

**Submission  
No 59**

## **SUPPORT FOR NEW PARENTS AND BABIES IN NEW SOUTH WALES**

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Red Nose welcomes this opportunity to provide a submission to the Legislative Assembly Committee on Community Services' inquiry into support for new parents and babies in NSW

## **Background of Red Nose**

Founded in 1977, Red Nose (formerly SIDS and Kids) is a not-for-profit organisation providing health promotion and education, research, bereavement support and resources to all Australian States and Territories including Victoria. The organisation is dedicated to saving the lives of babies and children during pregnancy, birth, infancy and childhood and to supporting bereaved families. We aim for excellence in accordance with our values in the four key result areas of client services, sustainability, research and governance. Red Nose brings evidence based recommendations to parents, carers and health professionals to help prevent the sudden death of an infant. For those families that children have died suddenly and unexpectedly Red Nose brings hope, support and guidance showing that there is light in the darkness of grief, aiding in reducing mental health conditions potentially caused by unresolved grief.

## **Red Nose Vision**

***A future where no child dies suddenly and unexpectedly during pregnancy, infancy or in childhood.***

## **Red Nose Mission Statement**

***Saving the lives of children during pregnancy, infancy and childhood and ensuring all people affected by the death of a baby, infant or young child, are supported, cared for and connected to what they need to continue engaging with life.***

Red Nose has contributed to an 80% reduction in Sudden Unexpected Death in Infancy (SUDI) in Australia. This has been attributed to the safe sleeping public health campaign introduced in 1991 by Red Nose and implemented in collaboration with researchers and health authorities promoting evidence-based safe sleeping practices to reduce the risks. The Red Nose 'Saving Little Lives' public health program is an evidenced based health promotion and education program providing new and expectant mothers, carers and health professionals with recommendations on how to sleep baby safely and reduce the risk of sudden infant death.

Red Nose and our National Scientific Advisory Group (NSAG) a group made up of experts in the fields of research, health care and midwifery are working to find answers for parents by funding and supporting vital research into Sudden Unexplained Death in Infancy (including SIDS), Stillbirth and Safe Sleeping Practices.

Red Nose Grief and Loss is a bereavement support service for any person affected by the sudden and unexpected death of a baby or child. Red Nose Grief and Loss assists families who have experienced the sudden and unexpected death of a baby or child, during birth, pregnancy infancy and childhood, regardless of the cause.



With reference to the Legislative Assembly Committee on Community Services' inquiry into support for new parents and babies Terms of Reference, Red Nose recommends the committee take consideration of the below combined response for all six references:

**Please note that the data and information below is abstracted from the NSW Mothers and Babies 2015 report and NSW Child Death Review Team Child death review report 2015;**

**In 2015 there were 96,391 births in NSW. The perinatal mortality rate was 8.2 per 1,000 births of which 76.4% of all reported perinatal deaths were stillbirths and 23.6% were neonatal deaths. The perinatal mortality rate in Aboriginal or Torres Strait Islander mothers was 9.6 per 1,000 births. It is also noted that 1 in 4 pregnancies result in miscarriage.**

**504 children aged from birth to 17 years died in NSW in 2015; a mortality rate of 29.61 deaths per 100,000 children. The majority of the children (294, 58%) were infants under the age of 12 months. 14% of infant deaths (42) were classified as Sudden Unexpected Death in Infancy (SUDI). SUDI is a not a cause of death. The term describes the death of an infant aged less than 12 months that is sudden and unexpected, where the cause was not immediately apparent at the time. SUDI includes Sudden Infant Death Syndrome (SIDS).**

**All 42 of the infants whose deaths were classified as SUDI were found to have at least one known risk factor, and nearly all were exposed to at least one modifiable risk factor. For many of these infants, a combination of a number of modifiable risk factors were present:**

**Two-thirds (27) of the 42 infants were bed sharing, either intentionally (21) or unintentionally (6).**

**In most cases, the shared sleep surface was an adult mattress or bed, but sofas and couches were the other main shared surface.**

**The majority of infants who were bed sharing were exposed to tobacco smoke during pregnancy and/or in the household; a third of the infants were born premature and/or of low birth weight; a third had previously been ill with an infectious disease; and five infants were sleeping with alcohol or drug affected adults.**

**In 2015, 7.9% of babies were born prematurely (less than 37 weeks gestation) and 6.6% of babies were born of a low birth weight (less than 2,500 grams). 6.5% of mothers reported smoking in the second half of pregnancy, 45.0% of Aboriginal or Torres Strait Islander mothers reported smoking at some time during pregnancy.**

**SUDI is disproportionately affecting infants in disadvantaged and vulnerable families. Families residing in areas of low socio-economic advantage; families with a child**



protection history and Aboriginal and Torres Strait Islander families are over represented in SUDI.

There is a clear need to better target initiatives to work effectively with these families to promote safe sleeping and other preventative practices.

Safe sleeping advice should include strategies to avoid unintentional bed sharing. Around one in 15 SUDI (18) over the five years up to 2015 died in circumstances where adults unintentionally fell asleep while feeding or caring for the child. It may be warranted to include SUDI education advice and practical strategies to keep infants safe in this context.

Recommendations made by the NSW Child Death Review Team Child death review report 2015 (in part)

**6. NSW Health, in consultation with Red Nose, should review current advice and educational strategies, with a view to:**

**a. The inclusion of advice and preventive strategies to parents and carers in relation to unintentional bed sharing as part of NSW Health education and advice programs, and the Red Nose 'Safe Sleep My Baby' public health program.**

**b. Strategies targeted to young mothers, including use of alternative avenues of advice through social media and parenting blogs, and targeting grandmothers for safe sleep education.**

Red Nose's evidence based Safe Sleep Education supports cessation of smoking during pregnancy to reduce the risks of preterm births, low birth rates and SUDI. Red Nose Safe Sleep Education also supports sleeping infants in their own safe sleep space for the first 6-12 months in the same room as the parent / carer which aids in reducing fatal co-sleeping accidents.

Evidence shows that up to 60 people can be affected by the death of a child. Research has shown that the experience of grief and loss following the death of a child is particularly intense and can often lead to more serious mental health conditions such as depression, anxiety, post-traumatic stress and suicide ideation. Making access to bereavement counselling and support services vital for all those effected by the sudden and unexpected death of a child.

On analysis of the data provided, Red Nose would like to present the following recommendations to enhance the support services for new parents and babies in NSW and further reduce the statistics outlined above;



**Increase Red Nose evidence based Safe Sleep Education across Metro and Regional NSW to Health Professionals, parents and carers with a target focus of young mothers during the prenatal and perinatal period to aid in the further reduction of infant mortality rates.**

**Increase education across Metro and Regional NSW to Health Professionals, parents and carers around risks of smoking during pregnancy and after birth to aid in the decrease in rates of preterm births, low birth rates and SUDI.**

**Provide culturally appropriate Safe Sleep education and resources to the Indigenous communities of NSW to aid in reducing the disparity between Indigenous and non-Indigenous smoking rates during pregnancy, pre-term births, low birth rates and infant mortality rates.**

**Increase in distribution of both Red Nose Saving Little Lives and Red Nose Grief and Loss resources across Metro and Regional health and community facilities.**

**Increase Red Nose specialised support groups targeted at those affected by the death of a child from termination for abnormalities, miscarriage, stillbirth, SUDI, subsequent pregnancy after a loss, grandparents and siblings, across Metro and Regional Victoria.**

### **Red Nose Services**

Red Nose can offer the following established services to NSW communities, but to be able to provide the quantity required to cover the entire state it would be crucial for Red Nose to secure additional funding to increase current staffing levels and produce the required quantities of resources.

### **Red Nose Safe Sleep Education Services**

#### **Safe Sleep Education**

Red Nose Educators across Australia deliver evidence based education sessions to health professionals, parents and carers about ways to reduce the risks of SUDI. The education is based on the information that has been developed and reviewed by Red Nose NSAG our content experts in the area of optimal infant care practices and strategies to reduce SUDI. The education is available via face to face sessions or through video link.

#### **Reducing the Risks of SUDI in Aboriginal Communities (RROSIAC) program**

The Red Nose RROSIAC program seeks to reduce unacceptably high risk Aboriginal infants dying of SIDS and fatal sleep accidents. The program has been successfully operating throughout WA since 2005. A cultural and clinical delivery of SUDI evidence based information identifying the risks associated with sleep accidents and education on ways to reduce the risks of SIDS.



### **Safe Sleep eLearning**

Red Nose Safe Sleep eLearning courses are currently under review and due for release in 2018. The courses are aimed at Health Professionals, Early Childhood Educators, Community Services, Parents and Carers.

### **Smart Phone Applications**

Safe Sleeping application provides evidence-based education on Safe Sleeping, Tummy Time and Safe Wrapping in five languages including English, Chinese, Vietnamese, Hindi and Arabic. Available for iOS and Android.

### **Red Nose Safe Sleeping Brochure and information suite**

Printed resources are available to order through the Red Nose website in a variety of languages along with downloadable evidence based Information statements on a range of related topics.

### **Red Nose Grief & Loss Services**

#### **24 Hour Bereavement Support Line 1300 308 307**

All calls to the Bereavement Support Line during business hours are taken by Service staff. All calls to the Bereavement Support Line after business hours and across the weekend are taken by trained Red Nose Grief and Loss Counsellors or Telephone Support Workers. All Telephone Support Workers are trained Parent Supporters who have undertaken further training for the afterhours bereavement support line.

### **Intake**

The centralised Intake Service for all bereavement calls to Red Nose Grief and Loss was introduced on 1st July 2014 (2016 in NSW, VIC, WA, ACT, Hunter and QLD). This service operates during business hours out of the Sydney office. All intake staff are fully qualified to provide bereavement support, information, resources and referral.

Our Online Professional Referral Form (OPRF) is located on our website and acts as a simple and effective way of ensuring that any bereaved parent requiring support is linked as quickly as possible to our support services.

Red Nose intake support pathway has been designed in order for the caller to access the services that best meet their needs.



## **Professional Counsellors**

Available at Red Nose Grief and Loss offices located in Lilyfield and Hamilton South, NSW and nationally. Counselling services can be either face to face, by phone, video link or live chat. All counselling staff are fully accredited, appropriately trained and highly professional with many years' experience and include Registered Psychologists, Social Workers and Counsellors.

## **Trained Parent Supporters**

Peer/Parent Supporters play a vital role in the delivery of our services. After a period of 18 months into a client's grief journey they have the option to become a Peer / Parent Supporter. Potential Peer/ Parent Supporters then go through a rigorous training program to ensure they are well positioned to support newly bereaved families and friends.

Trained Peer/ Parent Supporters offer a very special and personal service that can only be delivered by those parents who have directly experienced or been impacted themselves by the loss of a baby or child.

Red Nose Peer Support Training enhances and builds upon the existing knowledge and skills (experiential learning) acquired by those who have experienced the devastating impact of the death of a child.

Trained parent supporters are matched with clients who have had a similar experience and supported by our professional counsellors.

## **Support Groups**

The counselling staff at Red Nose Grief and Loss facilitates a range of monthly Support Groups in each location. There are also a range of groups that are supported by Red Nose Grief and Loss, which are run by trained Red Nose Grief and Loss parent/peer supporters. Specialised groups are available for those affected by the death of a child from termination for abnormalities, miscarriage, stillbirth, SUDI, subsequent pregnancy after a loss, grandparents and siblings.

Each school holiday period, Children's Groups are held for bereaved siblings. Ages generally range between 5 years up to 12 years and are run by our professional counsellors.

## **Literature and Resources**

Red Nose Grief and Loss printed brochures and information provides an outline of services/resources available through our service and gives phone and website contact details so that people can engage further if they wish.

Current brochures and printed information -

- Bereavement services brochure



- Bereavement services postcard
- Health professional's brochure

A variety of booklets and articles relating to different aspects of grief and written in collaboration with bereaved parents, children and health professionals are available. These can be also found on our website for downloading with topics including:

- Miscarriage
- Choices in arranging a child's funeral
- Sudden Unexpected Death of an Infant (SUDI) - including SIDS
- Stillbirth
- Termination
- Having another baby
- Grandparent grief
- Sibling grief
- Relationships
- Men's grief

These are available to all newly bereaved families through Intake, counselling staff, Hospital Social Workers or via the Red Nose Grief and Loss website.

### **Bereavement Website**

Red Nose Grief and Loss Website has been developed in collaboration with bereaved families to offer information and further accessibility to our support services. The website has sections for Parents, Family/friends, Professionals and Parent Supporters. There are many specific sub-sections including information for Bereaved Dads, Grandparents, Siblings, Employers and Colleagues.

Examples of supporting articles available on the Red Nose Grief and Loss Website;

<https://rednosegriefandloss.com.au/support/article/supporting-parents-through-grief-after-a-stillbirth-or-perinatal-death>

<https://rednosegriefandloss.com.au/support/article/further-reading-for-health-professionals-stillbirth-and-newborn-death>

### **Newsletter**

Red Nose Grief and Loss publishes a newsletter, 'Guiding Light', three times a year. This ties in with Mothers' Day, Fathers' Day and Christmas. These newsletters are designed to provide information on grief & loss, bereavement services available, suggestions on how to deal with anniversaries and important dates.





## **Memorial/Remembering Services**

Memorial/Remembering services are conducted each year by every office of Red Nose Grief and Loss. These services are scheduled to align with Red Nose Day activities or Christmas time. These services provide the opportunity for bereaved parents, families and friends to pay tribute to the baby or child who has died.

## **Advocacy**

Red Nose provides free, confidential and professional support and service to anyone impacted by grief and loss due to the sudden and unexpected death of a baby or child during pregnancy, birth, infancy and childhood.

## **Summary**

Red Nose currently receives a proportion of funding from the NSW Health Department which covers around 20% of the costs incurred to provide Bereavement Support Services for parents who experience the death of their baby or young child during pregnancy, birth and infancy up to age 6. Provision of training for previously bereaved parents and maintaining the skill level of those already trained to continue the provision of 24 hour Bereavement (peer) Support Services and to educate health and allied professionals, emergency services personnel and the community about the needs and feelings of bereaved parents, and Red Nose recommendations for appropriate care in NSW.

Red Nose greatly appreciates the contribution from the NSW Health Department and the commitment to supporting Red Nose Grief and Loss services in NSW. As outlined above there is a whole lot more that is required to be done in NSW to save little lives and support those affected by the sudden and unexpected death of a child through any cause. For Red Nose to effectively provide our essential services across NSW it is crucial that Red Nose secures additional funding to support the financial component.

Red Nose would like to thank you for your consideration of our submission and praise you for reviewing the current support available to new parents and babies in NSW. Red Nose looks forward to working collaboratively with you to enhance the support services within NSW.

Kind regards,

Theron Vassiliou  
Chief Executive Officer  
**Red Nose**

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