 Overall Responsibility for the document

Plymouth Hospital Trust CONI co-ordinator based within the Children's Community Nursing Team.

7 Consultation and ratification

The design and process of review and revision of this policy will comply with the development and Management of Trust Wide Documents.

The review for this document is set as a default of five years from the date it was last ratified, or earlier if developments within or external to the trust indicate the need for a significant revision to the procedure described.

As this policy is based on the pathways of the Lullaby Trust any evidence based changes implemented by the Lullaby trust will need to be integrated within the policy.

8 Dissemination and Implementation

Following approval and ratification, this policy will be published in the Trust's formal documents library and all staff will be notified through the Trust's normal notification policy.

Senior managers will be informed by email and they will be responsible for cascading information to their staff.

Document control arrangements will be in accordance with the Development and Management of Trust Wide Documents.

The document author will be responsible for identifying and carrying out the training requirements associated with the newly ratified document with the director and for working with the Trusts training function if required.

Line managers are responsible for ensuring this policy is implemented across their area of work.

9 Monitoring compliance and effectiveness

The Chief Executive is ultimately responsible for ensuring compliance with the policy.

The Coni –ordinator will monitor referrals and a Datix will be completed for missed referrals that become apparent following delivery .

10 | References and associated documentation

Rehttp://www.bbc.co.uk/news/health-27251908

Office of national statistics 2014

Coni co-ordinator manual 2011

www.lullabytrust.org.uk SIDS facts and figures 2014

The health Professionals guide to “caring for your baby at Night “, Blair, P. Inch,S.Baby Friendly Initiative Unicef

Sudden unexplained deaths in infancy.The CESDI SUDI studies 1993-1996. London :the stationary office 2000.

Core Information				
Document Title	Care of the Next Infant and Care of the Next Infant Plus			
Date Finalised	November 2017			
Dissemination Lead	Brigitte Price Care of the next infant co-ordinator			
Previous Documents				
Previous document in use?	No			
Action to retrieve old copies.	NA			
Dissemination Plan				
Recipient(s)	When	How	Responsibility	Progress update
All trust staff		Vital signs	Information governance	

Review		
Title	Is the title clear and unambiguous?	yes
	Is it clear whether the document is a policy, procedure, protocol, framework, APN or SOP?	yes
	Does the style & format comply?	yes
Rationale	Are reasons for development of the document stated?	yes
Development Process	Is the method described in brief?	yes
	Are people involved in the development identified?	yes
	Has a reasonable attempt has been made to ensure relevant expertise has been used?	Yes
	Is there evidence of consultation with stakeholders and users?	yes
Content	Is the objective of the document clear?	yes
	Is the target population clear and unambiguous?	yes
	Are the intended outcomes described?	yes
	Are the statements clear and unambiguous?	yes
Evidence Base	Is the type of evidence to support the document identified explicitly?	yes
	Are key references cited and in full?	yes
	Are supporting documents referenced?	yes
Approval	Does the document identify which committee/group will review it?	yes
	If appropriate have the joint Human Resources/staff side committee (or equivalent) approved the document?	yes
	Does the document identify which Executive Director will ratify it?	yes
Dissemination & Implementation	Is there an outline/plan to identify how this will be done?	yes
	Does the plan include the necessary training/support to ensure compliance?	yes
Document Control	Does the document identify where it will be held?	yes
	Have archiving arrangements for superseded documents been addressed?	yes
Monitoring Compliance & Effectiveness	Are there measurable standards or KPIs to support the monitoring of compliance with and effectiveness of the document?	yes
	Is there a plan to review or audit compliance with the document?	yes
Review Date	Is the review date identified?	yes
	Is the frequency of review identified? If so is it acceptable?	yes
Overall Responsibility	Is it clear who will be responsible for co-ordinating the dissemination, implementation and review of the document?	yes

Core Information	
Manager	Sue Stock
Directorate	Women and Children
Date	24.05.16
Title	Care of the Next Infant and Care of the Next Infant Plus
What are the aims, objectives & projected outcomes?	To provide a consistent approach to the scheme and ensure that professionals are aware of what process to follow.
Scope of the assessment	
All protected characteristics have been considered in the development of this. Service user monitoring , analysis and publication will be undertaken to ensure compliance,	
Collecting data	
Race	Reasons for this category having an impact are: - Language - Understanding of NHS (UK health system) - Transient population (for some) Consideration should be given to people who may have communication difficulties e.g. cultural barriers, and language. The appropriate translation service or format for information will be used.
Religion	Consideration must be given to all individuals beliefs.
Disability	Consideration must be given to people who may have communication difficulties e.g. learning disabilities, speech, and hearing difficulties. The appropriate translation service or format for information should be used.
Sex	Has no impact on this policy.
Gender Identity	Has no impact on policy
Sexual Orientation	Has no impact on policy
Age	Has no impact on policy
Socio-Economic	Evidence demonstrates that SID is higher in, lower socio –economic groups.
Human Rights	Individuals consent to the scheme .
What are the overall trends/patterns in the above data?	Evidence demonstrates that certain babies are at a higher risk of SIDS ,twins , low birth weight babies , babies to young mothers , to have parents who smoke,

Specific issues and data gaps that may need to be addressed through consultation or further research	The number of families that are not offered the scheme is an unknown the policy will clarify process when missed babies are identified. This will require monitoring via Datix.			
Involving and consulting stakeholders				
Internal involvement and consultation	Safeguarding children and adult services , paediatric and neonatology governance systems.			
External involvement and consultation	Lullaby Trust driving force in the research and information available to families on the scheme.			
Impact Assessment				
Overall assessment and analysis of the evidence				
Action Plan				
Action	Owner	Risks	Completion Date	Progress update

Referral to CONI Project

Name:		<u>Unborn Baby</u>	
DOB:		EDD:	
Address:		Gravida:	
Post Code:		Para:	
Tel No:			
Hospital No:			
NHS No:			
Date of referral			
Religion:		Ethnicity	
GP Details:		Obstetrician Details:	
Midwife details:		H/V details (if known)	
Is this family on vulnerable family pathway? YES/NO If no then please complete Vulnerable Family Pathway			
Details of children including the child who died is very important			
Child who died from Sudden Unexplained Death in Infants:- Name: DOB: Date of Death: Any further information			
Any other children:- Name:		DOB:	

'All families with young babies worry about the possibility of cot death. When a family has already suffered this tragedy it is inevitable that the next pregnancy and the first few months of the child's life will be a time not only of joy but also of anxiety'. (Care of the Next Infant Guidelines 2011)

CONI should be offered to parents expecting a new baby where either parent has previously suffered the sudden unexpected death of a child less than 2 years of age.

Contacts

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