

## PRE-BUDGET 2021-22 SUBMISSION

EXPANDING HOSPITAL TO HOME PROGRAM TO PROVIDE ACCESS ACROSS AUSTRALIA TO ALL BEREAVED PARENTS WHO EXPERIENCE THE DEATH OF A CHILD THROUGH STILLBIRTH, NEWBORN DEATH OR SUDDEN UNEXPECTED DEATH IN INFANTS (SUDI)

### THE PROPOSAL

The death of a child is, indisputably, one of the most difficult and painful of all life experiences. There are three broad categories of perinatal and infant death: stillbirth, neonatal death and sudden unexpected death in Infancy (SUDI) and each year in Australia around 3,000 families experience such a loss.<sup>1</sup> The psychosocial consequences are immense for parents, families, and the health care system. An estimated 70% of women will experience grief-related depressive symptoms at clinically significant levels one year after stillbirth.<sup>2</sup>

High quality bereavement care is vital to the immediate and longer-term wellbeing of parents and families. Support around the transition from hospital to home and community is critical, but is often inadequate. More than 30% of Australian and New Zealand mothers whose baby was stillborn described their experiences of support after leaving hospital as “poor” or “very poor” and many expressed feelings of “abandonment” once they left hospital.<sup>3</sup> The Hospital to Home program addresses this gap by providing targeted short-term peer support to assist parents as they navigate the complex loss experience following the death of a baby.

Peer support, the provision of support from someone who has experienced the same or similar health event or experience, is a hallmark of Red Nose support services and has a strong evidence base that

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<sup>1</sup> Australian Institute of Health and Welfare. (2020). Stillbirths and neonatal deaths in Australia. Retrieved from <https://www.aihw.gov.au/reports/mothers-babies/stillbirths-and-neonatal-deaths-in-australia>

<sup>2</sup> Heazell, A.E., et al. (2016) Stillbirths: economic and psychosocial consequences. *Lancet*, 2016. 387.

<sup>3</sup> Boyle, FM, Ratnayake, J, Horey, D, Flenady, V. (2017). Post-hospital care after stillbirth in Australia and New Zealand: how well are women’s needs met? Meeting abstracts from the International Stillbirth Alliance Conference 2017. *BMC Pregnancy and Childbirth*.

shows multiple benefits for those dealing with sudden loss, including reduced grief symptoms, improved well-being, and personal growth.<sup>4</sup> Collaboration between a hospital and peer supporters is an innovative approach that has been shown to produce positive outcomes for bereaved mothers.<sup>5</sup>

Red Nose requests Government to consider funding the expansion of the currently funded Hospital to Home program from the 5 pilot sites to all Australian parents experiencing stillbirth, newborn death, or SUDI.

## **BACKGROUND**

Sands Australia, now merged with Red Nose Limited, was fortunate to receive funding from the federal Department Health to pilot Hospital to Home at 5 pilot sites (one hospital per mainland state). The program uses Bereavement Outreach Workers, who have experienced perinatal loss themselves, to provide both practical and emotional support in the critical acute stages of grief following perinatal loss through a model based on continuity of care. This program is funded through to November 2021.

The program was developed following feedback from bereaved families who stated how isolated and confused they felt following the death of their baby and suggested many situations where help was wanted in the immediate aftermath of their loss; particularly from those who had experienced a similar loss and who genuinely understood.

## **EMERGING IMPACTS OF THE FORMATIVE PILOT**

COVID-19 has created challenges in terms of getting into hospitals, but the program has proven to be a robust model of support for bereaved parents in the critical acute stages of grief following a stillbirth or newborn death and has in fact been enhanced by the adaptations made to facilitate remote support. Necessary changes to in-hospital care due to the pandemic have seen increased reliance on Red Nose services and we have responded rapidly to meet the needs of bereaved parents and their care providers.

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<sup>4</sup> Bartone, P. T., Bartone, J. V., Violanti, J. M., & Gileno, Z. M. (2019). Peer support services for bereaved survivors: a systematic review. *OMEGA-Journal of Death and Dying*, 80(1), 137-166.

<sup>5</sup> Aho AL, Åstedt-Kurki P, Kaunonen M. Peer supporters' experiences of a bereavement follow-up intervention for grieving parents. *OMEGA-J Death Dying*. 2014;68(4):347–66.

An external evaluation partner from The University of Queensland is evaluating the pilot that will provide formative information about implementation to guide ongoing service development and refinement of the program. External evaluation will also be conducted for the expansion project.

Strong interest in the Hospital to Home pilot has been expressed by hospitals outside of the pilot study, particularly rural hospitals where families have no local support services, as well as service providers in the funeral and community health sector, supporting the increase of access to the program.

Emerging themes are beginning to show in the pilot amongst the families who are currently being supported in the program indicating that the program has effectively provided individualised and targeted support and have made significant impacts. Examples include:

- Supporting families to attend follow-up medical appointments and assistance with information retention
- Helping a family make funeral arrangements when social workers couldn't get in contact with the parents and their baby had been at the hospital morgue for 6 weeks.
- Assisting families to return to work and completing Centrelink forms
- Supporting CALD families without extended family in Australia
- Companioning parents who have experienced significant birth trauma
- Supporting mothers who have expressed the intent to self-harm
- Providing parents with information and assistance to guide their other children through grief.

Connections with local community groups have enhanced the pilot and given the program team an understanding of the diverse needs of the parents accessing the program. Examples include SydWest Multicultural Services (in NSW) for CALD families and Rainbow Families Victoria for LGBTIQ families. We have also engaged a Community Education Officer from Centrelink to help the team understand how to help families navigate Centrelink processes and systems.

## REQUEST OF GOVERNMENT

Red Nose has seen a dramatic increase in demand for service over the last twelve months with a 49% increase in new clients accessing the service and a 55% increase in the number of support sessions being delivered. We are requesting funding to expand from 5 pilot sites targeting 250 bereaved parents to open up access to the program for all bereaved parents across Australia.

Using the learnings, we have gained from the pilot we can adapt the service model to increase reach to bereaved parents in need of support in the acute stages of grief. We propose to supplement our program delivery team of paid outreach workers with a team of highly trained parent supporter volunteers to expand delivery under a blended model of care using outreach and remote support. To ensure performance monitoring and reporting of outcomes we would once again engage an external evaluation partner from The University of Queensland to evaluate the project.

Following is the estimated cost to Government for the proposed expansion of Hospital to Home over a 12-month period. We would welcome a multi-year commitment from Government.

## ESTIMATED COST TO GOVERNMENT

Project Management Team (National Manager, Bereavement Outreach Workers, Intake Officer)	564,561
Counselling	118,526
Mobile phones / duress technology	10,272
Case Management System support & maintenance	10,800
Travel (outreach)	74,488
Admin (rent, utilities, office supplies, printing, governance and auditing)	126,547
Supervision	5,000
Evaluation	40,000
Comms and Marketing	20,000
<b>TOTAL:</b>	<b>970,194</b>
Red Nose in-kind contribution (the training, recruitment and utilisation of volunteer parent supporters)	564,561

## **EXPECTED IMPACTS AND BENEFITS**

Stillbirth and newborn death create enormous psychological and emotional tolls on parents, with an estimated 60 to 70 per cent of mothers experiencing grief-related depression one year after their baby's death.

Appropriate and effective support is vital to reducing the adverse psychological and social consequences of stillbirth, newborn and infant death. Ensuring bereaved parents receive the right care at the right time has important benefits for parents and families and for the health system. Early and appropriate support is likely to prevent, manage or help resolve issues that may be associated with longer term mental health problems and the need for higher level services. Peer support offers numerous benefits and has been shown to be a cost-effective service intervention with likely cost-savings for the health system.<sup>6</sup>

This project is based on a family services model of care and will extend the reach of peer support for bereaved parents while addressing the ongoing health systems challenge of improving the interface between hospital and community.

By initiating early intervention in the critical and acute stages of grief the program has the capacity to positively impact on one's individual grief experience, parenting and relationships whilst reducing the risk of family breakdown, family violence and the onset of adverse mental health co-morbidities.

## **ALIGNMENT WITH NATIONAL STILLBIRTH ACTION AND IMPLEMENTATION PLAN**

The Hospital to Home program aligns with the National Stillbirth Action and Implementation Plan, in particular the priority of improving holistic bereavement care and community support following stillbirth. Expanding Hospital to Home to provide access to the program for all bereaved parents across Australia will provide a cost-effective way to support bereaved parents during the acute stages of grief and connect them to ongoing supports and specialist services as required.

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<sup>6</sup> Peers for Progress. (2014). Global Evidence for Peer Support: Humanizing Health Care. In Report from an International Conference hosted by Peers for Progress and the National Council of La Raza. Leawood, KS: American Academy of Family Physicians Foundation.

## **ABOUT RED NOSE**

With our recent amalgamation, Red Nose, including Sands, is now the only national provider of specialist services for parents and families bereaved by the loss of a pregnancy, stillbirth, or the sudden and unexpected death of a baby or child.

The organisation's Best Practice Bereavement Services Framework is informed by Red Nose's collective bereavement expertise and the lived experiences of parents. It is built on the integration of professional and peer-support, therapeutic interventions, risk management and best practice in the prevention of prolonged and complex grief.

We have strong relationships with maternity services across Australia. These relationships are nurtured by our staff and ensure that the broader hospital network is aware of the work done by Red Nose and are both comfortable and confident to refer newly bereaved families to us. We are also collaborators with the NHMRC Centre for Research Excellence (CRE) in Stillbirth.

Red Nose including Sands, supported over 5,200 bereaved families in the last financial year. Between July 2019 and the end of June 2020, Red Nose answered 1,208 calls from distressed families through our 24/7 line and provided more than 7,000 hours of counselling and support sessions. At the same time, Sands supported 4000 families through their national support services.

Sands conducts a bereavement experience survey each year, open to the bereaved community to share their experience of bereavement care from their time of loss; including their hospital experience and subsequent support received. 1500 bereaved parents shared their experience.

## **RED NOSE CONTACTS:**

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