



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON HEALTH, AGEING AND COMMUNITY SERVICES
Ms Bec Cody MLA (Chair), Mrs Vicki Dunne MLA (Deputy Chair)
Ms Caroline Le Couteur MLA

Submission Cover Sheet

Inquiry into Maternity Services in the ACT

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The Committee Secretary
Standing Committee on Health, Ageing and Community Services,
Legislative Assembly for the ACT,
GPO Box 1020,
CANBERRA ACT 2601
Via e-mail: LACCommitteeHACS@parliament.act.gov.au

Dear Committee Secretary,

Re: Submission to the Inquiry into Maternity Services

Sands Australia welcomes the Australian Capital Territory Inquiry into Maternity Services and is pleased to provide the following submission.

We hope the information provided is of assistance and we would be very happy to be contacted to clarify or provide more information if needed.

I can be contacted on or by email at

Yours Sincerely

Jackie Mead
CEO Sands Australia

miscarriage, stillbirth & newborn death support
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Sands Australia Response to the ACT Inquiry in to Maternity Services in the ACT.

Sands Australia welcomes the opportunity to provide this submission to The Standing Committee on Health, Ageing and Community Service who are currently inquiring in to maternity services across the ACT.

Background of Sands Australia

Sands is a community of bereaved parents providing support, information and education to other bereaved parents and their families across Australia that have experienced pregnancy loss or a newborn death. Sands also works in partnership with healthcare professionals to improve the quality of care and support for bereaved parents.

Sands exists to ensure that hope and understanding are available to bereaved parents across Australia. Sands has existed for over 40 years and in that time has seen many changes and challenges in how we deliver our services to bereaved parents across Australia. Sadly, the one area that hasn't experienced much change throughout this period is the rate of miscarriage, stillbirths or neonatal deaths.

Despite the many advancements in technology, research and medicine approximately, 1 in 4 pregnancies end in miscarriage impacting 103,000 families every year. 1 baby in every 120 births will be stillborn or die within the first 28 days.

Sands Australia considers itself to be the voice of bereaved parents following pregnancy and infant loss across the country. The experiences of bereaved parents provide a different insight in to maternity services and we hope this unique perspective assists the Committee in their deliberations

Sands Model of Support

The Sands model of support is voluntary peer-to-peer support, where bereaved parents, who themselves have experienced the devastation of the death of a baby receive specialised and ongoing training as volunteer Parent Supporters to enable them to provide emotional support to other bereaved parents.

How we deliver our Services

Through federal funding Sands delivers the following:

- National 24/7 Support Line – 1300 0 SANDS
- Men's National Support Line

miscarriage, stillbirth & newborn death support

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- LiveChat
- Email
- Brochures for parents (direct & Healthcare Professionals)
- E-learning Course – Caring for bereaved parents
- In house Information Sessions for professionals

Through State funding in Queensland and Victoria face to face support services are also offered, along with community events to raise awareness regarding pregnancy and infant loss.

Impact of Peer Support

A literature review undertaken by Canadian researchers (Leung et al 2002) revealed that people participating in Peer Support report:

- Increased self-esteem.
- Better decision-making skills.
- Improved social functioning.
- decreased mental health symptoms (i.e. anxiety, depression, etc.).
- lower rates of isolation, larger social networks.
- Greater pursuit of educational goals and employment.

Peer support is based on shared experiences and understanding. Bereaved parents accessing our support can experience:

- feeling accepted into a safe environment with someone who has walked a similar path;
- having a whole range of grief responses normalised, without judgment or fear of being pathologised;
- feeling less alone and truly 'heard' and understood;
- the realisation they have access to a support network; and
- experiencing a feeling of hope!

Cacciato & Bushfield (2007) studied a group of mothers who had experienced the stillbirth of their babies at various gestational ages, identified that talking with other bereaved parents was the most helpful in dealing with the death of their baby.

They listed the following as being *invaluable* to them:

- sense of belonging and affiliation,
- reversal of isolation; and
- validation of their experience and of the baby's life

The role of our Parent Supporters

Our Parent Supporters are not counsellors and do not give advice. Through listening to the bereaved parents and family's grief stories and validating/normalising their grief responses, and providing them with options where appropriate - we provide a safe space for them. And importantly, we: **Give them permission to grieve.**

Terms of Reference – Sands Australia Response:

Provision of private maternity services including centre and non-centre services;

With the provision of maternity services comes the responsibility to adequately respond to parents when a baby dies.

Our community of bereaved parents report that although from a clinical point of view they feel generally well looked after, from a bereavement support point of view, there was real inconsistency between staff.

Examples of inconsistencies or lack of grief education are (but not limited to):

- Allied health professionals such as sonographers being ill prepared to respond upon finding no heartbeat.
- Instances of hospital staff asking after a baby when it had died.
- Bereaved parents being placed on a maternity ward with crying babies in the background. Although, we are sure that every attempt is made for this not to occur, this as imagined is quite distressing for bereaved parents
- Differences between changes of shift (midwives and nurses) having to explain what happened to their baby, the nurses not knowing what support that they may have received or not received. This has resulted in real shortfalls of service and support offered to parents.
- Lack of knowledge around funeral arrangements, memory making activities and other services required to be organised in a short period of time by parents.
- Health professional themselves reporting a lack of consistency between staff knowledge of perinatal loss and grief.
- Expectations for follow up care to occur in waiting rooms with heavily pregnant women or with babies present.

Using Federal funding, Sands has developed a set of Bereavement Principles, aimed at providing hospital staff, in all roles with an understanding of what bereaved parents would like and should be able to expect whilst in hospital. Sands Australia believes that a roll out of these bereavement principles, including education and support resources, could dramatically improve the quality of emotions care offered following the loss of a baby.

The impact on staff including, but not limited to, rostering policies and practices, staff-to-patient ratios, optimum staffing levels, and skills mix;

Sands strongly supports the concept of “continuity of care” during pregnancy. Bereaved parents tell us that the development of a trusting relationship based on interactions over a period of time makes a considerable difference when things go wrong or when difficult decisions related to pregnancy need to be made.



We acknowledge that continuity of care is difficult to achieve and that it impacts significantly upon rosters and skills mixes across maternity settings. There are however some economies associated with the practice particularly around pregnancies following pregnancy loss or in high risk pregnancies. Bereaved parents have expressed that a significant amount of their time in medical appointments in public health settings is spent repeating their story, creating additional distress and reducing the time available to deliver high quality care.

Continuity of care needs also to apply to bereavement support. Bereaved parents tell us that leaving hospital to go home without their babies is the most difficult time they face. In general, the level of support available is minimal and knowing where or how to continue with life is very difficult.

Sands has been funded to run a pilot program, called Hospital to Home, in some jurisdictions. This program provides intensive support to bereaved parents following stillbirth and newborn death. With input from midwives or others in the hospital setting a tailored support plan is developed to meet the individual needs of the bereaved parents. It extends for a three-month period and aims to link bereaved parents to other services, to support groups and to reconnect with their own support networks whilst also assisting in getting through some of the difficult days as the beginning of grief. It is expected that the program will see bereaved parents remain better engaged with health settings and reduce the likelihood of mental health concerns as a result of complicated grief.

Sands would be very happy to deliver this program in the ACT if the required funding was available.

Technology and other related matters.

Access to Sands services is essential for bereaved parents. Much literature suggests the benefit and unique nature of peer support bereavement care in contrast to other forms of support, counselling and psychological help. We strongly advocate for a variety of bereavement services, ensuring that bereaved parents can choose what might best meet their needs.

Our community of bereaved parents through conversations on the phone lines, LiveChat and in our support groups have regularly commented how help for bereaved parents is hard to find. We are often told that 'they wish they knew about us' when first losing their baby and have found us many years later. We are there for our bereaved parents, no matter how long ago they experienced miscarriage, stillbirth or neonatal death.

Although we support many bereaved parents around Australia and the ACT, we are acutely aware that our services are not being offered to every bereaved parent. In particular we know that bereaved parents in the ACT do not have access to face to face peer support services. Our aim would be to raise awareness, have frontline support and persons on the ground, so that each and every bereaved parent in Victoria and Australia are aware of our large range of support services. Sands believes that no parent should ever feel that they are on this journey alone.



The availability of resources is the main factor in not getting a reach to each and every bereaved parent, but we believe it should be best practice guidelines, that each bereaved parent be informed by our services. We cannot possibly attend each time that a hopeful parent is informed that they are now a bereaved parent, but with extra resources and funding, we can extend the education to nurses, midwives, doctors, counsellors, psychologists and sonographers to ensure that they are educated in our services.

The reach and support for bereaved parents could be further strengthened using technology. We know that most bereaved parents use mobile devices and computers to seek information to support what their health professionals are telling them. The development of an "app" to provide a source of information on all services available as well as information related to grief and loss would be an extraordinary step forward for families in the ACT. Sands would be happy to partner with other organisations such as Red Nose and PANDSI to develop something that might be suitable.

We leave you with some words from bereaved parents:

"It wasn't a little loss, I lost a little life"

"Imagine a love so strong that it made saying goodbye and hello in the same day, worth all of the pain".

"Before you tell a grieving parent to be happy for the children that they have, think about which one of yours that you could live without" – (this is a common message conveyed to bereaved parents – to be happy for their surviving children)

"She was born silent into this world, but her little life spoke volumes".

We can honour the babies lost and support the parents who live a lifetime of grief by providing improved bereavement services and support across the ACT.