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SUDDEN INFANT DEATH SYNDROME IN QUEENSLAND: AN UPDATE

Summary

- Despite a decrease in the national and Queensland incidence of Sudden Infant Death Syndrome (SIDS) deaths, SIDS remains a leading cause of death in infants beyond the neonatal period.[1-3]
- Evidence shows that the implementation of infant care practices in Queensland that are known to reduce the risk of SIDS has been sub-optimal.[4-6]
- Although recent initiatives, such as *Child Health Information: Your guide to the first 12 months* universally provides SIDS risk reduction information to new parents,[7] further effort is required to educate child health professionals, parents, a wide range of non-parental carers, families, and communities.
- Infant care practices to reduce the risk of SIDS should be practised in hospital and community settings to model such behaviours for parents, and the provision of 'Safe Sleeping' information to parents should be an integral component of care and discharge planning.
- The Queensland Health Statewide "Policy for Safe Infant Care to reduce the risk of SIDS" has been developed to support staff to identify risk factors for SIDS, practice safe infant care and provide accurate information to parents.[8]

Background

This information circular is intended to provide an update of evidence relating to Sudden Infant Death Syndrome in Queensland. This replaces the former version of Information Circular No 35[9], incorporating updated data from 1991 - 2002, and reflecting current evidence-based best practice regarding prevention of Sudden Infant Death Syndrome. This circular is based on data from the Australian Bureau of Statistics Death Registration Data Set[3], and is supplemented by data obtained from the Queensland Paediatric Quality Council from reviewed and re-classified SIDS in Queensland[10,11]. The purpose of this circular is to support the development and the statewide implementation of the Queensland Health *Policy on Safe Infant Care to Reduce the Risk of Sudden Infant Death Syndrome (SIDS).*

Definitions and Incidence of Sudden Infant Death Syndrome

- Sudden Infant Death Syndrome (SIDS) can be defined as "*the sudden and unexpected death of an infant under one year of age, with onset of the lethal episode apparently occurring during sleep, that remains unexplained after a thorough investigation including performance of a complete autopsy and review of the circumstances of death and the clinical history.*"[13]
- Sudden and Unexpected Death of Infants (SUDI) is defined as "*death where insufficient findings were present to support a particular diagnosis but when sufficient abnormal features in the history or at the scene examination, autopsy, or laboratory work-up were found that were not typical of SIDS*".[14] SIDS is by definition, a subset of SUDI which is determined following an investigation of death scene, circumstances of death, and post-mortem examination where all other possible causes of death are excluded.
- Although there has been a substantial reduction in the incidence of SIDS since 1991, SIDS is the most common causes of death in infants between 1 month and 12 months of age, accounting for 31% of deaths in this age group.[3]
- The decrease in SIDS rates observed since 1991 may be attributed to the national health education campaign highlighting the risk factors that were thought to contribute to SIDS, including sleeping position, feeding practices and exposure to tobacco smoke.[2]
- From 1994 to 2001, Queensland's SIDS mortality rates were higher than the Australian average. In 2002, the Queensland rate was 0.43 per 1000 births, compared to the Australian average of 0.47 per 1000 births. [1-3]

Risk Factors for Sudden Infant Death Syndrome

- A large body of international research has shown certain factors relating to environment and infant care practices increase the risk of SIDS, in particular:
  - Prone (on the stomach) sleeping position
  - Exposure to tobacco smoke, in utero and through passive and environmental smoking after birth[15,16]
- Most at risk for SIDS are infants who are premature, of low birthweight or from multiple births; whose mothers are young, have low levels of education, live in poor socio-economic circumstances, smoke and leave little intervals between pregnancies; whose fathers are absent or unemployed.[15-17]
- The risk of SIDS is higher for male infants, and the risk peaks between 1 and 3 months of age. Deaths usually occur during the night, and are more frequent in the winter months.[3,15-17]
- Indigenous infants in Queensland are 3.5 times more likely to die from SIDS.[3]
- Increased maternal education is associated with greater knowledge of SIDS, and the use of infant care practices that reduce the risk of SIDS.[14]

- Many known risk factors for SIDS are also common to SUDI and sleep accidents, therefore safe infant care and sleeping strategies will target all three causes of infant death.

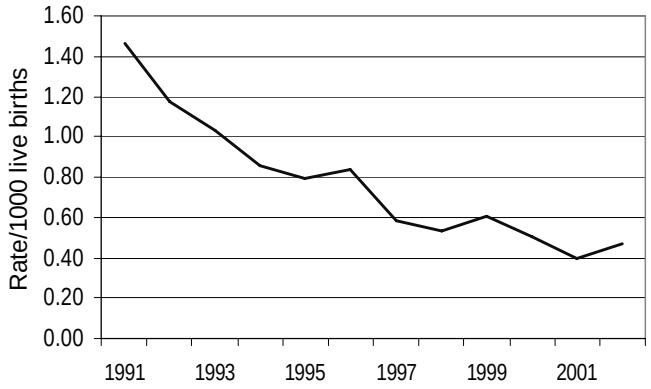
Reducing the Risk of SIDS

- In 1991, SIDS and Kids Australia (formerly the National SIDS Council of Australia) introduced the *Reduce the Risks* program. The recommendations have been revised over the years to be congruent with updated research and current best-practice. The following are current evidence-based key recommendations to reduce the risk of SIDS.
    - Sleep baby on the back from birth – never on the tummy or side
    - Sleep baby with face uncovered
    - Keep baby smoke free, before and after birth
    - Provide a safe cot, safe mattress, safe bedding and safe sleeping place.[18]
- To ensure a safe sleeping place to reduce the risk of SIDS:
    - The cot must meet the Australian standard for cots
    - Put baby's feet at the bottom of the cot
    - Tuck in bedclothes so bedding is not loose
    - Keep quilts, doonas, duvets, pillows and cot bumpers out of the cot
    - Use a firm, clean mattress that fits snugly in the cot[18]
    - The safest place to sleep a baby is in a cot next to the parents' bed until the baby is 6 – 12 months of age.[19]
- The key recommendations are supported by Queensland Health's *Child Health Information: Your Guide to the First 12 Months*,[7] which is distributed as an insert in the Personal Health Record to all parents of new infants, and through *Child Health Information FactSheets*[20], as well as the Queensland Health Statewide *policy for safe infant care to reduce the risk of SIDS*.[8]

Rates of Sudden Infant Death Syndrome in Queensland

- Since SIDS prevention recommendations have been made, there has been a marked decline in SIDS deaths in Australia from 1991 – 2002 as shown in Figure 1.[1-3]
- In 1991, SIDS incidence in Australia was 1.46 per 1,000 live births. In 2002, the death rate from SIDS was 0.47 per 1,000, representing a decrease of 68% over this time period.[3]

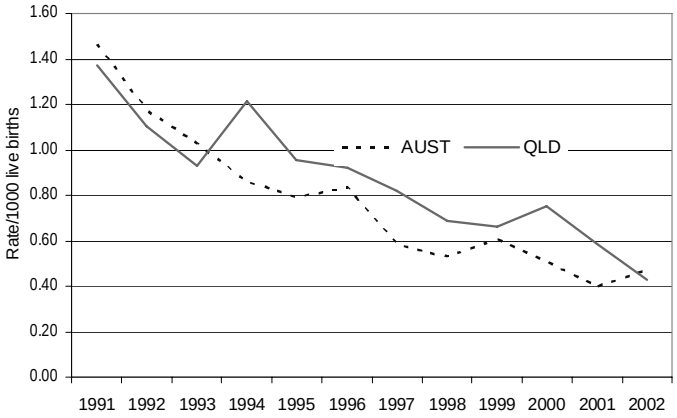
Figure 1: Sudden infant death syndrome (SIDS) mortality rates, Australia, 1991-2002



Source: ABS Cause of Death File, 1991-2002

- Queensland trends in SIDS mortality over the last 12 years mirrored the decreasing trend for Australia. In 1991, the Queensland incidence of SIDS was 1.37 per 1,000 births and declined to 0.43 per 1,000 births in 2002, representing a decrease of 69% over this time period.[3]
- However, from 1994 – 2001, Queensland SIDS rates were higher than the Australian rates as shown in Figure 2. although this was not statistically significant.[3]

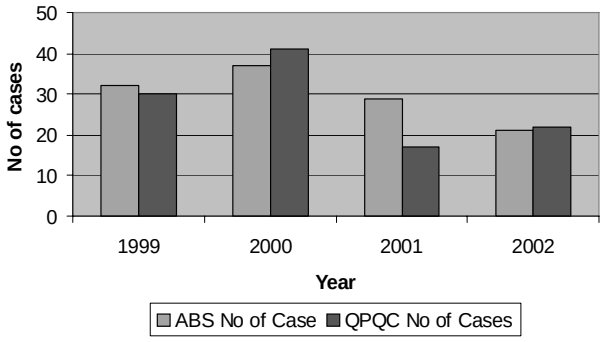
Figure 2: SIDS mortality rates, Queensland and Australia, 1991-2002



Source: ABS Cause of Death File, 1991-2002

- The Queensland Paediatrics Quality Council (and formerly the Queensland Council on Obstetric and Paediatric Morbidity and Mortality), have retrospectively reviewed, re-classified and collated data on SIDS deaths in Queensland since 1998. The Councils have utilised a review process that consists of a detailed re-examination of the medical charts and autopsy report, police and ambulance officer reports, including death scene examination where available to determine a final classification of cause of death. Because of the time differential from death reports to re-classification, the ABS data do not reflect the more accurate re-classified rates of SIDS, as shown in Figure 3.[3,11-13]

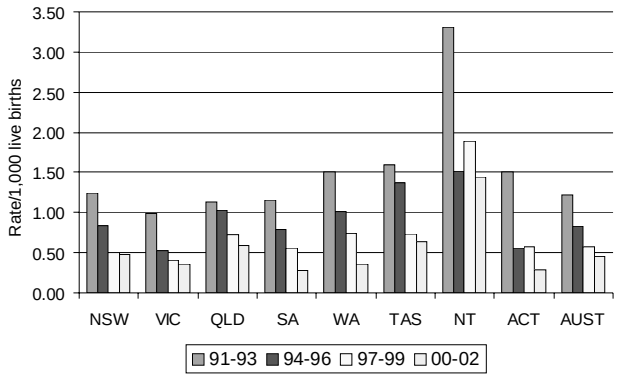
Figure 3: Comparison of ABS and QPQC number of SIDS cases in Qld 1999-2002



Source: ABS Cause of Death File, 1991-2002 and Queensland Perinatal Quality Council Reports 1999-2002

- Figure 4 presents trends in the comparative incidence of SIDS (1991 – 2002) in each of the states. For all states and territories, there has been a general decreasing trend in the incidence of SIDS.[3]

Figure 4: Sudden infant death syndrome (SIDS) mortality rates, States and Territories, 1991 to 2002



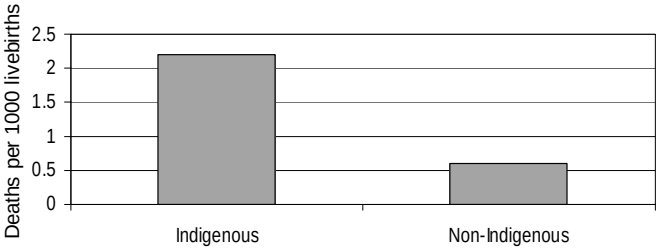
Source: ABS Cause of Death File, 1991-2002

- In 1991-1993 the Queensland SIDS mortality rate was below the Australian average. By 2000-01 the Queensland SIDS rate was higher than the national rate. In this time period, Queensland had the third highest SIDS rates after the Northern Territory and Tasmania. However these differences were not statistically significant, and some of the differences may be due to population differences or inconsistencies between states in their classifications of SIDS and procedures for death scene investigations. The most recently available data indicates the Queensland rate is below the national average of 0.47 per 1000 births.[3]

SIDS and the Indigenous population

- Indigenous infants in Queensland are 3.5 times more likely than non-Indigenous infants to die from SIDS,[3] and some studies have estimated Indigenous infants are up to 6 times more likely to die from SIDS.[21]
- In 1996 - 2002, the SIDS rate for the Queensland Indigenous population was 2.2 per 1000 live births. During the same period, the SIDS rate for the Queensland non-Indigenous population was 0.61 per 1000 live births, as shown in Figure 5.[3]

Figure 5: SIDS ratesin Qld 1996-2002: Indigenous and Non-Indigenous



Source: ABS Cause of Death File, 1991-2002

- The Indigenous SIDS rate is thought to be an under-estimation due to inaccuracies in the identification of Indigenous status in data collections.[22,23]
- Research suggests that the prevalence of SIDS risk factors is higher in the Indigenous population, including maternal and passive smoking, co-sleeping and prone sleeping position.[4,24,25] This suggests a new approach to education to promote SIDS awareness in Indigenous communities is required.

Co-sleeping and Infant Death

- For the purposes of this information circular, co-sleeping is defined as the practice where a parent or another individual sleeps in the same bed or shares the same sleeping surface with an infant.[26]
- Bedsharing refers to the practice where a baby is taken into an adult bed without sleep, for the purposes of breastfeeding, comforting or settling.[27]
- Room-sharing is the practice of the infant sleeping in the same room, but on a separate sleep surface, as one or more adults. This is often referred to in maternity units as "rooming-in" and has been shown to be beneficial for initiating breastfeeding.[27,28] Sleeping in a cot or other separate sleeping surface in the same room as the parents for the first 6 to 12 months of life has been shown to be protective against SIDS, and also to promote breastfeeding[27]. SIDS and Kids Australia currently recommends that the safest place for a baby to sleep is in a cot in the parents' room[18].
- Research regarding the risks and benefits of co-sleeping is controversial and somewhat inconclusive. In some circumstances, co-sleeping increases the risk of SIDS, SUDI and fatal sleep accidents.[27,29]

- The risk for infant death while co-sleeping is substantially higher than that for SIDS, since infant deaths may occur as a result of sleeping accidents (eg suffocation or falls) during co-sleeping.[14] The risks of co-sleeping are difficult to estimate accurately, due to limited data being available on fatal sleeping accidents and co-sleeping.
- Infants who are most at risk of SIDS while co-sleeping are infants who are less than 4 months of age, infants who are born preterm or of low birthweight.[16] There is a significant risk of SIDS whilst co-sleeping with parents who smoke, or who are affected by alcohol or drugs. There is a particularly high risk for SIDS when infants sleep on a sofa, couch or bean bag, or with other siblings or pets.[17,27]
- Co-sleeping is a more common practice for Indigenous mothers.[24]
- The Queensland Paediatric Quality Council reported that 8 out of 9 (89%) infant sleeping deaths in Queensland over 2000 and 2001, occurred while the infant was in a co-sleeping environment.[10,11] However, other risk factors, such as parental smoking, alcohol or drug use, or the sharing of a sofa or other hazardous sleep surface, may have been implicated in these co-sleeping deaths.

SIDS and Kids Australia recommends that the safest place for a baby to sleep is in a cot next to the parents' bed until 6 to 12 months of age[18]. However if parents choose to co-sleep with their infant, the following conditions may enhance the safety of the sleeping environment when co-sleeping:

- Put baby on the back to sleep, never on the tummy or side.
- Make sure the mattress is firm.
- Make sure that bedding cannot cover the baby's face.
- Make sure baby cannot fall off the bed. A safer alternative is to place the mattress on the floor.
- Pushing the bed up against the wall can be hazardous. Babies have died after being trapped between the bed and the wall.
- Co-sleeping must be avoided where either parent is a smoker, or under the influence of alcohol or drugs or is overly tired.
- Baby should not be placed to sleep on a sofa, beanbag, waterbed or soft or sagging mattress, or on a sleeping surface with other children or pets.[18]

SIDS Diagnosis and Classification

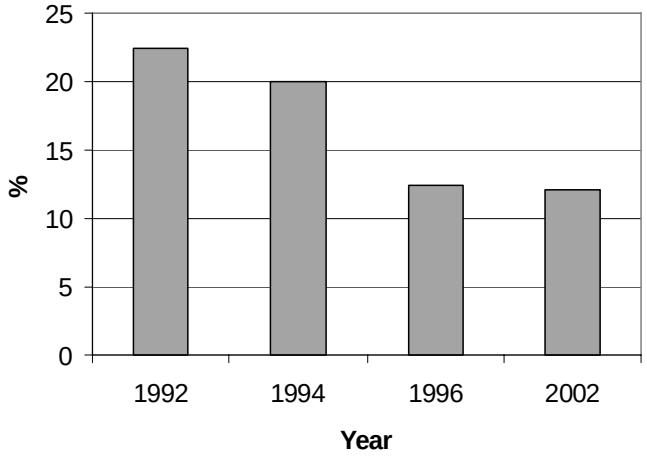
- Prior to the establishment the Coroner's Act of Queensland (2003) and the Office of the State Coroner in Queensland in 2003, the lack of a standard system for post-mortem and death scene investigation and reporting was a major impediment in the accurate classification and data collection regarding SIDS in Queensland.
- Consequent changes to the investigation, definition and classification of SIDS should be considered when interpreting the data.
- International comparisons are difficult due to inconsistencies in definition, diagnosis and classification.

Infant Care Practices in Queensland

Prone Sleeping

- In 1992, the Australian Bureau of Statistics reported that 22.5% of surveyed Queensland parents routinely put their infants to sleep in a prone (face down) position.[30]
- A survey of Queensland parenting practices conducted in 1994 indicated that approximately 20% of respondents placed their baby in a prone position to sleep.[5]
- A 1996 survey, conducted following an intensive *Reducing the Risks* media campaign showed that 12.4% of Queensland parents routinely put their baby to sleep in a prone position.[9]
- A survey conducted in 2002 of Queensland parents' infant care practices found that approximately 12.1% of infants were routinely placed to sleep in a prone position, and less than 2/3 of infants aged 3 months were routinely placed in the recommended supine position.[5]
- A survey of infant care practices in Townsville reported in 2002 that 36% of Indigenous infants were placed prone to sleep, compared to 17% of non-Indigenous infants.[24]

Figure 6: Prone sleeping 1992-2002



- These trends show a significant reduction in the proportion of Queensland parents placing infants in the non-recommended prone position since 1992, but

little change since 1996. The higher rates of prone sleeping reported in the Indigenous community is a matter of concern, and may partially explain the higher rates of SIDS deaths in this population. This indicates there is potential for further implementation of risk reduction strategies in Queensland overall, and in particular, in Indigenous communities. A survey reported that television advertising was the most preferred source of information about SIDS for Indigenous and non-Indigenous mothers[24].

Other risk factors in Queensland

- Maternal smoking in the post-partum period showed a slight decrease from 27% in 1994, to 22% in 2002.[9,5] A survey conducted in Townsville in 2001 revealed that approximately 1/3 of mothers smoked during their pregnancy, and 38% smoked post-natally in the infant's environment[24]. Data should be interpreted with caution, as surveys were conducted using different methodologies.
- Furthermore, the 2002 survey reported that co-sleeping was a common practice for 45% of respondents and 25% of these infants co-sleep with a mother who smoked[6]. Co-sleeping with a parent who smokes is a factor known to significantly heighten the risk of SIDS.[16]
- In the 2002 survey, a considerable proportion of infants used a pillow, slept on sheepskin, or slept with a cot bumper or soft toys in the bedding environment, which are known risk factors for SIDS, and contrary to current SIDS risk reduction recommendations.[6]
- The prevalence of many risk factors for SIDS is higher in the Indigenous population[24,25] and awareness of SIDS and its risk factors has reported to be lower than for the non-Indigenous population.[25]
- A 2002 statewide survey of Queensland Health nurses and midwives found many knowledge and attitudinal deficits relating to infant care practices to reduce the risk of SIDS that influence nursing practice and information provided to parents.[6] This survey also identified that many service providers do not always ensure that parent education relating to safe sleeping recommendations is incorporated into routine care and discharge planning in neonatal, baby, maternity and community health units in Queensland.

Conclusions

- Despite a decrease in the national incidence of SIDS, it remains a leading cause of death in infants beyond the neonatal period. Queensland has experienced one of the smallest decreases in SIDS death rates of all states and territories, and until recently had one of the highest incidences of SIDS in Australia. [1-3]
- Evidence suggests that the implementation of infant care practices that are known to reduce the risk of SIDS has been sub-optimal in Queensland.[4, 5, 9, 24, 25,30]
- Although recent initiatives, such as *Child Health Information: Your guide to the first 12 months* universally provides SIDS risk reduction information to new parents,[7] further effort is required to educate child health professionals, parents, families and communities, particularly for those at greater risk.
- Infant care practices to reduce the risk of SIDS should be practised in hospital and community settings to model such behaviours for parents, and SIDS information should be an integral component of care and discharge planning.
- The Queensland Health statewide policy *Safe infant care to reduce the risk of Sudden Infant Death Syndrome* has been developed. The objectives of this policy are:
  - To provide staff, parents, families and communities with accurate and current evidence-based information about SIDS and infant care practices to reduce the risk of SIDS, SUDI and fatal sleeping accidents;
  - To ensure safe sleeping environments and care practices for babies and infants in Queensland Health facilities;
  - To ensure that health professionals in birthing, postnatal, paediatric, child health services and facilities, in both acute and community settings, practise, demonstrate and promote safe sleeping positions and care practices for infants;
  - To ensure that parents receive consistent and accurate information and observe correct infant care practices to reduce the risk of SIDS and are encouraged to maintain these practices when they are in their home environment.
- The policy includes minimum practice standards to assist staff in their key role in providing information and influencing infant care practices for new parents.
- The implementation of *Safe infant care to reduce the risk of SIDS* will be supported by the development and statewide implementation of an education package for nurses and midwives to enhance knowledge, attitudes and practices relating to reducing the risk of SIDS.
- Communication strategies for populations at greater risk for SIDS, SUDI and fatal sleeping accidents will be developed.

Glossary of terms

SIDS – Sudden Infant Death Syndrome – defined as " the sudden and unexpected death of an infant under one year of age, with onset of the lethal episode apparently occurring during sleep, that remains unexplained after a thorough investigation including performance of a complete autopsy and review of the circumstances of death and the clinical history".[1]

SUDI – Sudden and Unexpected Death in Infancy – defined as "Death where insufficient findings were present to support a particular diagnosis but when sufficient abnormal features in the history or at the scene examination, autopsy, or laboratory work-up were found that were not typical of SIDS" (cited in 3).

Fatal Sleeping Accident – A death occurring during sleep, as a result of an accident, such as a fall, or suffocation.

Prone – positioned lying with the face, front or stomach downward.

Supine – positioned lying on the back or having the face upward.

Lateral – positioned lying on the side of the body.

Co-sleeping - the practice where a parent or other individual sleeps together with the baby on a shared sleep surface, for example a bed.

Bedsharing - where an infant may be taken into a bed with a parent or other individual for purposes other than sleep (for example breastfeeding or cuddling) and without the intention to co-sleep.

Roomsharing - sleeping the baby in a cot or other separate sleeping surface in the same room as the parents.

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