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# Conversations with families about reducing the risk of Sudden Infant Death Syndrome

**Abstract**

Inequalities in the burden of sudden and unexpected deaths in infancy make targeted action by health care professionals a viable option for intervention. Most of the deaths that now occur have at least one known, modifiable risk factor present and so the potential impact of supporting families with implementing safer sleep strategies is great and may bring about a further reduction in infant deaths. This paper describes the latest evidence for action on three of the major risk factors for SIDS: sleeping position, smoking and co-sleeping. We then discuss how to translate this evidence into effective communication strategies for families, including giving information about why or how the messages increase safety for sleeping babies.

**Key terms: Sudden Infant Death Syndrome, safer sleep, co-sleeping, portable sleep spaces, Pepi-Pod®, Wahakura**

**Reflective questions for Health Visitors**

1. When discussing safe sleep with families how do we make sure they understand *why* the messages are important?
2. When is the best time to discuss safer sleep for babies?
3. What more could be done to support families with planning for infant safety when routines are disrupted?

**Introduction**

Since the introduction of the *Back to Sleep* Campaign in 1991, health care professionals have been engaging families with evidence-based conversations about reducing the risk of Sudden Infant Death Syndrome (SIDS). A baby dying suddenly and unexpectedly is undoubtedly one of the biggest tragedies for any family. The ramifications spread to wider friends and relations, and to those health care professionals who supported them during pregnancy, birth and postnatally (1). In the UK, the

SIDS rate has been steadily decreasing overall, from 0.52 per 1,000 live births around the millennium to a low of 0.28 per 1,000 livebirths in 2015 (2). An increase in the number and overall rate in 2016 (from just under 200 deaths to 240 deaths, a rate of 0.31 per 1,000 live births) has led to calls for renewed action on reducing the risks for SIDS (3).

There is a stark inequity in the burden of these deaths, with young mothers living in deprivation experiencing the highest death rates. In 2016, the overall rate for mothers under 20 was 0.98 per 1,000 live births, more than 3 times the rate in the general population (2). While most deaths occur with at least one known risk factor present, the importance for health professionals to engage in effective conversations about safer sleep cannot be overstated. In this review we describe the latest evidence surrounding three major SIDS risk factors; infant sleeping position, parental smoking and co-sleeping, and how best to translate this evidence into effective communication strategies for conversations with families.

**Infant Sleeping Position**

Several important case-control studies starting in the late 1980s consistently began to find associations between infant sleeping position and increased risk of SIDS. In the UK, a study by Fleming and others from 1987-1989 found that 93% of infants who had died had been put down to sleep on their front, with only 57% placed in this position in control group babies who had not died (4). This finding showed the popularity of this particular sleeping position at the time but the stark contrast between the cases and surviving controls was enough to begin recommending back or side positions in the Avon region of England, from 1989, two years before the national campaign started. This led to a halving of the cot death rate in Avon at a time when the national rate changed little (5). In 1991, New Zealand published the first results of its own “cot death” study (6). With one of the highest SIDS rates in the developed world, the New Zealand study also found that sleeping on the front was a clear risk factor for SIDS. These major studies along with studies from the Netherlands (7) combined with increasing evidence on the significance of sleeping position from around the world, led to the UK’s Back to Sleep Campaign.

We now know that a clear association exists between the risk of SIDS and placing babies on their tummies for sleep. Once implemented nationally in 1991, the recommendation to place babies to sleep on their backs was followed by an immediate reduction in SIDS of more than 46% in the UK, and large reductions in SIDS deaths have been seen in every country to introduce similar advice on sleeping position. A later UK study (8) identified the side sleeping position as a risk in its own right, and from then on the evidence was clear, babies sleep most safely on their backs.

The mechanisms for how front and side sleeping might increase the risk of SIDS are still being investigated and no one causal mechanism has yet been found. A single underlying cause for SIDS is highly unlikely and there are probably multiple mechanisms responsible with different mechanisms interacting in different ways. Several physiological differences between babies sleeping on their front or back have been found including a higher arousal threshold and reduced heat loss for front sleeping (9). There is also some evidence that sleeping in an *unaccustomed* side or front sleeping position further increases the risk (10) and so maintaining a back sleeping position for every sleep is also important until the infant is old enough to turn into any position they choose (normally this happens at 5-6 months).

A recent survey of higher risk families found that as few as one third identified back sleeping as a risk reduction strategy for SIDS (11), and related qualitative work found a lack of understanding about why or how sleeping position is related to SIDS (12). Future interventions in this area should therefore consider effective ways to improve understanding as well as knowledge.

**Smoking**

The association between tobacco exposure and SIDS has been apparent since the earliest observational studies and has been consistently identified as a risk factor with a biological gradient (increased risk with increased exposure). The risk is highest for smoking during pregnancy, but increases as the number of cigarettes smoked increases, and remains significant for post-natal smoke exposure by either the mother or her partner (13). Fortunately in England the rates of maternal smoking during pregnancy are steadily falling, from as high as 25% in 1996, (14) to 14%

smoking at delivery in 2009, 11.5% in 2014, and 10.5% in the second quarter of 2018 (15). Despite the fall, these recent figures represent approximately 73,000 women each year who are smoking at the time of their baby's birth.

Current trends developing in the UK which may further reduce smoking during pregnancy are to offer financial incentives alongside current quit services, and to increase the use of e-cigarettes (or "vaping"), which usually contain nicotine but fewer of the other harmful toxins present in cigarette smoke. Several studies have indicated a positive effect on quit rates using financial incentives (16) and trials so far have shown promising results (17). However, the mechanisms by which this method works are poorly understood, (18) and there are some interesting ethical concerns with this type of intervention in terms of fairness, motivation and personal autonomy (19).

E-cigarettes are currently unregulated in the UK. They work by heating a liquid solution normally containing nicotine which is inhaled upon vaporization, leaving a mist behind to imitate the act of smoking. Considerable debate exists around their use and safety, however a large scale review of the evidence by Public Health England concluded that e-cigarettes were 95% safer than tobacco smoking (20). In pregnant women there have been few studies looking at the safety or otherwise of e-cigarettes and pregnancy outcomes, and it is unknown at this stage what effect this new product will have on the health and well-being of babies (21). A review of the literature in 2018 estimated prevalence of the use of e-cigarettes in pregnancy as between 0.5%-15%. The review found nicotine absorption at similar levels to tobacco smoking, and lists the many harms associated with nicotine use during pregnancy seen in animal models. For this reason, the development of a robust evidence base and associated clinical guidance is an urgent requirement. In the meantime, sensible advice to replace tobacco with e-cigarettes for the purposes of quitting, in the same way that NRT products are currently recommended may be beneficial and is the approach currently taken by both the NHS and tobacco control charities (22, 23).

**Co-sleeping**

Sleeping on a sofa with a baby constitutes a significant risk for SIDS and this is clearly seen in every study that asks about this practice (24). The risk also extends beyond SIDS and a study into all sofa related deaths in 24 United American States found that 12.9% of all sleep related infant deaths occurred while sleeping on sofas (24). Advising parents not to sofa share has been a major part of SIDS advice since 1999, however longitudinal data from Avon, UK reported in 2006 an increase in the numbers of SIDS cases occurring on sofas with adults, from one in the period 1989-1993 to five from 1994-1998 and four from 1999-2003 (25). Anecdotal evidence from several SIDS cases highlighted that the sofa or armchair was in some cases, chosen as a place to feed the baby in the night in order to avoid bed-sharing, rather than it being the usual place for sleep. When considering the importance of known risk factors for SIDS there is a need to communicate the main risks based on the evidence currently available. The risk of sleeping with a baby on a sofa or an armchair is undeniably great (18-fold greater according to evidence from 2 combined studies (28)) and this advice should be clear, consistent and emphasised along with the other major risk factors of smoking and non-supine sleeping positions.

Co- sleeping with a baby in an adult bed has been a much-debated issue within the field of SIDS research (26). Most case-control studies have looked at bed-sharing and found an overall association with increased SIDS risk, (27-29) leaving some countries to advise against the practice altogether, especially in the United States.

However, case-control studies conducted in the UK constructed an analysis model that incorporated factors seen as relevant to bed-sharing in order to assess the risk for each scenario more accurately. These findings proposed that it is not bed-sharing alone which is risky, but certain hazardous circumstances which make it so. The three main factors associated with hazardous bed-sharing are maternal smoking, recent alcohol consumption and recent drug use (30) (31). It is also crucial to consider the reasons that families choose to bed-share with their babies, and the strong association between bed-sharing and continuation of breastfeeding. In a longitudinal analysis, Blair et al found that breastfeeding was significantly higher in families that bed-shared in the first 15 months(32). Any

broad-based campaign to discourage bed-sharing must consider the impact this could have on breastfeeding.

### *Advice to families*

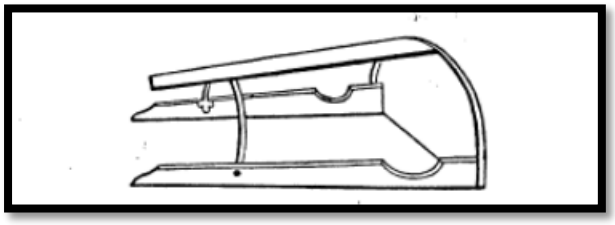
Pease et al conducted 20 qualitative interviews with mothers living in deprived circumstances in Bristol to understand how these mothers at higher risk of SIDS interact with risk reduction messages (33). Mothers in this study described how the credibility of the advice influenced how readily they accepted it, and that pressure from health professionals was unhelpful. They wanted more information about why risk reduction messages are important including how they might confer protection for babies. Other studies have also found that tailoring advice to families and increasing understanding of why messages are important may also improve uptake of risk reduction advice, moving away from the more traditional 'simple is best' approach seen in the past (34). It is within this traditional model that some continue to argue that it is still safer to advise against all bed-sharing (35). The problem with this particular issue when it comes to advising parents is not just the clear lack of evidence of effectiveness for a blanket ban on bed-sharing, but the need to acknowledge bed-sharing within a wider cultural practice (36). Sharing a bed with a baby is a common practice in the UK with approximately 50% of babies under 6 months sleeping next to a sleeping parent at some point, some intentionally and some unintentionally (37). A large longitudinal study from the US by Colson et al in 2013 found that bed-sharing rates were highest in Black families and rates for these babies have been increasing over the 17-year study period, despite strong campaigns against it (38). Studies in the UK using overnight observations show the complexity of sleep sharing behaviours, where babies are in a variety of safe and unsafe situations across each night (39). While epidemiological studies try to simplify behaviours as good or bad, risk management on an individual level is much more nuanced. A review of reasons cited by mothers for bed-sharing conducted in 2014 (40) found many highlighting some benefit to bed-sharing including: easier breastfeeding, getting more sleep, being able to monitor the baby, improved bonding and cultural tradition. Our more recent work with high risk families highlighted unintentional bedsharing

scenarios where last-minute decisions to bedshare were related to a number of competing factors on any one night (33). Taking these reasons into account is a vital part of any risk reduction public health campaign if it is to be effective. Indeed, infant death rates in the USA, where a stricter no bedsharing message has been promoted, have stalled, leading some to reconsider the effectiveness of this approach (41). As part of UNICEF's Baby Friendly Initiative, (42) a resource for parents and health professionals was produced, called "Caring for your baby at night: A guide for parents". This leaflet recognises that bed-sharing occurs both intentionally and unintentionally, contains information on both the risks associated with hazardous bed-sharing and advice for those who do decide to share a bed with their babies, aimed at making the parental bed as safe as possible for a baby. Similarly, the Lullaby Trust has recently updated their advice on co-sleeping to align with this approach (43). Risks associated with shared sleeping scenarios are clearly stated alongside a risk minimisation approach to bed-sharing. These approaches allow for more detailed conversations with families that address both the needs and individual circumstances of the baby and the carer.

***Targeted Interventions***

Addressing the risks to sleeping infants in adult beds is not a new endeavour, indeed a report in the BMJ from 1895 described the use of a wooden and iron frame from Tuscany, Italy, known as an "Arcuccio" (Figure 1) which was placed over the baby sleeping in an adult bed (44). The report in the BMJ describes a time when many infants were dying in adult beds and how "special legislation forbidding mothers to sleep in the same bed with their infants under special penalties in the event of injury" had been proposed but acknowledged the lack of public and political support for such a move. The report describes how the Arcuccio was used in Tuscany, for both day and night sleeps. The idea of protecting the space around a sleeping baby's head is sound, though support for such a device in modern times is probably, understandably, very low.

*Figure 1: The "Arcuccio", 1895, image reproduced with permission from the British Medical Journal.*



More recent interventions from other countries have shown promising results for increasing infant safety during sleep, especially for vulnerable populations. The Pēpi-pod™ (Figure 2) from New Zealand is a portable infant sleep space for use in a variety of locations for the first 3-4 months. This plastic device is low-sided with clear panels for observing babies while lying next to them in adult beds and can also be used on sofas, or in makeshift beds and in temporary living arrangements. They are supplied with bedding and targeted educational materials with information about how babies breathe and how to maintain open airways at all times, especially during sleep. The intervention has become popular in both New Zealand and Australia (45) and a trial is planned in the United States. The aim of the device is to separate out the risks from smoking and co-sleeping while maintaining closeness to a responsive carer, but the strong educational component where parents are asked to sign a 'safe use contract' may also be providing effective protection. A similar device, also from New Zealand in the form of a woven flax bassinet called a Wahakura (Figure 3) works using similar principles but includes the additional benefit of being culturally appropriate for Maori communities in New Zealand.

*Figure 2: Pepi-Pod®*

*Figure 3: Wahakura*

In the UK, there has also been a recent interest in 'baby boxes': cardboard boxes with high sides and a fitted mattress, filled with essential items for the first weeks of a baby's life. The box and mattress then act as a baby bed, although the box is far too large and cumbersome to be used as an 'in-bed' device. The concept originated in 1938 in Finland, where the boxes have been available free to families who attended antenatal appointments, called a 'maternity package'. It was extended to all families in 1949 and remains popular today. While Finland enjoys one of the lowest SIDS rates in the world, the 'baby box' has never been cited or tested as a preventative measure to reduce SIDS whilst neighbouring countries Sweden and Norway have similarly low rates and no box scheme. Despite this, the concept has been introduced in Scotland by the government for every family since 2017 (Figure 4). Although a free gift, providing high quality baby essentials seems intuitively a good idea,

concerns have been raised (46) about the lack of any evidence that the boxes actually reduce the risk of SIDS, and that private box manufacturers have been promoted in England without oversight.

*Figure 4: Scottish Baby Box*


***Conclusions***

Current interventions show promise in certain areas and it may be that combining positive aspects of a variety of recent interventions, tailored to the specific context of our most vulnerable babies in the UK, may provide scope to develop a valuable intervention to improve infant sleep safety while maintaining closeness and responsiveness to parents and carers. Health care professionals engaging in conversations with families about safe sleep may find it beneficial to extend their current advice towards understanding the individual circumstances of each family and tailoring their advice accordingly. Engaging in planning conversations for what to do on busy nights where established routines might change may also increase safety for babies.

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