

the
lullaby
trust

coni

Implementation of the Care of Next Infant (CONI) Programme

Information for Commissioners and
Public Health Leads

National Lead for CONI:

Stella Parkin SCPHN (HV) RGN PGCE

National CONI Coordinator:

Bettina Bavi SCPHN (HV) RMN



coni@lullabytrust.org.uk

Contents

Background	3
Elements of CONI	4
Health professionals providing support	5
Benefits of providing CONI	6
Conclusion	8
Appendix	9
• Considerations	
• Costs	
References	11



Background

For over 35 years, the Care of Next Infant programme (CONI) has provided support to bereaved families across England, Wales and Northern Ireland who have experienced a sudden unexpected death of a baby who have a subsequent baby. To date 25,000 babies have been enrolled on to CONI.

Emotional support, and practical information and advice is provided to families for a period of six months. It is usually delivered by the provider of the community public health visiting service. This support can help parents reduce anxiety, gain confidence in caring for their new baby and enjoy the first year of their new baby's life.

CONI is coordinated nationally by the CONI Team at The Lullaby Trust. They provide specialist advice and information, support and training to the CONI coordinators, health visitors and other health professionals. With parental consent, they also review and report on feedback collected from families. This helps inform practice and audits the programme.



Eligibility

The CONI programme should be offered when either parent has experienced the unexpected death of a child aged under two years. It should also be offered to support families with a surviving child or children from a multiple birth where one baby dies unexpectedly.

CONI support may be extended to other families whose babies may be at increased risk of sudden infant death or who have reason to be anxious about their baby. This is determined at local level based on need and availability of resources.

The number of families per year supported by the CONI programme locally will vary by area. The geographical size of the county needs to be considered, as does the eligibility criteria the county/area adopts. In addition, the number of families supported is likely to reflect the number of sudden infant death syndrome and sudden unexpected deaths in infancy (SIDS/SUDI) deaths at local level.

The Office for National Statistics (ONS) releases SIDS rates annually for England and Wales, as does the

Northern Ireland Statistics and Research Agency (NISRA). Child Death Overview Panels (CDOPS) or Child Death Teams in England can provide numbers of local SUDI and SIDS deaths, as can the National Child Mortality Database (NCMD) ⁽¹⁾.

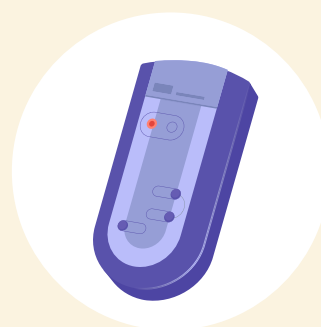
The CONI Team at The Lullaby Trust: coni@lullabytrust.org.uk are able to provide historical numbers of enrolments by county.

Elements of CONI support

The support parents receive on CONI can be as much or as little as they like. They can choose from:

Movement (breathing) monitor

Detects movements as the baby breathes and can be lent or given to the family (depending on the type of monitor and local resources). Although monitors do not prevent SUDI/SIDS, parents report that they provide reassurance, especially at night and can gradually build confidence.



Basic life support instruction (BLS)

BLS should be provided to the family and ideally other carers. It is important that the family feel more prepared and confident, in the unlikely event that the monitor alarms and their baby has stopped breathing.



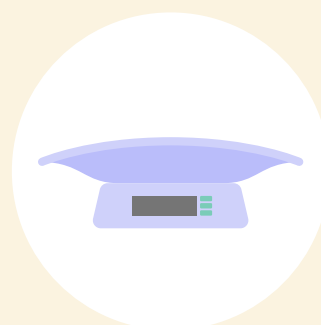
Symptom diary

Enables parents to note changes in their baby's health, appearance and behaviour. The diary helps them to learn about their baby so that their confidence grows. The diary helps with the early recognition of ill health and can make it easier for parents to be able to discuss concerns with their health visitor. When used in conjunction with the Sheffield Weight Chart, it enables health professionals to assess whether any weight changes are concurrent with symptoms in the symptom diary.



Sheffield Weight Chart

Increased weighing is offered using a specialized A1 size chart. Its large size means that any slowing in a baby's growth or sudden weight loss can be detected quickly. Infants who subsequently die of SIDS are more likely to be born with low birth weights compared to living controls and to gain weight more slowly ⁽²⁾



Baby Check app

A free mobile phone app that helps parents decide if their baby needs medical help.



Room thermometer

Helps parents follow safer sleep advice by ensuring that they keep the room where their baby sleeps at a safer temperature.

Leaflets

Give parents safer sleep advice, and information about bereavement support. Available as physical leaflets or as printable pdfs.



CONI healthcare passport

A printable pdf sheet placed inside the baby's Personal Child Health Record (Red Book) so that if the baby is unwell, they can be seen quickly by the right health professional, especially in A&E.



Information for GP records

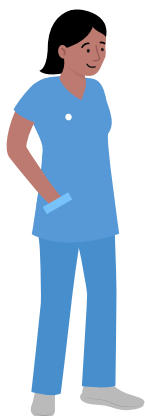
A printable pdf sheet provided to the GP surgery by the CONI coordinator to alert the surgery staff that the baby is on the CONI programme, and to prompt them about the baby's previous medical history or family history with regard to SIDS.

Health professionals providing support

CONI coordinator

Specifically trained local health visitor who coordinates the programme at local level. Typically, they receive referrals from midwives and other professionals, enrol families, store and provide CONI equipment and resources, liaise with and refer to other professionals e.g. paediatricians and GPs, support the health visitor providing care to the family, and liaise with the CONI Team.





Local health visitor

Provides weekly support, usually by home visit. However, the aim of the programme is that as the confidence of the parents grows, the support then lessens over time. Their role is to listen to the anxieties and concerns of the parents, offer strategies, advice and information, assess the family's needs, weigh the baby more frequently and assess the baby for signs of ill-health.

Midwives

Ideally the midwife identifies parents early during pregnancy, and introduces CONI to them. With consent, they refer to the local CONI coordinator and support parents in the early few days after their new baby is born.



Paediatricians

Ideally a paediatrician will be involved with local CONI programme. Parents may be offered an ante-natal contact with a paediatrician, routine checks or examine the baby if the parents are concerned. Their role is decided locally.

Benefits of providing CONI

Health promotion and risk minimisation

The risk factors associated with SIDS/SUDI remain high in the CONI population, and bereaved CONI families are some of the most vulnerable and socio-economically deprived families. Mapped to the Index of Multiple Deprivation

(IMD) last published in 2019, 55% of 2023 CONI families lived in the most deprived areas with England (Deciles 1-4) ⁽³⁾.

The risk of repeat SUDI in a family is 10 times that of the general population, reflecting both inherent genetic risks as well as environmental factors such as maternal smoking, hazardous co-sleeping and unsafe sleeping positions ⁽⁴⁾.

Although CONI is primarily a bereavement support programme, it also creates opportunities for health visitors to have ongoing in-depth conversations about health promotion and risk minimisation at a time when parents are often the most receptive to behaviour change interventions ⁽⁵⁾. They can work in a strengths-based way to promote compliance with safer sleeping advice, reduce smoking, and support breastfeeding to lower the risk to the baby and reduce health inequalities. The clinical elements also provide an opportunity to detect early signs of ill-health and faltering growth in the baby.

Parental mental health

An infant death affects parents' mental health and they are often anxious and fearful for the survival of subsequent babies. Severe symptoms and heightened risk for prolonged grief disorder (PGD) is seen in mothers after their infants died of SIDS ⁽⁶⁾. Untreated perinatal mental illness can have a devastating impact on mothers, fathers and their families ⁽⁵⁾.

A history of child loss is also an important risk factor for a mother's ability to bond with a subsequent baby. Under the effect of perinatal grief anxieties, it becomes even more complex for some mothers to form an attachment with a new baby because their ability to offer the necessary emotional care is impaired ^{(7) (8) (9)}. Feedback from parents consistently reports that support from the programme reduces their stress and increases their parenting confidence, enabling them to bond and enjoy their baby. 92% of parents scored the CONI programme as four or five (very helpful) in 2024 -2025.

Feedback from parents:

"CONI made me feel more confident, less anxious and more relaxed."

"I feel like my baby wouldn't be here today if it wasn't for the CONI programme."

"Best experience we've ever had. Best support, comfort, kindness and reassurance. 100% stopped me getting postnatal depression and without a doubt calmed our anxieties."

"A good programme for mums with anxiety, mums that lost their confidence in raising a baby. It gave me reassurance that this baby will be well and I have all the support that can possibly exist."

The CONI programme offers the opportunity for parents to express their concerns and feelings and develop the confidence needed to develop a full relationship

with their new baby during the first six months when the risk of SIDS is greatest.

Bereavement support

The CONI programme is recommended by the National Bereavement Care Pathway (NBCP) when parents have a subsequent pregnancy ⁽¹⁰⁾.

The NBCP is now used in 100% of NHS England hospital sites. A Trust that meets these standards is considered to be providing high quality bereavement care and support.

In general, all bereaved people make greater use of healthcare services including GP services, mental health services, acute and psychiatric hospitals, and increased use of medicines ⁽¹¹⁾. Organised bereavement support can reduce the use of health care services, including GP consultations ⁽¹²⁾. 68% of CONI parents have said that they would definitely, very likely or likely consult their GP more often if they had not had support from CONI (2024).

Full cost benefit analyses of bereavement services are underdeveloped nationally. However, the unit costs of providing bereavement services can be set against the unit costs of other types of health and social care provision that parents might access in bereavement.

Importantly, in the absence of the CONI programme, the enhanced support that CONI families need means that the local health visiting service still needs to provide Targeted Services under the modernised health visiting and school nursing service delivery model ⁽¹³⁾.

Conclusion

The CONI programme has been supporting families for more than 35 years. It is a well-established and valued package of support for families who have previously had a baby die or who have experienced an event where their anxieties and confidence have been significantly compromised to require enhanced support.

The CONI programme isn't completely cost neutral. Its value isn't purely a financial one but can be measured in terms of positive impact on parents, babies and the wider family, delivery against public health outcomes and targets, reduced impact on wider services, and reputational benefits. The quality of babies' lives should be a sufficient return on investment.

Appendix

Considerations

- Storage facilities needed for equipment, resources and publications.
- Printing facilities required where leaflets are printed from pdf, if not purchased from The Lullaby Trust.
- No servicing requirement by manufacturer for movement monitors.
- Minimal cost regarding infection control.
- Low cost regarding training and updates.

CONI coordinators

- Contact time with the family i.e. phone contact following referral, enrolment visit and visit at end of the programme
- Time to liaise with local health professionals
- Time to complete training and updates

Health visitors

- Time to deliver support for six months on average. Initially weekly by home visit, and then reducing. As parental confidence grows, home visits lessen in frequency and are often replaced with other forms of contact e.g. by phone or at the child health clinic.

Costs

Training and updates of CONI coordinators

Numbers of CONI coordinators will vary by area depending on geographical size.

- Online initial training for health visitors to become CONI coordinators - £55 (includes a resource pack)
- Online update training for CONI coordinators (minimum requirement every three years) - £25

Resources and equipment

1. Movement (breathing) monitors

- Must have a medical devices certification
- Families should be offered a choice of monitor to suit their preference and capability

Guide costs for the most popular monitors (contact suppliers for up-to-date costs):

- Nanny BM-02 mattress monitor (control unit lasts 10 years; mattress is single use)
 - Complete monitor £112.99
 - Replacement mattress pad £59.99
- Snuza Hero MD monitor (single-use monitor given to the family to keep) £78.99

There are no servicing requirements for either of these monitors. However, it is recommended to follow local servicing guidelines for monitors that can be re-loaned out to families e.g. the Nanny BM-02 monitor.

2. Seca 384 class III weighing scales and carry case (contact suppliers for up-to-date costs): £336

However, health visiting teams will already have scales/carry case and cleaning wipes as part of their role.

The Lullaby Trust periodically receives donations to purchase equipment e.g. monitors, replacement mattress pads and weighing scales to donate to areas/regions which helps to reduce local costs.

3. Paper resources and publications

Item	Cost (excl. VAT)
Sheffield Weight Chart	£2
Symptom Diary tear-off pad	£3.50
Room thermometer	£3.95
CONI leaflet	£0.70 or free pdf
Bereavement support leaflet	£0.50 or free pdf
Safer sleep easy read card	£0.35 or free pdf
Safer sleep product guide	£0.70 or free pdf
Information for GP records sheet	Free pdf
CONI healthcare passport	Free pdf

Single items/small quantities of publications and paper resources can be ordered via the Lullaby Trust online shop: lullabytrust.org.uk/shop

Alternatively, for larger quantities, orders can be placed centrally by procurement departments via: lullabytrust-orders@partridgesuk.com

4. Basic life support (BLS) instruction for families

BLS training needs to be arranged at local level. For example, with your organisation's Resuscitation Officer, the British Red Cross or St John Ambulance. Some health visitors are training locally to deliver BLS. It is preferable that training is available one-to-one in the family's home as they may have experienced the need to perform BLS on the baby who died.

If local BLS training is unavailable then the CONI Team: coni@lullabytrust.org.uk can signpost to reputable BLS instruction via free video links.

References

1. National Child Mortality Database (NCMD) <https://www.ncmd.info/>
2. Blair, PS, Nadin, P, Cole, TJ, Fleming, PJ, Smith, IJ, Platt, MW, Berry, PJ, and Golding, J. (2000). Weight gain and sudden infant death syndrome: changes in z scores may identify infants at increased risk. *Arch Dis Child*, 81, 112-11.
3. Ministry of Housing, Communities & Local Government (2019) English indices of deprivation 2019 <https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019>
4. Garstang, JJ, Campbell, MJ, Cohen, MC, Coombs, RC, Daman Willems, C, McKenzie, A, Moore, A, Waite, A. (2020). Recurrent sudden unexpected death in infancy: a case series of sibling deaths. *Arch Dis Child*, 105:945–950. doi:10.
5. Public Health England (2021) Health visiting and school nursing service delivery model Guidance.
6. Goldstein, RD, Lederman, RI, Lichtenthal, WG, Morris, SE, Human, M, Elliott, AJ, Tobacco, D, Angal, J, Odendaal, H, Kinney, HC, and Prigerson, HG. (2018). The Grief of Mothers After the Sudden Unexpected Death of Their Infants. *Pediatrics*, 141(5).
7. Al-Maharma, DY, Abujaradeh, H, Mahmoud, KF, & Jarrad, RA. (2016). Maternal grieving and the perception of and attachment to children born subsequent to a perinatal loss. *Infant Mental Health Journal*, 37(4), 411–423.
8. Druguet, M, Nuno, L, Rodo, C, Arevalo, S, Carreras, E, and Gomez-Benito, J. (2018). Emotional effect of the loss of one or both fetuses in a monochorionic twin pregnancy. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 47(2), 137–145.
9. Flach, K, Gressler, NG, Marcolino, MAZ, and Centenaro Levandowski, D. (2022). Complicated Grief After the Loss of a Baby: A Systematic Review About Risk and Protective Factors for Bereaved Women. *Trends in Psychology*, 1-35.
10. National Bereavement Care Pathway (NBCP) 2022 Sudden Unexpected Death in Infancy (SUDI) Bereavement Care Pathway <https://www.nbcpathway.org.uk/pathways/sudden-unexpected-death-in-infancy-sudi-bereavement-care-pathway/>
11. Stroebe, MS, Schut, H, and Stroebe, W. (2007) Health outcomes of bereavement, *Lancet*, 370, 1960-73.
12. Relf, M. (2000). The effectiveness of volunteer bereavement care. An evaluation of a palliative care bereavement service. PhD thesis, Goldsmith College, The University of London.
13. Public Health England (2016) Healthy Child Programme 0-19: Health visitor and school nurse commissioning. Office for Health Improvement and Disparities, 2023.



**For every baby.
For every family.
Forever.**

lullabytrust.org.uk

coni@lullabytrust.org.uk

T: 020 7802 3200

General enquiries: 0207 802 3200