



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON HEALTH, AGEING AND COMMUNITY SERVICES
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Submission Cover Sheet

Inquiry into Maternity Services in the ACT

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STANDING COMMITTEE ON HEALTH, AGEING AND COMMUNITY SERVICES - Inquiry into Maternity Services in the ACT.

Executive Summary

Red Nose Australia, the national authority on research, education and bereavement support for perinatal and infant death, applauds the national parliamentary Standing Committee on Health, Ageing and Community Services for commencing an inquiry into Maternity Services in the ACT. Thank you for investing your efforts to ensure the safety of patients, children, as well as mothers and families in the community. We agree wholeheartedly that it is so important that maternity services continue to improve across all modes of delivery and that the timely provision of education and support to families of young children from birth to school age occurs. This focus on the well-being of our Australian families, recognising strengths and vulnerabilities is vital for the overall improvement of their health and development.

As national authority on safe sleeping and the key player in reducing SIDS in Australia through public health campaigns by 85%, we remain strong innovators of community education and bereavement support; and are recognised for these attributes on both the national and international stage.

We believe that all parents, carers and health professionals have the right to receive free safe sleep education that is easy to access and understand in order to keep babies and children safe.

We believe that the continual provision of safe sleep education, along with the right bereavement support, has the potential to prevent future long term complex physical and mental health issues.

We believe that more work needs to be done to ensure the numbers of deaths of children occurring in pregnancy, infancy and childhood decrease and lives continue to be saved. Already, Red Nose Australia is making positive inroads into finding answers for families who suffer loss in pregnancy.

Through this, we believe that collaboration is key to ensure public messages are streamlined, easy to understand and not fragmented. Red Nose welcomes the opportunity to work with government as well as like-minded organisations to ensure everyone is armed with up-to-date, evidence-based knowledge to keep babies and children safe.



Introduction

Founded in 1977, Red Nose (formerly SIDS & Kids) is a not-for-profit organisation providing health promotion and education with regard to safe sleeping practices, research and bereavement support for all Australians. For the past 40 years, Red Nose has been committed to saving the lives of babies and children from 20 weeks gestational age to four years with particular attention to stillbirth, sudden unexplained death of an infant (SUDI), sudden infant death and fatal sleep accidents. Through our world leading safe sleep recommendations, and the facilitation of one of Australia's most successful public health campaigns, Red Nose reduced the incidence of SUDI in this country by 85%. Having invested more than \$17 million in research, our evidence- based safe sleeping recommendations help prevent the sudden loss of a child during pregnancy and childhood. In accordance with our core values, we offer an extensive suite of bereavement services to anybody impacted by the loss of a child.

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.

GOALS

- *All Australians receive access to up to date evidence based safe sleep information and support*
- *Contribute to the reduction of the rate of stillbirth in Australia*
- *Anyone affected by the loss of a child has access to quality bereavement support*
- *Continue to drive research, turn breakthroughs into education, advocacy and positive change for Australians and our international counterparts.*



RED NOSE AUSTRALIA

Red Nose is in an optimal position to continue to make a significant impact into rates of SUDI in this country. Recognised as a national authority on safe sleeping practices for infants and children, our unique programs have been developed in consultation with our National Scientific Advisory Group, made up of leading researchers and health professionals.

As evidenced by our successful safe sleeping campaigns, we can educate and support medical staff as well as families to ensure best practice outcomes for early childhood, particularly in establishing good safe sleep habits and strategies for safe sleep contributing to healthier futures. In addition, Red Nose can help parents and carers directly by ensuring they have access to up-to-date, evidence-based information for keeping babies safe through the night and hospital and at home. This will improve overall well-being and will promote positive parenting interactions, giving parents the tools to reduce the risk of sudden and unexpected death.

In addition, for the families who tragically don't have the pregnancy and birth outcomes they planned for, our professional clinical bereavement care services provide a strong foundation of support to assist in navigating the unimaginable grief journey of the loss of a child.

As many health professionals working within maternity services would know, sleep is at a lifetime maximum during infancy, and the maturation of sleep is one of the most important physiological processes occurring during the first year of life, particularly the first 6 months (Horne, et al 2007). This is why it is vital that we ensure from the very beginning, healthy and safe sleep practices are introduced, forming good habits that are continued throughout the child's life. Good sleep health and safe sleeping practices are extremely important across the full continuum of care from pregnancy to birth, during infancy and into childhood. Red Nose remains true to its commitment to actively seek research opportunities that can be translated into the provision safe sleep education that can be delivered to all Australians.

Our most vulnerable babies with a higher risk of SUDI, SIDS and sleep accidents are those born pre term or of low birth weight. Further, these babies often require more sleep than their well-grown term peers to assist them to cope with emotional and psychological development and their ability to cope under stress (Schwichtenberg, et al 2013). If these babies are not given the appropriate opportunities to sleep, in a safe way, from early on in life, they become at risk of SUDI as well as developing social problems as they develop. Red Nose provides support and education to hospitals and parents about



safe sleeping, specifically targeting the Neonatal Intensive Care but acknowledges that more could be done for this high risk group of babies.

Through our parallel focus on stillbirth, we are seeing emerging research that will shape vital educational programs and reduce the number of stillbirths, babies being born pre term or of low birth weight. Through collaboration with our partners and our contributions to the development and implementation the National Stillbirth Action Plan including proposed education training programs for maternity staff, Red Nose Australia will be able to help reduce the numbers of pre-term and low birth weight babies being born. This will in turn, reduce the physical and economic burden on hospital Neonatal Intensive Care Units (NICU) and Special Care Nurseries (SCN). In addition, pre-term birth, stillbirth and neonatal death is a major cause of family separation; of babies from their mothers, and of women from their families and communities. We have the ability to make a positive impact on this through the provision of good education and bereavement support.

Terms of Reference

1. Provision of private maternity services including centre and non-centre services

Education training and professional development available to healthcare staff and patients.

As a key education contact point as part of the broader maternity service, a key focus of Red Nose is to ensure all health professionals have access to, and are trained in, our key recommendations to reduce risks associated with SUDI. This also applies to parents and carers. Currently, Red Nose provides vital safe sleeping education to expectant parents, families, and health care professionals nationally. Our research-backed and evidence-based education recommendations and practices are developed and reviewed by leading experts in the area of optimal infant care practices.

Red Nose Australia supports research under the guidance of its National Scientific Advisory Group (NSAG) made up of leading researchers and health professionals. This guidance in turn supports our resources, programs and products targeted to parents, families and health professionals.

Vigorous research into SUDI and stillbirth-related sleep health continues in Australia and overseas. From this clinical research and systematic evidence reviews, NSAG and Red Nose Australia can in turn decide on effective interventions and combat emerging challenges.

Currently, Red Nose Australia is co-funding an exciting research project lead by Dr Adrienne Gordon from The University of Sydney into maternal going-to-sleep position and the risk of stillbirth. The



prevention of stillbirth remains one of the greatest challenges in modern obstetric practice and yet, despite advances in the care of women and estimated 2.64 million babies die before birth globally each year. In Australia, we lose six babies per day to stillbirth. In order to reduce this statistic, modifiable risk factors need to be identified, and then comprehensive health promotion and community education programs must be developed.

Aside from those that rely on the clinical management of the pregnancy, going-to-sleep position in the last three months of pregnancy is a recently identified and modifiable risk factor that women can change themselves. The results of this research continue to evolve and the results will provide vital evidence to help midwives and obstetricians change the sleeping messages provided to women. Building on ongoing efforts and existing structures, Red Nose Australia will in turn create a public health campaign to guide all Australian families to reduce their stillbirth risks. Through education and support of midwifery staff as part of this campaign we can ensure that this crucial information is built into the normal dialogue when counselling women throughout their pregnancies.

SUPPORT TO MATERNITY SERVICES IN ACT

A key focus of Red Nose Australia is its education provision, designed to ensure all health professionals have access and training in our key recommendations to reduce risks associated with sudden unexplained death in infancy. This also applies to parents and carers. In addition, the organisation provides a suite of bereavement training and support options and is currently working on a revised collection of tools to incorporate the wider sector. Currently, Red Nose Australia provides vital safe sleeping education to expectant parents, families, and health care professionals nationally. Our research-backed and evidence-based education recommendations and practices are developed and reviewed by leading experts in optimal infant care practices.

At present, Red Nose Australia provides strong support and education with regard to safe sleeping and bereavement care throughout Canberra's two major tertiary hospitals: Centenary Hospital for Women and Children (CHWC) and Calvary Public Hospital (CPH).

CENTENARY HOSPITAL FOR WOMEN AND CHILDREN

Safe Sleeping

Our vital services are provided to staff in areas of Maternity Services, Neonatology and the Paediatric department free of charge via different platforms and modes of delivery.



Resources include:

- Monthly education sessions to midwives, nurses and families within the Neonatal Intensive Care Unit (NICU) and the Special Care Nursery (SCN) as part of the Neonatology “Partnering with Parents Program”;
- Regular safe sleeping education for all staff across all areas of maternity, neonatology and paediatrics;
- The provision of evidence-based resources including safe sleeping brochures and posters in 11 languages including English, Chinese, Vietnamese, Hindi and Arabic;
- The provision and maintenance of safe sleep displays - visual tools for new parents to access;
- Programs assisting health professionals and child care workers in compliance with national policy and standards in the area of safe sleeping and child safety;
- Tailored safe sleeping education to Neonatology Graduates;
- Safe sleeping education sessions for families of multiples via links with Canberra Regional Multiple Birth Association.

Bereavement Care

Resources include:

- Strong referral and partnership with the Fetal Medicine Unit including, but not limited to, onsite and offsite counselling support prior to and during subsequent pregnancy, decision making pertaining to palliative care, palliative pregnancy, termination of pregnancy and follow up support;
- Support for families who experience the death of a baby (or babies) due to early term miscarriage, IVF journey, medical termination of pregnancy, stillbirth, life limiting illness, death after and during birth, neonatal death, and death of one or more babies;
- Support in Neonatology Intensive Care Unit (NICU) and Special Care Nursery (SCN) for bereaved families of previous bereavement, loss of multiple, and life limiting conditions;
- Support throughout subsequent pregnancy via counselling or chaperone for appointments and scans;
- Online and printed bereavement-specific suite of materials;
- Professional debriefing for hospital staff;
- Treasured Babies Program including printed resources, clothing, memorial keepsakes, naming certificates and coffin/angel boxes;



- Donated infant coffins/angel boxes created in partnership with Tobin Brothers and Red Nose volunteers;
- 24hr support phone number, grief and loss website, group, face to face, peer support counselling.

CALVARY PUBLIC HOSPITAL

Safe Sleep

Resources include:

- Regular education sessions to midwives, nurses and families within all areas of maternity;
- The provision of evidence-based resources including safe sleeping brochures and posters in languages including English, Chinese, Vietnamese, Hindi and Arabic.

Bereavement Care

Resources include:

- Grief and Loss training delivered to Midwifery staff;
- Support for families bereaved of one or more babies, or for those transitioning between CHWC NICU and CPH SCN;
- Support for families who experience the death of a baby/babies tailored to individual circumstance ie: early term miscarriage, IVF journey, medical termination of pregnancy, stillbirth, life limiting illness, death after and during birth, neonatal death, and death of one or more babies;
- Free bereavement support for palliative pregnant families and recently bereaved;
- Support through subsequent pregnancy via counselling or chaperone for appointments and scans;
- Online and printed bereavement specific suite of materials;
- Professional debriefing for hospital staff;
- Treasured Babies Program including free printed resources, burial clothing and boxes, memorial keepsakes and naming certificates;
- Donated infant coffins/angel boxes created in partnership with Tobin Brothers and Red Nose volunteers;
- 24hr support phone number, grief and loss website, group, face to face, peer support counselling;



- Ongoing working relationship with the social work team.

In addition to the important work we are doing with the maternity staff in these two facilities, we are also working hard to support the next generation of midwives to continue to carry out lessons learnt by teaching our vital messages to families. At present, Red Nose Australia conducts annual safe sleep education sessions to all first year midwifery students and grief and loss education to all second and third year midwifery students through the University of Canberra Midwifery Program.

Recommendations CHWC

We would like to continue to grow our partnership with CHWC in the following ways:

- Formal inclusion in the model of care for CHWC for bereavement and education pathways during pregnancy, birth and the postnatal period;
- Grief and Loss education delivered to all staff in areas of Neonatology, Maternity (Birthing Centre, Delivery Suite, Postnatal, Antenatal) Maternal and Child Health nurses (MACH), Paediatrics and Emergency department staff and paramedics;
- Stillbirth Education for all Neonatology, Maternity (Birthing Centre, Delivery Suite, Postnatal, Antenatal) Maternal and Child Health nurses (MACH) staff;
- An element of the birthing class program providing education on safe sleeping and stillbirth.

Recommendations CPH

We would like to continue to grow our partnership with CPH in the following ways:

- Formal inclusion in the model of care for CPH Maternity services;
- Safe sleeping education sessions for staff in Neonatology including new graduates;
- Grief and Loss education delivered to Neonatology staff;
- Grief and Loss education delivered to emergency department staff;
- Safe sleep education sessions provided to all families with a baby/babies in the Neonatology SCN;



- Stillbirth Education for all Neonatology, Maternity (Birthing Centre, Delivery Suite, Postnatal, Antenatal) Maternal and Child Health nurses (MACH) staff;
- Display cots with an example of how to sleep your baby safely as well as free information brochures for families located in Postnatal;
- An element of the birthing class program providing education on safe sleeping and stillbirth.

Recommendations within Maternity Services across ACT

We would welcome the growth of our partnership with maternity services across the ACT in the areas of:

- Formal inclusion in the model of care for all maternity services in the ACT;
- Referrals to allow continued care for regional families having birthed in the ACT via telecommunication services during the postnatal period;
- More opportunities to provide debriefing for health professionals;
- Opportunities to engage with GP's providing shared care through the maternity services to undertake grief and loss education, stillbirth education, safe sleeping education and a more comprehensive understanding of referral pathways;
- More opportunities to present to midwifery and nursing students at the Australian Catholic University, Australian National University and University of Canberra;
- Sudden unexplained death in infancy (SUDI) education and stillbirth sessions for all paramedics
- Grief and Loss education for all paramedics;
- SUDI education and Stillbirth sessions for all paramedic students at The Australian Catholic University;
- Grief and Loss education for all paramedics at The Australian Catholic University.

Additional Recommendations

- All Australians continue to receive access to up-to-date, evidenced-backed safe sleep information and support through research and innovation;
- Digitally delivered interventions that work;
- Better access for all Australians, especially those in CALD communities and those living in rural and remote areas;



- Improvements to digital access points;
- Resources to mature the current systems to continue to support the community and evolve;
- More staffing and education;
- Continue to drive research, turn breakthroughs into education and advocacy, and affect positive change for Australians and our international counterparts.

Conclusion

With thanks to the enormous efforts of everyone who believed that we could make a difference and drive change, we were able to demonstrate tremendous success in one of Australia's largest public health campaigns – the 85% reduction of SIDS. This success means we are a well-credentialed and trusted brand, a symbol of hope for families and best placed to be at the centre of any future public health project implementation.

At Red Nose, we are in a strong position to create and distribute evidence-backed, high quality and meaningful education resources and public health campaigns that are easily accessible to all members of the community. As the leading, national authority we are confident in our ability to continue educating the wider Australian community in vital safe sleeping practices as well as the provision of stillbirth prevention materials and bereavement care tools.

Red Nose Australia greatly appreciates the opportunity to provide a submission to the Senate with regard to maternity services and for the opportunity to share with you the support and education we can provide to this incredible group of health care workers. We thank you for your consideration and look forward to working collaboratively with you to enhance the current support services within Australia. Together, with your support, we can end preventable perinatal and infant deaths.

References

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