

# WHAT IS THE CARE OF NEXT INFANT PROGRAMME? (CONI)

## Information for Commissioners and Public Health Leads

The Care of Next Infant (CONI) programme was set up in 1988, and is run in partnership with The Lullaby Trust and public health services.

It provides support for families who have experienced or are at higher risk of SIDS or sudden and unexpected baby death, and who are expecting or have given birth to a new baby. The CONI programme provides specialist advice, information and support to health professionals. They in turn, support bereaved families with their subsequent babies to help them enjoy the first year of their baby's life as these families are often very anxious.

### How does the CONI programme support families?

The help parents receive on CONI can be as much or as little as they like. They 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. It can be used in conjunction with the Baby Check App.

#### **Baby Check**

Baby Check is an 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. It can be used with babies until they are one year old.

#### **Regular weight review**

Healthy babies show regular gains in weight, vulnerable 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 (ideally weekly), and those gaining weight either too slowly or too quickly. It is used as an 'early warning' tool so the baby can be seen by a local paediatrician. Children 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 (Blair et al 2000).

#### **Movement/apnoea/breathing monitor**

Movement monitors detect babies' 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 and can gradually re-build confidence.

#### **Basic life support training (BLS)**

It is encouraged that parents are offered training in BLS. Those who choose to take a movement monitor home must have had some BLS training as it prepares them to help their baby until the arrival of additional professional support.

#### **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 and keeps them aware that changes in temperature require parenting interventions.

## Who supports the parents registered on CONI?

### Local CONI Coordinators

Coordinators are responsible for facilitating the programme in each area liaising with the family doctor, health visitor, midwife and paediatrician. The Coordinators make sure parents know all about the programme and are trained in the use of their chosen equipment. They also order any of the resources required by families when they enrol on the CONI Programme.

Coordinators are usually experienced health visitors and are key to the programme as they coordinate referrals and pathways and liaise closely with The Lullaby Trust CONI team and own organisation staff in relation to equipment or any issues arising. The role has developed in many organisations as an invaluable resource in relation to Safer Sleep practice and dissemination of information to colleagues.

### Health visitors/health practitioners

It is encouraged at the initial contact, where CONI is discussed, that parents can discuss the frequency of this support and how and when it will take place but this will require regular review. The named health visitor/health practitioner will assess the family's needs and a plan of contact should then be agreed both to complete regular weight reviews and for any additional emotional support that may be required. Parents say that they particularly appreciate these contacts and value their health visitor as a 'listening ear' for their worries and as a go-between for the parents and the doctor.

### Paediatricians

It is also encouraged that parents are offered contact with a paediatrician. Their role is decided locally. This can include giving advice to parents regarding the death of their previous baby and during a subsequent pregnancy. CONI Coordinators feed back that support from a consistent paediatrician works well and supports both professionals and parents.

After a new baby is born, they can offer routine checks or examine the baby if the parents are

concerned. A 'Paediatric Passport' is used to fast-track babies through adult emergency departments to the paediatrician.

### General Practitioners

Their role is to offer advice and support, particularly during any illness in the baby. It is important that any previous death from SIDS is communicated to the GP to encourage continuity of care to the family.

### Midwives

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

Ensuring all members of the antenatal team are aware of CONI, have the current advice and pathways of referral is another important role of CONI Coordinators.

### The Lullaby Trust team

The CONI team at The Lullaby Trust are health professionals who have significant training and development on all aspects of caring for bereaved families and on current developments locally, nationally and internationally in relation to research and developments regarding SIDS.

The CONI team provides support and training to the local CONI Coordinators and is responsible for the distribution of Lullaby Trust resources and support information. The Lullaby Trust supports the purchase of the monitors and negotiates a discount to the CONI host organisation that is ordering equipment.

The CONI team, with parents' consent, review and report on the information collected from families. This helps inform practice and audits the programme.

## Why CONI is still relevant for today's families

Figures from 2016, published by ONS in August 2018, identify that over 240 babies died of SIDS which equates to 5 babies dying each week. This is the first increase in babies dying of SIDS in 3 years.

Statistical data identifies that certain groups have a higher risk of SIDS. These include boys (52%), babies who have a mum under the age of 20 (x 3 higher rate) and babies who are premature or low birth weight (x 6 increased risk).

Review of the data collected from CONI families in comparison to the general population has identified that there is a significant vulnerability of CONI families (Waite et al, 2011), as described more fully below.

More recent research by Garstang et al 2018 reviewed 70 SUDI Deaths in the West Midlands over 2 years. She identified that parenting choices, which are known SIDS risk factors and increased vulnerability in families is a common theme in these deaths. The role of CONI supporting these parents in subsequent pregnancies in the future will require the networks and pathways that the programme offers to ensure these families are identified and get the support they require.

The CONI Programme is discussed within the Bereavement Care Pathway ([www.nbcpathway.org.uk](http://www.nbcpathway.org.uk)). This is a National Programme, led by a multi-agency core group of baby loss charities and professional bodies, to improve bereavement care for parents and to reduce the variability of experience for families suffering the loss of their baby.

The CONI programme has been supporting families for more than 30 years and evaluations from parents have consistently reported that the support that the programme has given them has been valuable by reducing their stress, increasing their parenting confidence and enabling them to enjoy their baby.

The CONI Programme is a well-established and valued package of support for families who have previously lost a baby or who have experienced an event where their anxieties and confidence have been significantly compromised enough to require further support. The programme is flexible with user-friendly resources that families can choose to opt in and out of as they require, and as their confidence increases or worries grow.

## CONI Programme mapped to current public health priorities and responsibilities

The outcomes of the CONI Programme link closely with public health outcomes and drivers. Public Health England's (PHE) document: **Best start in life and beyond: Improving public health outcomes for children, young people and families** (March 2018) states that upper-tier local authorities have commissioning responsibilities for child health and wellbeing. Under the terms of the Health and Social Care Act 2012, they are responsible for improving the health of their local population. The core public health offer for all children includes:

- information, advice and support for children, young people and families
- early intervention and targeted support for families with additional needs
- health promotion and prevention by the multi-disciplinary team

The various elements of the CONI Programme encompass all three of these public health priorities.

**The Healthy Child Programme** (DH 2009; PHE 2015; PHE 2016c; PHE 2016d) provides the opportunity from early in a child's life to identify families that are in need of additional support and children who are at risk of poor outcomes. Within this, the PHE's **4-5-6 Model** is the evidence based approach to deliver the Healthy Child Programme. The Model has 4 levels of service and the CONI Programme falls within the scope of Universal Plus: To identify vulnerable families, provide, deliver and co-ordinate evidence based packages of additional care, including maternal mental health & wellbeing, parenting issues, families at risk of poor outcomes.

Within the Model there are 6 Health Visiting Early Years High Impact Areas. The CONI Programme has relevance to three Early Years High Impact Areas. In particular:

1. transition to parenthood and the early weeks
2. maternal mental health
3. breastfeeding (initiation and duration)

## 1. Transition to parenthood and the early years

According to the **NHS Outcomes Framework 1.6.i and Public Health Outcomes Framework Indicator 4.01**, reducing infant mortality is one of the Outcome measures for the transformed health visiting service model and is part of High Impact Area 1.

Evidence from the CONI Programme has consistently indicated that compared with national data for babies and parents, siblings of previous sudden infant death syndrome (SIDS) babies are themselves more at risk (Waite et al, 2011):

- Twice as many CONI babies have a birthweight of less than 2500g
- 50% more CONI babies born preterm
- Only half as many CONI babies are breastfed
- Risk of SIDS increases with parity (Smith and White, 2006), and 41% mothers had three or more previous live births when enrolling on CONI for the first time
- The incidence of unemployment is over five times higher

One of the four key ambitions of the Government's **Tobacco Control Plan (2017)** is to reduce smoking in pregnancy (as recorded at time of delivery) to 6% or less by the end of 2022. Smoking during pregnancy can cause serious pregnancy-related health problems. These include: complications during labour and an increased risk of miscarriage, premature birth, still birth, low birth-weight and sudden unexpected death in infancy (Royal College of Physicians 2010). Smoking during pregnancy also increases the risk of infant mortality by an estimated 40% (Department of Health 2007). The Royal College of Physicians (2010) estimates that illnesses among children caused by exposure to second-hand smoke lead to an estimated 300,000 general practice consultations and about 9,500 hospital admissions in the UK each year. Compared with national data, twice as many CONI parents are smokers (Waite et al, 2011).

The period of preconception to age 2 provides a unique opportunity for professional involvement because it is the time when parents are often the

most receptive to behaviour change interventions and where the evidence suggests it is most effective (PHE 2016a; PHE 2018). It has been shown that intensive health visitor contacts with infants identified as having a high risk for SIDS reduced the number of predicted deaths in the target population (Taylor et al, 1993).

## 2. Maternal Mental Health

It states in PHE's document **Early Years High Impact Area 2: Maternal mental health (2018)** that 'ensuring that all women receive access to the right type of care during the perinatal period is a key Government priority to reduce the impact of maternal mental health during pregnancy and the first 2 years of life on infant mental health and future adolescent and adult mental health'.

It continues with: 'perinatal mental illness can impact on a mother's and father's ability to bond with their baby and be sensitive and attuned to the baby's emotions and needs. This in turn will affect the baby's ability to develop a secure attachment. Untreated perinatal mental illness can have a devastating impact on mothers, fathers and their families. The effects can be of particular concern in the absence of other carers able to provide the quality emotional contact every infant needs'. This is also reiterated in NICE Quality Standard [QS115] Antenatal and Postnatal mental health.

An infant death can make parents depressed and anxious and fearful for the survival of subsequent babies. Goldstein et al (2018) found that severe symptoms and heightened risk for prolonged grief disorder (PGD), as per the International Classification of Diseases 11th Revision, was seen in mothers after their infants died of SIDS. It is important that they are able to express their concerns and feelings and develop confidence to help them develop a full relationship with their new baby during the first 6 months when the risk of SIDS is greatest. We know that the development of a secure and stable attachment is essential for the baby in the first year. The nature of this early attachment sets the template for later relationships, and can predict a number of physical, social, emotional and cognitive outcomes (Hogg, 2013).

This is supported by the positive feedback that we receive from parents enrolled onto the CONI Programme. For example:

“[The] CONI programme gave me the help and advice I needed for my own peace of mind. Everyone was helpful, and I was able to enjoy moments with my baby without being scared/paranoid to leave him. Thank you so much! You all have helped a lot, and do an amazing job helping us.”

An Internet discussion forum used by The Lullaby Trust to talk with a group of CONI parents revealed that it is clear that while anxious about their new baby their thoughts are also focused on the child that has died. The new baby is a reminder of the baby that is lost and for some their identities are confused. These parents are coping with a maelstrom of emotions encompassing anxiety for their baby, feelings of inadequacy and bereavement and in addition are more likely to have financial concerns and other social stresses. 88% of parents on the CONI Programme report through feedback questionnaires that they were helped by the health visitor listening to them.

### 3. Breastfeeding (initiation and duration)

High Impact Area 3 states that ‘breastfeeding is a priority for improving children’s health and research continues to find that breastfed infants have a reduced risk of respiratory infections, gastroenteritis, ear infections, allergic disease and sudden infant death syndrome’ (PHE 2016b; PHE 2018). As long ago as 1965, Carpenter and Shaddick showed that babies who died of SIDS were significantly less likely to be exclusively breastfed than control infants who did not die, at all ages between birth and 3 months. The most recent meta-analysis published in 2011 (Hauck et al) supports the findings that breastfeeding is associated with lower rates of SIDS.

Parents in the CONI Programme are attracted by the provision of an apnoea (movement) monitor, which is relatively low cost to this high-risk group. As part of the Programme it creates opportunities for health professionals to engage with parents to provide

targeted support to promote compliance with safe sleeping advice, reduce smoking and support breastfeeding to reduce the risk to the baby and reduce inequalities in health.

## Conclusion

The risk factors associated with SIDS remain high in the CONI population, and bereaved CONI families are some of the most vulnerable and socio-economically deprived families. When the four domains of the current public health outcomes framework are taken into consideration: improving the wider determinants of health; health improvement; health protection and; reducing premature mortality, CONI families should be among the groups targeted as part of current public health priorities (Health and Social Care Act 2012).

The CONI team within The Lullaby Trust offer training and support, and are continually reviewing data and resources to ensure CONI Coordinators are kept updated in relation to all aspects of bereavement support and Safer Sleep.

If your organisation would like any further information regarding the CONI programme please contact the Team: [coni@lullabytrust.org.uk](mailto:coni@lullabytrust.org.uk)

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