

Safe Start Education

Supporting health professionals with
influencing infant safety



Prepared by Stephanie Cowan

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Supporting health professionals in influencing infant safety

atawhaitia ahau i roto moemoea

“from my earliest beginning, pursue protection so that I may dream”

(given to the project by Whaea Terehia Kipa)

Prepared by

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“We have the knowledge to prevent death and disease for most children of the world. What we do not have is a health workforce skilled to turn that knowledge into action.”

*Dr Michael Ostergren,
World Health Organisation, Denmark
From his opening address:
“Health Needs in Paediatric Care: a Global Perspective”
Seventh SIDS International Conference
Florence, Italy
September, 2002*

Welcome

A warm welcome to professionals everywhere as you read this resource and embrace the education it supports. The resource was first prepared for midwife educators in 2004 and has been personalised for different professional groups each year since. In 2009, it is for everyone.

We have a particular interest in the education of parents about best practice infant care. Our work began with education that responded to high parental anxiety about SIDS more than twenty years ago. At that time, babies were dying unexpectedly at the rate of five per week in this country and there was no understanding for why. Education then was a mechanism for managing fear, for sharing knowledge about normal infant needs and directing parents' towards decisions for reducing risks. The goal was to empower parents, restore perspective and control, and to facilitate confidence and calm in their relationship with their baby. This is still the goal.

But we are in a different time now. There is far more certainty about preventing sudden infant death and, because parents have acted on prevention recommendations, there are far fewer deaths. Yet they still happen and at relatively alarming rates for some groups and compared to other developed countries. Sudden unexpected death in infancy (SUDI), be it explained or unexplained, is still the main cause of death of children under one year of age. And so we come together to appreciate this fact and find ways to focus education that will optimise a parent's confidence and a child's safety.

The legacy of fear from the 1980s challenges parent education efforts. The media love SIDS stories and keep the fear alive with attention to single study findings and even the most obscure research. Product manufacturers, too, have had a field day and an appraisal of packaging information is most telling. Trusted professionals are a conduit between parents and perspective, between what is heard and what is understood, between bias and objectivity. And so you are in a position of considerable influence.

And influence is what is needed for there to be change. This programme is an opportunity to align our understandings, coordinate our action and influence for good.

Thank you for participating. The material is offered with deep respect for your own knowledge, understandings, competence and experience. Please share this resource with others or pass it on when you have no further need of it. And may our combined efforts result in protection for the parent-child relationship as well as protection for the child.

Stephanie Cowan
April 2009

Contents

	Page
Why we need this resource	6
Statistics update	7
From SIDS research	8
Topic 1: Triple Risk Model	9
Topic 2: The Triple Protection Model	10
Topic 3: Infant Positioning	11
Topic 4: Exposure to smoking: Fetal Effects	12
Topic 5: Exposure to smoking: Infant effects	13
Topic 6: Accidental Asphyxia	14
Topic 7: Sleeping Environments	15
Topic 8: Head Shape	16
Topic 9: Grey Zone Deaths	17
Topic 10: Priority Babies	18
Topic 11: NICU and SCBU settings	19
Topic 12: Parent education	20
Please tell my parents	22
Suggested reading	23
Information resources (available from the Ministry of Health)	
Back is best (Code 1228)	
Changing smoking in pregnancy (Code 1231)	
Protecting your baby's head shape (Code 1227)	
Babies bed sharing and safety (Code 1226)	
Everyone please ... cot card (Code 1229)	

Why we need this resource

Complacency - the new risk for babies

New Zealand babies have a new risk – complacency about their vulnerability to sudden death. While the incidence has reduced in recent years, a baby's vulnerability to sudden death has not changed. We need to maintain high levels of life-protecting practices if we are to sustain and improve on the gains made. We also need to build and maintain a high level of understanding of the vulnerability that helps explain known risk factors. Too many babies continue to die with known risks factors present and too many deaths are preventable.

Education has a key role

Sudden infant death syndrome persists as the leading cause of preventable death of children in the first year of life and as such needs a coordinated education response such as we see for meningitis, accidents, family violence. Although SUDI stands out as a category of infant deaths, it is largely invisible to health services, antenatal education and professionals. It happens in homes not hospitals or classes and strikes quietly, claiming lives one by one scattered through the community. As a problem now more for challenged families, SUDI deaths can too easily go unnoticed.

Health promotion is a health professional activity. Just as breastfeeding needs systems and strategies to protect, promote and support it, so, too, do other infant safety practices e.g. back sleeping and a smokefree start to life. We need our communities to care; to understand a baby's vulnerability to sudden death and be aware of ways to increase protection for them.

Coordination needed

Traditionally, responsibility for preventing SUDI has fallen largely to pregnancy and well child health care providers. The strategy has been parent to parent education about known risks. Society is now demanding that health inequalities be addressed. It is increasingly unacceptable for death and disease to be more common in certain groups. SUDI has moved from being a largely personal health issue to being a largely public health one. The need now is for coordinated education and action on social and economic determinants of SUDI as well.

Are we doing enough?

The evidence suggests we are not.

- We know "back is best", yet babies still sleep and die in side and front (non-supine) positions and some staff still struggle to promote best practice.
- We know smoking leads to an hypoxic environment for an unborn baby. Yet one in three pregnancies are still smoke-exposed. Referrals to cessation services are low and late. Professionals still respond in an ad hoc way. Promotion campaigns are lacking.
- We know that when a baby's face becomes covered or wedged against something, oxygen may not get through to the lungs. Yet babies still sleep and die in unsafe environments and professionals still tread carefully around sleep safety issues.

This resource is to support health professionals to respond to our high ranking infant mortality rates so that all children can enjoy protection from sudden unexpected death in infancy.

Statistics update

Sudden infant death syndrome (SIDS)

Before 1990, SIDS claimed 250 NZ babies per year. Community anxiety levels were high. Parents responded swiftly to recommendations to avoid sleeping babies on their tummies and death rates fell dramatically from 1990.

Currently around 50 babies per year die from SIDS - a rate of 0.8/1000 live births. SIDS remains the single leading cause of preventable death in the first year of life, after the early neonatal period.

Sudden unexpected death in infancy (SUDI) includes SIDS as well as unexpected deaths from all other causes. Due to coroners' variations in diagnosis and preference for explanation (see topic 9) SUDI is being used as a collective label for such deaths.

Figure 1. traces the change in SIDS rates in New Zealand from 1980 to 2004.

Falling SIDS/SUDI Rates
New Zealand 1980-2006

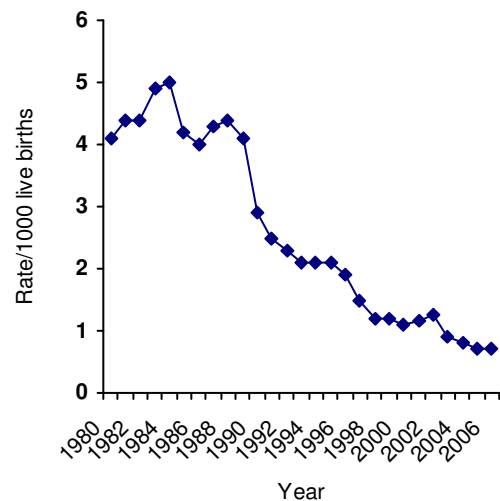


Figure 1. Falling SIDS/SUDI rates in NZ

Accidental asphyxia

Accidental asphyxia is another cause of sudden unexpected death in infancy. Deaths from suffocation during sleep averaged 10 per year (range 7-14) in the seven years from 1996 to 2002. This highlights the need to promote to parents and professionals the importance of "face clear" sleep and raise awareness of hazardous sleeping conditions.

Back sleeping rates in hospitals

In the sixteen years from 1992 to 2008, rates of observed back sleeping for newborns in hospitals increased from 6% to 90%^{2,3}. A national audit of hospitals in 1998 identified just 52% of new-born infants observed sleeping on their backs. The Infant Positioning project used peer education to influence change. A recent audit confirmed that continuing high rates of modelling back sleeping had been maintained.

Infant Back Sleeping Rates
NZ Hospitals 1992-2008

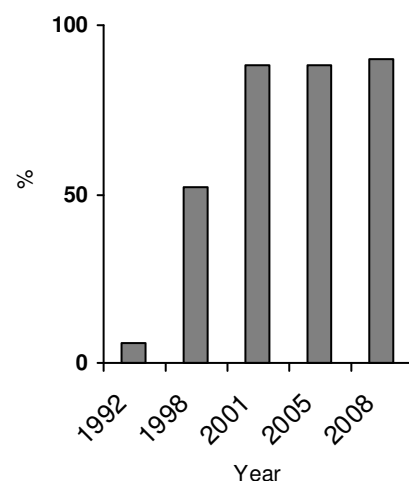


Figure 2. Infant Back Sleeping Rates

1. Fetal and infant deaths—2003-4. NZHIS 2007
2. Cowan SF et al. Study of infant sleeping practices in Canterbury Hospitals. Report to participating hospitals. FES, 1992
3. Clarke J and Cowan S Infant Sleep Positioning. Education for Change, 2008
4. Cowan and Clarke. Promoting a safe start to life for New Zealand babies. Education for Change. 2005

From SIDS research

Extracts

The following comments are taken from abstracts of published research. The studies reported give evidence for the “face-up, face clear, smokefree advice” for protection from SIDS.

Evidence for potential to save more infant lives

“Avoidable risk factors such as those associated with inappropriate infant sleeping position, type of bedding used, and sleeping arrangements strongly suggest a basis for further substantial reductions in SIDS incidence rates.”

Carpenter RG, Irgens LM, Blair PS et al. Sudden unexplained infant death in 20 regions in Europe case control study. *Lancet*, 2004 Jan 17; 363(9404): 185-91

Evidence for increased physiological control on back

“The majority of findings suggest a reduction in physiological control related to respiratory, cardiovascular and autonomic control mechanisms, including arousal during sleep in the prone position.”

Galland BC, Taylor BJ, Bolton DP. Prone versus supine sleep position: a review of the physiological studies in SIDS research. *J Paediatr Child Health*. 2002 Aug;38(4):332-8.

Evidence for extra protection for “at risk” infants on back

“Both prone (front) and side sleeping increased the risk of SIDS. The risk was increased further in low birth weight infants, preterm infants, and infants at the age of 13 to 24 weeks, suggesting that SIDS may be triggered by non-supine (side or front) sleeping in infants with prenatal risk factors during a vulnerable period of postnatal development.”

Oyen N, Markestad T, Skjaerven R et al. Combined Effects of Sleeping Position and Prenatal Risk Factors in Sudden Infant Death Syndrome: The Nordic Epidemiological SIDS Study *Pediatrics* Vol. 100, No. 4, October 1997, pp. 613-621

Evidence for a smokefree start to life as best

“The use of tobacco products by pregnant women is associated with placenta previa, abruptio placentae, premature rupture of the membranes, preterm birth, intrauterine growth restriction and sudden infant death syndrome.”

Andres RL, Day MC Perinatal complications associated with maternal tobacco use. *Semin Neonatol*. 2000 Aug;5(3):231-41.

Evidence for potential to save lives from avoiding side

“After adjustment for potential confounders, prone and side sleeping positions, maternal smoking, and the joint exposure to bed sharing and maternal smoking were associated with statistically significant increased risk of SIDS. A change from the side to the supine sleeping position could result in a substantial reduction in SIDS.”

Mitchell EA, Tuohy PG, Brunt JM et al. Risk factors for sudden infant death syndrome following the prevention campaign in New Zealand: a prospective study. *Pediatrics* 1997; **100**,5:835-840

Evidence for the “face clear” message

“This study confirms the importance of certain risk factors for the sudden infant death syndrome and identifies others--for example, covers over the head, side sleeping position--which may be amenable to change by educating and informing parents and health care professionals.”

Fleming PJ, Blair PS, Bacon C et al. Environment of infants during sleep and risk of the sudden infant death syndrome: results of 1993-5 case control study for confidential inquiry into stillbirths and deaths in infancy. *BMJ* 1996;313:191-195

Topic 1: Triple Risk Model

Triple risk model

Current thinking amongst SIDS researchers is that death from SIDS results from the presence of three factors at the same time¹. A baby dies only if all three factors exist together (e.g. aged 2 months old, smoke-exposed in pregnancy, face in pillow). The three factors are:

- Critical stage of development
- Vulnerable baby
- External stressor

The first four to six months are the critical stage of development through which all infants must pass. Smoking is one factor that increases infant vulnerability, and hazardous sleep conditions are factors that can act as stressors.

Critical stage

Most SIDS events happen during the first 1-5 months of life. The peak incidence, at 2-3 months, occurs during a major reorganization of the autonomic nervous system.

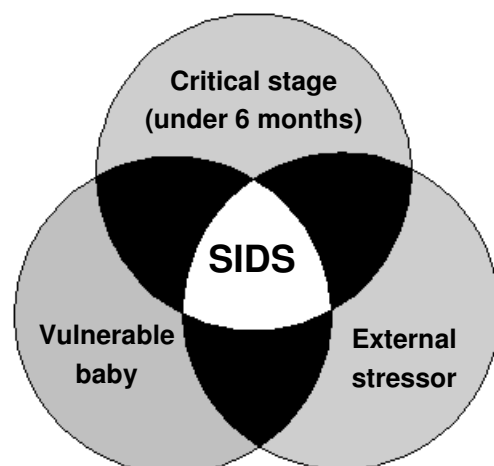
Vulnerable baby

We know, for example, that a sub-optimal environment during pregnancy identifies a group of babies more at risk of SIDS, but it is not yet possible to identify individual babies. This is why all babies need protection from SIDS.

External stressor

When a vulnerable baby passes through a critical stage of development events that would not usually be significant may trigger death for that baby. This explains why most babies do not die when exposed to the known risk factors.

The Triple Risk Model



Triple risk scenarios leading to sudden infant death

A baby exposed to smoking in pregnancy adapts to the hypoxic (low O₂) conditions caused by reduced placental blood flow. The baby is born with a suppressed arousal response which means reduced ability to perceive low oxygen or high carbon dioxide levels. (*vulnerability*).

- One night, at two months of age, (*critical stage of development*) the baby is sleeping in bed with his mother and a pillow falls across his face (*stressor 1*). He dies.
- Or, he has fallen asleep on the couch with his dad and rolls into the gap between the back of the couch and the cushions (*stressor 2*). He dies.
- Or, his grandma is caring for him this night and places him to sleep on his side because he “won’t settle on his back”. He rolls to his front (*stressor 3*) and dies.

1. Source: Filiano and Kinney, *Biol Neonate*, 65: 194-7, 1994

Topic 2: Triple Protection Model

Triple protection model

Of more value to health education and prevention, is a concept of *triple protection*. We promote this as the three environments in which a baby needs protection: family, pregnancy and sleep. When care is optimal in all three, a baby is best protected from sudden death, whatever the cause, be it SIDS, asphyxia, infection or violence.

The Triple Protection Model



Family

Protection starts in families. Young parents need families to prepare them to care for a child and to support them to do what is best. Families and friends are a trusted source of information and advice. Safe Start promotion needs to be inclusive of both parents, their whanau/families, friends and other care givers.

Pregnancy

Early antenatal attendance links parents into health care, education and support. Smoking and other issues can be addressed early. An optimal pregnancy is especially important where there are the social risks challenging the pregnancy such as young maternal age.

Sleep

Face-up, face clear, close by sleep is important for all babies. It is especially important for babies challenged by risks in family or pregnancy circumstances.

The “healthy adopter” phenomenon

The triple risk model helps explain why so many babies who slept on their tummies did not die from SIDS. It helps explain why all babies need to be protected from risks especially those with a known vulnerability such as smoke-exposure or prematurity. And it also helps explain the “*healthy adopter*” phenomenon whereby a practice that is high risk for some, and is widely adopted by those at low risk, dilutes perceptions of harm and makes the problem hard to recognise without systematic mortality review¹. For SIDS, families at low risk were more likely to adopt the prevailing advice (sleep on the tummy) and this weakened the association between the practice and the risk. The “*healthy adopter*” phenomenon is a caution to health professionals and any group where observational studies are used to assess the safety of health education and promotion.

¹ Gilbert R, Salanti G, Harden M, See S. Infant sleeping position and the sudden infant death syndrome: systematic review of observational studies and historical review of recommendations from 1940 to 2002. *Int J Epidemiol.* 2005 Apr 20;

Topic 3: Infant positioning

Back is best for sleep

Infant positioning has risen in status as an infant health issue due to the strong association between sleep position and SIDS. Around the world the message to parents is “**back is best**” for all babies (Oyen et al, 1997). The back is six times safer than the front and twice as safe as the side (Mitchell et al, 1997).

Back sleeping is an age-old tradition in infant care for many parts of the world, including Europe, as is clearly depicted in art. Despite this fact, and the overwhelming evidence for “back is best”, parents and professionals in New Zealand and elsewhere have been slow to trust the “back is best” advice. A misguided fear that babies will aspirate on their backs or develop a flat head, and a desire for babies to ‘sleep better’, has stood in the way. The distrust has slowed the potential for reduced rates of sudden infant deaths in the past eighteen years.

Extra protection from back

The strength of the association between positioning and SIDS is modified by other factors e.g. while back sleeping is recommended at all times and for all babies, it is even more protective:

- between one and six months of age
- in winter compared to summer and in the South Island compared to the North
- during illness compared to well times
- when a baby has excessive compared to moderate clothing and/or bedding
- during day sleeps (noon to midnight) compared to night (midnight to noon)
- for premature babies compared to term
- for low birth weight babies (<2500 grams) compared to normal birth weight
- for babies sleeping in a separate room compared to those sharing with an adult

Extra risk from side

The side is an unstable position for babies. Side sleepers change position most of all. While most roll to the back, those that roll to the front are at extra risk from inexperience in this position. This is called the “*unaccustomed prone*” risk and it affects babies usually placed on their side to sleep who are placed prone for the first time, or, who roll to prone. Twenty percent of SIDS deaths in the NZ Cot Death Study involved such babies. Unlike SIDS babies who usually slept prone, most of the “*unaccustomed prone*” babies were also found with their face down into bedding. It was a lack of skill rather than age of baby that made the difference. This finding is a caution against managing the “unsettled” baby with a change in sleep position.

“Tummy time” when awake

Lying prone is safe when a baby is awake and supervised. Such “tummy time” gives practice in “nuzzling” (head turns) and “bobbing” (head lifts) which help protect a baby. Time on the tummy assists all-round development, as does time spent upright (being held). Such care also helps protect head shape by varying the action of gravity on a baby’s head.

Topic 4: Smoke-exposure: fetal effects

From social to health issue

Fetal tobacco syndrome¹ is a suggested diagnostic term for the constellation of adverse effects on a child due to smoking in pregnancy. The unborn child must adapt to a sub-optimal intrauterine environment. The compensatory responses in the womb compromise adaptation after birth². E.g. a suppressed hypoxic arousal may contribute to an increased risk of SIDS. These adaptations reduce the infant's options for normal health and care during infancy. Given that one in three pregnancies are smoke-exposed and that smoking is behind the major challenges to pregnancy and infant health, smoking needs to be considered a health and not a social issue by childbirth educators, health professionals and public health teams.

Impact on reproductive health

Professor Lesley McCowan, National Women's Health, Auckland DHB, is a champion of smokefree pregnancies. Her appraisal of the literature is: "Every reproductive outcome you can think of is made worse by smoking (except one - pre-eclampsia)." As well as its impact on maternal health and wellbeing, smoking has an adverse impact on fertility, the placenta, fetal development, labour, pregnancy outcomes, breastfeeding, infant care options and child health.

Impact on the newborn baby

Nicotine, and probably other chemicals in tobacco, cross the placenta, leading to:

- reduced placental blood flow and so reduced supply of nutrients and oxygen.
- increased vulnerability due to altered autonomic nervous system controls.
- Increased problems in the new born period e.g. smoke-exposed babies are more likely to be difficult to settle, highly aroused, reactive, hypertonic (tense), have a longer and more difficult period of adjustment and require a NICU or SCBU stay.³

What every parent needs to know

Damage to babies from smoking in pregnancy is hard to see with the naked eye. Every parent of a child exposed needs to know that their baby requires special care to compensate.

- They need to know that their baby is more vulnerable to sickness, asphyxia and SIDS, but that there are ways to reduce the risks.
- They need to understand that, for best protection, it is even more important for a smoke-exposed baby always to be placed for sleep on the back, to be fully breastfed, always to sleep in their own bed and not with others, always to sleep with no risk of their face or head becoming covered and never to smell or breathe in tobacco smoke.
- They need to ensure these things also happen when their baby is in the care of others.

1 Nieburg P, Marks JS, McLaren NM, Remington PL. The fetal tobacco syndrome JAMA. 1985 May 24-31;253(20):2998-9

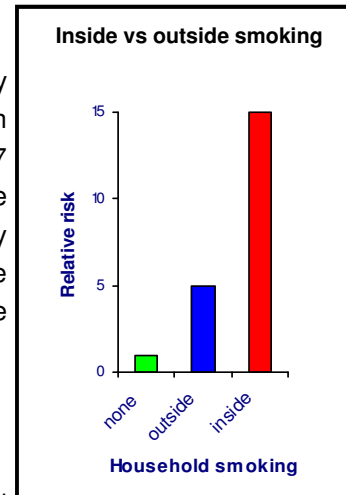
2 Habek D, Habek JC, Ivanisevic M, Djelmis J. Fetal tobacco syndrome and perinatal outcome. Fetal Diagn Ther. 2002 Nov-Dec;17(6):367-71

3. Law K, Stroud L and LaGasse L et al. Smoking during pregnancy and newborn neurobehavior. *Pediatrics* June 2003

Topic 5: Smoke-exposure: infant effects

Smoking outside not enough

Smoking outside and away from children does not completely protect them from other people's smoke. Studies have shown that child exposure, as measured by hair cotinine levels, is 5-7 times higher in smoking households where people "smoke outside" compared to smokefree households where nobody smokes at all. Least protected are children in households where people smoke inside. These children have 3-8 times the smoke exposure of "smoke outside" households. (Matt, *BMJ*, 2004)



Greater risk for children than adults

The young are more at risk than adults from second-hand smoking (SHS) due to the fact that their vital organs are still developing and they are more exposed than adults. Babies and young children:

- are trapped in smoking wombs, cars and homes; they cannot move away from it.
- spend a lot of time with caregivers and so they are exposed for a longer time.
- are not aware of the danger that tobacco smoke represents and will not try to protect themselves from it.
- have smaller lungs and lighter body weight than adults so the dangerous substances in smoke are more harmful to them.
- breathe at a faster rate than adults so inhale more smoke per unit of body weight (2-4 times faster that is 30 breaths/minute or 40000 breaths per day for a 2 year old).
- spend 80-90% of their time in confined places and, if they are inhaling smoke and seeing people smoke, their health risks and smoking uptake risks are heightened.

Air care approach

The "Smokefree Children" programme of Change for our Children (formerly Education for Change) promotes an "air care" approach to smokefree interventions for children. The focus is on the child's air and not the parent's smoking. Discussion with families is centred on where the child's air is already smokefree and where and how to build on this. It encourages parents to consider the 40000 or so breaths their child takes in each day and to make more and more of them smokefree.

This approach aligns with "family centred care". It shares responsibility for the child's recovery and health, with families through a guided smokefree assessment and planning discussion. This positive and action-oriented approach gives a clear message that family smoking is an issue, and opens the way for change.

Topic 6: Accidental asphyxia

Sleeping babies need to breathe

Dangerous sleeping conditions have been associated with infant deaths from all diagnoses: SIDS, accidental asphyxia and “cause undetermined”¹. This suggests that there is low awareness of hazardous sleeping arrangements and infant vulnerability. Shared sleeping conditions pose the greatest risk. An open airway is a baby’s life line. It needs protecting during sleep.

Asphyxia

Asphyxia is not being able to get oxygen to the lungs. The airways become obstructed in some way. Carbon dioxide levels rise and this stimulates the struggle to breathe. Breathing movements may continue, but no air gets through. The baby may go blue and if the airway remains closed the child will soon die. Asphyxia can be accidental or intentional.

How it can happen

There are four ways in which airways close and asphyxia occurs.

- The nose and mouth become covered making breathing difficult or impossible
- The inner part of the airway is blocked by a foreign body or tissue swelling
- The trachea is blocked by external pressure on the neck
- The chest is compressed (crush injury) and breathing is obstructed

Asphyxia patterns change with age

A large US study documented patterns of accidental asphyxia deaths for 2178 infants². There were three main causes:

- Wedging: becoming wedged between things or in gaps
- Covering: a covered face or head
- Overlying: being rolled on or against someone

These patterns changed with the age of the baby suggesting that what constitutes a hazard changes as a baby develops. Overlying was most common for very young babies (aged 0-3 months), a covered face for babies aged 0-7 months with wedging being the main cause of asphyxia for all age groups.

A baby’s response

When oxygen supply is reduced for any reason, babies need to escape that situation to stay alive. Usually they will sigh, wake up, swallow, take a deep breath or move about to try to clear the airway from any problem. In the early weeks, these life-protecting behaviours are under reflex control. At around 2 to 4 months a shift in control occurs and this is when babies are at greatest risk of SIDS and accidental asphyxia. This is the time when sleeping prone is especially dangerous. Babies have few options for removing an obstruction themselves.

Creating safety during sleep

Topic 7 deals with safe and unsafe sleeping conditions for babies.

1 Kemp et al. Pediatrics 2000 Sep;106(3) E41

2. Drago et al. Pediatrics 1999 May;103(5)

Topic 7: Sleeping environments

Infant sleep is a complex phenomenon. So, too, is research about it and the interpretation of findings. SUDI research is responding to death. It is trying to find clues for prevention. It needs to be respected for its place in the growth of knowledge and, at the same time, understood within the wider context of infant and family well-being. Where there is widespread agreement recommendations can be made. Where there is not, we must share the uncertainty with parents, hold back from advising and entrust families to decide for themselves.

Safety principles

Principles for enhancing infant safety during sleep are: face up, face clear, smokefree, close to parents, breastfed. These are a package of life-protecting principles which, together, give the best protection from SUDI. These are the 'top layer' conditions that benefit all babies in all cultures and times. Supporting parents to understand and apply these principles to their many infant care decisions is our educative purpose.

SUDI deaths happen significantly more in 'bed sharing'/surface sharing and significantly less in 'room sharing' situations¹. Bed sharing is the term for a broad range of conditions and practices. Just what it is about sleeping with parents in the same bed that raises the SUDI risk for some babies is still being discovered, although it is well established that smoke-exposed babies are at high risk and that sleeping alone, but close to parents, is a way to mitigate this risk. Also, there is widespread agreement that older babies (>4 months) 'bed sharing' with smokefree parents poses no increased risk. Some studies show a small risk for young babies of smokefree parents and more study is needed to clarify the conditions that make it so.

Sleep is a dynamic state. It is ever changing. People move, bedding shifts, arousal states vary. Rather than be drawn into a research debate about the pros and cons of infant-parent bed sharing, our education and prevention effort needs to focus on safety principles and restoring perspective and confidence to parents. The goal is: safe sleep for every baby, every sleep.

Hazards

A baby's airway can become obstructed by: soft surfaces, others in the bed, a heavy arm across a tiny chest, an unusual neck position, cords, car seat straps, falling, becoming trapped between a bed and the wall or becoming wedged into gaps. Whether a baby shares a sleep surface or not, these situations are potentially hazardous:

Unsafe position: Propped, side or front positions, between pillows or on cushions

Unsafe surfaces: Soft mattresses, bean bags, water beds, V-pillows, thin plastic

Unsafe places: Couches, chairs, in a room alone, make shift beds near walls

Unsafe bedding: Pillows, loose covers, duvets, cushions, loosely fitting mattress, toys

To help protect a baby, sharing a bed should always be avoided in the following situations¹:

- When a baby has been exposed to any smoking, especially smoking in pregnancy
- When a baby is born premature (< 36 weeks) or is of low birth weight (<2500 grams)
- When there is reduced awareness in the adult from extreme tiredness, smoking, alcohol, marijuana, medications or other drugs

1 Scragg et al NZ Med J 1995; 106;218-22

Topic 8: Head shape

With increasing back sleeping rates there has been a corresponding increase in babies presenting with misshapen heads. Understandably, heightened awareness has led to heightened concern amongst parents. The issues are serious for there is a potential risk of rising SIDS rates if parents try to manage the problem by avoiding the back position for sleep.

The problem of “flat heads”

The medical term for the condition is nonsynostotic plagiocephaly (NSP) or deformational occipital plagiocephaly (DOP). It needs to be distinguished from the more serious true synostosis (early closure of cranial sutures) and other causes of misshapen heads in babies. Commonly known as a “flat head”, it is a flattening of the back of the head which develops from too much time spent resting on the same part of the head.

The cause

The bones of a young baby’s skull are thin and soft. Pressure of a heavy head lying on the same spot each sleep can reshape the head. If this happens for a baby who sleeps supine, the flattening will happen to the back of the head, especially if the baby also spends a lot of time lying on the back when awake, or in car seats or bouncers more than being held.

How it develops

The condition develops when a back sleeping baby favours a certain head position. The baby may be born with a slight flat spot from moulding in utero or during delivery. This can cause the head to rest more easily on that spot. Or, the baby may have a favourite head position and so a flat area develops from habit.

Prevention and treatment

Education, of both professionals and parents, is the best way to prevent flat heads for most babies. Variation is the key: varied head position sleep by sleep for very young babies and varied posture and position when awake (supervised “tummy time” and “upright time”). These practices will vary the gravitational forces acting on head shape and help prevent or treat reshaping. Regular head checks starting from birth and early detection of flat spots will enable positional treatment to start early. More serious cases need referral to a specialist.

Risk Assessment

Head shape needs to be assessed at birth and positional treatment or prevention started. Assessment needs to consider the following characteristics of the more vulnerable infant¹:

Head shape:	has an existing flat spot
Behaviour:	has a strong preference for turning the head to one side has difficulty turning the head (limited neck rotation)
Infant:	first born, preterm, less active, developmentally delayed
Care:	head position not varied when placed for sleep has less than 5 minutes on the tummy each day in the first six weeks

1 Hutchison et al Pediatrics 2003

Topic 9: “Grey Zone” Deaths

Problems with diagnosis

SUDI is the name being used in New Zealand for all sudden unexpected deaths in infancy. Babies also die suddenly and unexpectedly from diseases, accidents, neglect, abuse and infanticide as well as from SIDS. Together these deaths make up the total group of SUDI deaths. To distinguish SIDS from other SUDI deaths, thorough investigations are needed by appropriately qualified teams. This is not always possible and so a “grey zone” develops. Pathologists in some countries are introducing vague new terms such as “unascertained” or “borderline SIDS” to classify sudden infant deaths in this “grey zone” between “definitely SIDS” and “definitely not”. In New Zealand, SUDI is now the more usual classification for this broader group of deaths.

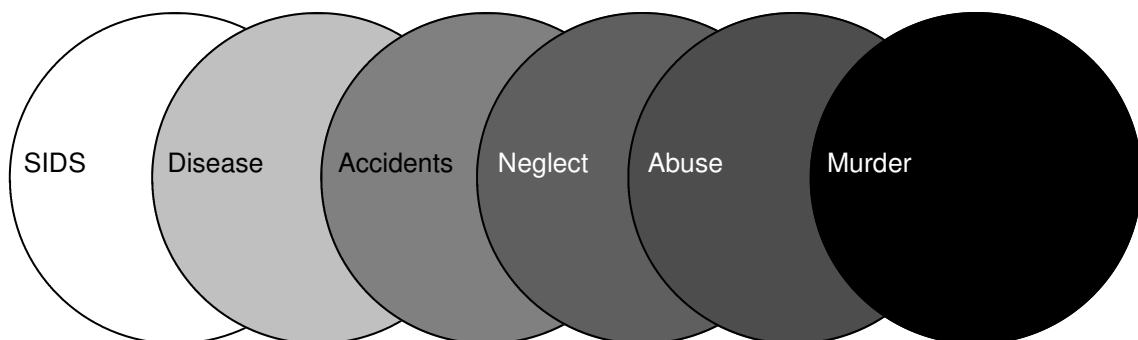
An uncertain diagnosis can lead to suspicion and gossip. While intentional suffocation does happen, it is rare. In Norway, infanticide is 2% of all SUDI deaths. In New Zealand in 2001, there were 2 deaths from infanticide and 57 SIDS/asphyxia deaths in babies under 1 year¹.

Coroner verdicts in New Zealand

Examples of coroner² verdicts identify the challenge for classifying sudden unexpected deaths:

- ▶ “Cause of death undetermined, such death being sudden and unexpected, occurring in infancy and at a time when she was sleeping in an unsafe environment.”
- ▶ “Likely to be due to accidental asphyxia, he having been placed in an unsafe sleeping environment, namely lying prone (on tummy) in his cot, with his head on a soft pillow and he having been found dead lying face down on that pillow.”
- ▶ “Likely due to accidental asphyxia, he having been placed in an unsafe sleeping environment, namely lying close to his mother in the parental bed, his mother having fallen asleep and he having been found with his head and face lying between her breast and the mattress.”

SIDS, SUDI and the ‘grey zone’ deaths



¹ Personal communication: Chris Lewis, NZHIS

² Coroner Reports, Mr Gary Evans, Wellington District Coroner

Topic 10: Priority Babies

Socio-economic position

SIDS is not an equal opportunity killer. It claims a disproportionate number of babies in families of low socio-economic status as do all causes of child death¹. Over represented within low socio-economic groups and associated with increased risk of sudden infant death are Māori, young mothers and pre-term babies. Health funders are now demanding that health inequalities be addressed. It is not enough to take a simple “reduce the risks” approach to SIDS prevention. This needs to go hand in hand with a more strategic attack on the underlying determinants of social disadvantage. A more supportive socio-economic environment for a family is likely to foster a more protective environment for a child. This is the work of Safe Start™, promoting supportive environments for families and protective environments for babies especially for these priority babies.

The Māori baby

The Māori baby is challenged on many fronts. Many Māori women have multiple maternal risk factors (young maternal school leaving age, young motherhood), live in poverty and disadvantage (low socio-economic status, poor education, unmarried motherhood), with poor access to health services (late use of antenatal care, young age at first pregnancy, multiparity), bear compromised babies (low birth weight, prematurity, admission to neonatal intensive care). All this sits alongside the high prevalence of bed-sharing, valued as a normal and cherished behaviour in Māori combined with high smoking prevalence and its disempowering addictiveness. (Source: www.maorisids.org.nz)

Māori communities and the Māori SIDS programme are not sufficiently resourced to shoulder full responsibility for preventing Māori SIDS. We need main stream health services to compliment this effort so that there is wider access to appropriate care and support for Māori.

The baby of a teenaged mother

Many studies are reporting an increase in the significance of “young maternal age” as a risk factor for SIDS following “back is best” campaigns and advising that preventive efforts need to focus on improved pregnancy care and parenting education. Young mothers are more likely to seek advice from family and friends than health professionals and may be missing out on current best practice information.

The pre-term baby

The combined effects of SIDS risk factors in the sleeping environment and being pre-term or low birth weight generate high risks for the pre-term and low birth weight infants. These risks come from being underdeveloped combined with side sleeping, bed-sharing with parents especially if they smoked and sleeping in a room separate from parents.

¹ Blakely T, Atkinson J, Kiro C et al. Child mortality, socio-economic position, and one parent families: independent associations and variation by age and cause of death. *Int J Epidemiol* 2003; 32:410-418

² Blair P, Ward Platt MP, Smith IJ, Fleming PJ. Sudden Infant Death Syndrome and sleeping position in pre-term and low birth weight infants: An opportunity for targeted intervention. *Arch Dis Child*.2005;

Topic 11: NICU and SCBU settings

The evidence

There are well documented advantages from sleeping prone (on the front) for very sick infants with breathing difficulties or on a ventilator. The highly monitored environments of NICU and SCBU protect such babies from the dangers of reduced arousal from sleeping prone, but parents may see this as best care and replicate it at home. The evidence from New Zealand and around the world is strong and consistent that avoiding behavioural risk factors is even more protective for the premature and low birth weight baby. Evidence highlights are below:

Are the risk factors for SIDS different for preterm and term infants?

Conclusion: SIDS rates have decreased at comparable rates in term and preterm infants, but preterm birth still remains a risk factor for SIDS. The magnitude of the odds ratios associated with modifiable risk factors were similar for both groups. There may however be a difference in risk associated with parity between term and preterm infants. The messages for risk factors for SIDS are applicable to mothers of preterm as well as term infants.

J M D Thompson et al
Archives of Disease in Childhood 2006;91:107-111;
doi:10.1136/adc.2004.071167

Positioning for acute respiratory distress in hospitalised infants and children

Conclusion: The prone position was significantly superior to the supine position in terms of oxygenation. However, as most patients included in the meta-analysis were ventilated, preterm infants, the benefits of prone positioning may be most relevant to these infants. In addition, although placing infants and children in the prone position may improve respiratory function, the association of sudden infant death with prone positioning means that infants should only be placed in this position if continuous cardiorespiratory monitoring is used.

Cochrane Database Syst Rev.
2005 Apr 18;(2):CD003645

Effect of Position on Sleep, Heart Rate Variability, and QT Interval in Preterm Infants at 1 and 3

Conclusions. Despite the commonly held belief, prone position did not substantially increase total sleep at these ages. On the other hand, prone sleeping decreased the number of sleep transitions at 1 month corrected age, increased QT and JT intervals, and reduced HRV, thereby potentially increasing the vulnerability for SIDS. This study supports "Back to Sleep" as the position of choice not only for term but also for preterm infants after discharge home.

Ronald L et al *Pediatrics* Vol.
111 No. 3 March 2003, pp.
622-625

Respiratory responses to hypoxia/hypercapnia in small for gestational age infants influenced by

Conclusions: Maternal smoking appears to be the key factor in enhancing infants' respiratory responses to hypoxia/hypercapnia, irrespective of gestational age.

Galland BC, *Archives of Disease in Childhood Fetal & Neonatal* ed. 2003;88:F217

Prone or supine for infants with chronic lung disease at neonatal discharge?

Conclusions: The supine position appears appropriate for very preterm infants with chronic lung disease (CLD) going home from the neonatal unit. Respiratory instability on neonatal discharge is more likely to be associated with immaturity than CLD.

Elder DE, Campbell AJ,
Doherty DA.J *Paediatr Child Health.* 2005 Apr;41(4):180-5.

Topic 12: Parent Education

Coordination

Coordination is the organised working together of individuals to bring about a purposeful change that is greater than the sum of the contributing parts. The *Safe Start™* programme is a coordinating process that gives shape and focus to a population effect from the learning. And this resource, and the module that follows, are coordinating tools. These are mechanisms for a standard of SUDI education that is accountable to evidence and provided to all.

SUDI Module

We offer a five step framework for including SUDI as a topic in your parent education sessions. It may be presented as a stand alone discussion, included in a 'sleeping set-up' demonstration, designed into a learning activity or integrated into course content as appropriate. The framework is developmental. It guides learning from aligning understandings to interpreting information and applying principles of care.

Context: Parents need to understand that the high rates of sudden infant death in the 1970's and 1980's from which SUDI research grew, led to a culture of fear for parents. Manufacturers saw opportunities for new baby care products and 'peace of mind' marketing and now we have a plethora of positioning aids, specialised bedding items, monitors and more. Memories, products and media reports help keep this fear alive.

Evidence: Parents need to know that we are in a different time now. From 1990, the world has seen a sharp fall in sudden infant death rates as parents heeded the 'back is best' recommendations for infant sleep. With back sleeping now the norm for babies, smoking has taken over as the main risk. Smoking suppresses arousal making shared sleeping hazardous for smoke-exposed babies. This 'smoking/bed sharing' combo is the most significant risk for today's babies. Although the current research focus is sleeping environments and infant vulnerabilities, enough is already known to protect most babies.

Principles: Parents need to apply a package of life-protecting principles if they are to give their baby the best protection. Principles derive from research and are: sleep face up, face clear, smokefree, breastfed, close to parents. These are important for all babies of all cultures in all times. This package of care is essential support for a baby through a critical stage of development.

Products: Parents need to be able to assess products and marketing information against the principles of best care and decide if they are necessary. Commercial products have rarely been scientifically tested to see if they change the odds. Babies must always be supervised when using products whatever the packaging may claim.

Interpretation: Parents need to interpret what the principles of best care mean for their baby and their family. For example, they need to consider potential hazards in the sleeping environment that may compromise the 'face clear' principle. They need to consider opportunities for gravity to help with head shape for their back sleeping baby. They need to consider their baby's need for closeness when they decide their sleeping and feeding arrangements. And they need to consider a baby's age and vulnerability when making care decisions.

Topic 12: ... continued

Health professionals have an opportunity to strengthen trust in infant safety principles and in so doing play a key role in the prevention of SIDS, accidental asphyxia, other causes of SUDI and flat heads. These practical education suggestions, already widely practiced, may also help.

Modelling with mannequins

- Always position 'babies' for sleep on the back
- Model varying positions for the awake 'baby' - tummy time and upright time (being held).

Discussion

- **Focus on principles.** Work with the universal principles of infant safety rather than bits and pieces of information. Principles support empowerment by fostering understanding. They give parents a 'true north' for interpreting what they see, hear and read beyond your talk. When discussion becomes sidetracked, draw people back to principles.
- **Focus on the usual.** Distinguish usual from exceptions and focus on usual. A non-supine position advised by a doctor for a baby with special needs is an exception, whatever the reason for the deviation from recommended practice.
- **Focus on the face.** Focus discussion on the child's face and the need to keep it clear for easy breathing and for cooling during sleep. Explain that babies have strong life-support reflexes (gagging, swallowing, sighs ...) to protect their airways. Breathing tubes lie above food tubes when on the back, so babies are better protected from choking.
- **Focus on the setting.** Ensure awareness of potential hazards wherever a baby sleeps.
- **Focus on gravity.** Reassure that gravity helps shape a head, too. Explain that the bones of a baby's skull are soft and that pressure from lying on the same position can cause flattening. Varying head position when asleep and having plenty of upright and tummy time when awake help support a rounded head shape. To summarise: "back for sleep, front for play, upright for cuddles and hugs". All work together to shape the head.
- **Focus on parent responsibility.** Education can raise awareness, provide perspective, encourage discussion and share recommendations. It cannot respond to the actual and varying needs of individual babies. This is the responsibility of parents. We need to respect that it is parents who decide what they see as best care for their particular baby.

Demonstration

A formal demonstration of the "going to bed" routine is a way to integrate safety principles and positioning messages with other messages about the sleeping environment, by giving a running commentary of what you are doing and why e.g.

- firm, clean, tight-fitting mattress, fitted or tightly tucked sheet to keep from covering face
- placing baby face-up (on the back) to help breathing and cooling and protect from SIDS
- checking baby's warmth and adjusting clothing and bedding to suit
- tucking covers firmly, removing toys et cetera to be sure the face stays clear
- dropping the head of the bed down, if inclined, to avoid slipping under the covers
- alternating head position (e.g. "In the night towards the right, in the day the other way")

Supervised practice

A practice session following a demonstration, to reinforce and encourage, gives parents a chance to consolidate what they have learned and to feel confident in their practice.

Please tell my parents ...

Please tell my parents what SUDI stands for and how they can protect me from it. Be clear about what is best and what is not because there are lots of people telling them things and they could get confused. Please be positive or they will worry. Do make sure they understand why I need the care you recommend as that will help them believe you. And ask them to tell everyone else in my family, too, so that I will be safe whoever cares for me. Some people have strong opinions that may be wrong or out of date so please help my parents make decisions that will protect me.

My parents need to know that oxygen keeps me alive. Anything that slows down the oxygen I need, will harm me. If this happens before I am born then I won't develop in a healthy way. All of me needs that oxygen, especially my brain. And if it happens afterwards and blocks my breathing I will also be in danger. Make sure my parents know that smoking can do this to me, especially before I am born. And make sure they know the kinds of hazards that could harm me when I sleep. I do not want to be a SUDI baby.

Please tell my parents that I have been designed to be smokefree from the start. This will protect me from SUDI the most. My 'wake-up monitor' will be strong and I won't be poisoned by all those chemicals in tobacco smoke. Smoking before I am born does the most harm of all to me and it lasts forever.

I have also been designed for sleeping on my back. My 'life support' reflexes work best on my back but some parents don't understand this. Please explain to my parents that my food tube is below my breathing tube when I lie on my back so spills get swallowed. When I gag, swallow or sigh that is my reflexes watching over my breathing. But when I am awake I like all sorts of positions. It helps gravity to shape my head evenly. It is just when I sleep, and for every sleep, that I must be on my back. Most SUDI babies did not sleep on their backs so make sure my parents do this for me.

I am worried that my parents might hear that babies sleep more soundly on their tummies or sides. And we do. But it is dangerous for me to sleep deeply when I am a baby. I need to make little startles and practice my 'wake-up' response. I am designed to need my parents more in the early months, to feed often, wake often, cuddle often. I need them close, even when we are all asleep so please ask them to have my cot near their bed at least for the first months. When they bring me into their bed they will need to be sure this is safe. Mostly it is.

Explain to my parents that most SUDI babies die in beds with others or on couches and chairs because people do not know the hazards. We can only breathe through our noses at the start so we need a clear face at all times. If we are premature, have a low birth weight or our mother smoked, then we may not have a strong 'wake-up monitor' so we are always best in our own bed. And if our parents have a weak 'wake-up monitor' from smoking, drinking, drugs or being very tired we are also best in our own beds. Otherwise, ask my parents to make sure that the pillows are gone, the mattress is firm and I cannot roll into gaps or under anyone when they bring me into their bed. If I am smokefree, my face stays clear and I can be on my back, I should be safe in their bed.

Probably everyone knows that 'breast is best' but I want my parents to know that it really really is. I need the food and the closeness as well as all the other things that breastfeeding does because I am designed for this. Breastfeeding feeds my mind and spirit as well as my body. My parents may need some help to get started so teach them well.

I know my parents will get tired looking after me because I need them for everything. Make sure to tell them to take some breaks and have support to turn to. I need to be handled gently even when my parents may feel stressed. Please tell them I am just being a baby when I cry or make demands, that I love them and when I am big and strong I will thank them for protecting me when I was new.

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