sands

Sands Australian Principles of Bereavement Care

Miscarriage, Stillbirth and Newborn Death
1st Edition, May 2018

Improving bereavement care for parents

Sands is a not-for-profit organisation supporting bereaved families across Australia whose baby has died through miscarriage, stillbirth or newborn death.

Visit: **www.sands.org.au** for more information about Sands' support services.

Phone: 03 8652 5020
Email: admin@sands.org.au

Level 2, 990 Whitehorse Road
Box Hill VIC 3128
Australia

This publication is supported by funding from the Australian Government Department of Health.

sands

Contents

Background and Purpose

Each year in Australia, there are approximately 106,000 miscarriages, stillbirths and newborn deaths. This includes 103,000 miscarriages (<20 weeks' gestation), 1700 stillbirths and 700 newborn deaths (abs.gov.au, 2017, Herbert, Lucke & Dobson, 2009). This number is catastrophic, meaning that miscarriage, stillbirth or newborn death will occur to 1 in 3 Australian women in their lifetime.

The Sands Australian Principles of Bereavement Care have been developed to identify key actions and behaviours that can ensure that all bereaved families receive high quality care and support following the death of a baby.

The psychosocial and emotional impact on mothers, families and society in general is substantial, yet the care received by parents in Australia is highly variable. Review of our survey results show bereaved parents' needs are frequently unmet. Parents face many critical decisions following the death of a baby and more support and guidance is needed so that healthcare professionals have the information they need to deliver high quality care to all bereaved families (Sands Bereaved Parents Survey, 2016).

Research carried out by the Stillbirth Foundation (2015) tells us that grieving parents want maternal staff to demonstrate sensitivity and empathy, validate their emotions, provide clear information, and be aware that the timing of information given may be distressing. Parents also want support and guidance when making decisions about seeing and holding their baby. Sensitivity, respect, collaboration, and access to information is essential throughout the experience of miscarriage, stillbirth or newborn death (Sands Bereaved Parents Survey, 2016).

Research shows that while there have been many improvements over the last three decades, there are still many parents and families who do not receive quality care and support following the death of their baby. Sands' data collected identified a number of key issues in the bereavement care experienced by many parents who went through early pregnancy loss, medically advised termination, stillbirth or newborn death.

Key findings

- 60% of bereaved parents surveyed felt cared for and supported by hospital staff. To some extent this depended on whether their experience was recent (generally more positive but not always) or more than 15 years ago when the culture of bereavement care for baby loss was lacking.
- 51% of parents felt ill-informed about the grief they were going to experience, 29% felt informed and 13% were unsure.
- Just over half of respondents (54%) were provided with supportive information or literature to take home.
- There is inconsistency in the services delivered and knowledge of appropriate bereavement care.
- There is a lack of continuing support for bereaved parents after they leave hospital.
- Many parents are not being referred to external peer-to-peer support services (Sands or similar).
- Health professionals lack adequate training in bereavement care.

Working in Partnership

Sands has worked in partnership with The Centre of Research Excellence in Stillbirth (The Stillbirth CRE) to develop these Principles. Whilst Sands has an array of knowledge and experience in the field of bereavement support and has a very strong understanding of parents' needs, the high-quality research provided by the Stillbirth CRE is a vital contribution and ensures that the Principles are underpinned by a strong evidence base.

About Sands

In 1979 Sands was founded as a place for parents who have experienced the death of a baby to meet up and discuss their shared grief. Whilst the organisation has expanded and grown since that time, it is still this yearning for belonging that underpins everything we do. Sands is the leading provider of bereavement support services in Australia, providing direct emotional support to over 5,000 bereaved families each year. Our model of peer-to-peer support places Sands in a strong and unique position to provide hope and understanding to bereaved parents and their families across Australia.

Sands' support services include a national support line, men's support line, email support service and live chat, the first online live support one-on-one chat for bereaved parents. Face-to-face support groups are also delivered across many states. Sands distributes key information via digital and print brochures, available through health services, Sands offices and our website. Sands trained volunteers and staff deliver thousands of hours of training for health professionals both online and face-to-face to help develop their bereavement care skills.

About the Stillbirth CRE

The Stillbirth CRE was established to reduce the rate of stillbirth and improve care for parents and families whose baby is stillborn. The Stillbirth CRE is an Australia-wide initiative, hosted at the Mater Research Institute, within The University of Queensland Faculty of Medicine and is funded by the National Health and Medical Research Council of Australia.

The Stillbirth CRE recognises that stillbirth has enormous economic and psychosocial impacts; that there has been virtually no reduction in rates of stillbirth for over 20 years; that large equity gaps exist; and that families whose child is stillborn often receive suboptimal care (Stillbirth CRE, 2017). The Stillbirth CRE works in close partnership with the Perinatal Society of Australia and New Zealand, a multidisciplinary society dedicated to improving the health and long term outcomes for mothers and their babies. The Stillbirth and Neonatal Death sub-committee of PSANZ (PSANZ SANDA) played a major role in the development of the Stillbirth CRE and the Stillbirth CRE is now the Coordinating Centre for PSANZ SANDA.

The Stillbirth CRE program is based on The Lancet's 2016 Ending Preventable Stillbirths Series Call to Action and the specific priorities identified for Australia (Flenady et al., 2016). As the same interventions that may reduce stillbirth can also reduce adverse maternal and newborn outcomes, by implementing these interventions, the Stillbirth CRE aims to reduce a range of adverse pregnancy outcomes, with stillbirth its core focus. The Stillbirth CRE is a collaboration of parents, parent advocates, clinicians, researchers, professional colleges and policy makers, to generate new knowledge that translates into practice change and improved outcomes.

Continuing the Partnership

Sands and The Stillbirth CRE will continue to work together to develop best practice bereavement care and research in the area of pregnancy loss. Sands has recently contributed to the update and expansion of the current PSANZ Bereavement Care Guidelines.

Endorsements

Sands would like to thank the following organisations for their endorsement of the Principles.

TBC

Principles of Bereavement Care

Principle A: Individualised Bereavement Care

Bereavement care should be individualised to recognise bereaved parents' personal, cultural or religious needs. To deliver tailored bereavement care, time needs to be spent with bereaved parents to gain an understanding of their wishes.

Principle B: Good Communication

Communication with bereaved parents should be clear and honest. Consideration should be given to specific language to ensure it is empathic and sensitive. The term 'your baby (or babies)' should be used in all conversations (terms such as fetus, embryo, spontaneous abortion should be avoided). Trained interpreters and signers should be available for parents who need them.

Principle C: Shared Decision Making

Parents should be provided with full information into any important decisions to be made regarding themselves or their baby (babies). Parents should be given adequate time and information to consider all options available to them.

Principle D: Recognition of Parenthood

Recognition of parenthood and the role of memory making is vitally important and is thought to assist with the actualisation of grief and the slow transition of the parents' relationship with their baby from one of presence to one of memory. One of the greatest regrets that bereaved parents report to Sands is the lack of memories of their baby.

Principle E: Acknowledging a Partner's and Family's Grief

Recognition that a partner's and family's grief can be as profound as that of the mother and that their need for support should be considered and met. It should be clearly communicated to both the mother and her partner that support services are available to them individually and that it is helpful to talk to someone if they require support.

Principle F: Acknowledging Grief is Individual

Recognition of the grief journey and that all bereaved parents will handle and react differently to grief. The intensity and duration of grief for each bereaved parent will be different. Recognition that it is common that even within the same family each parent may react and handle grief differently. Health professionals should make parents aware that different grief responses are normal and that there is no perfect way to grieve.

Principle G: Awareness of Burials, Cremations and Funerals

All babies, no matter the gestation, should be treated with respect at all times. Options for burial, cremation, taking baby home, home funerals and conventional funerals should be discussed before baby is born, if possible, to give as much time to organise, consider and for all options to remain open. Health professionals should be aware of burial, cremation and funeral options available in their local area.

Principle H: Ongoing Emotional and Practical Support

Bereaved parents should be provided with information and referrals to both professional support and peer-to-peer support services such as Sands. The concept of seeking support (professional or peer) should be normalised for the bereaved parents and encouraged. Bereaved parents who have accessed peer support services such as Sands have reported that they feel their grief was heard, understood, and validated and have greater prospects of hope for the future.

Principle I: Health Professionals Trained in Bereavement Care

All health professionals who interact with bereaved parents should be aware of the Sands Australian Principles and should aim to attend professional development opportunities on bereavement care to ensure that the goal of consistent bereavement care across Australia is achieved.

Principle J: Health professionals with Access to Self Care

It is ok to not be ok after the death of a baby. All staff who care for bereaved parents before, during and after the death of a baby will be affected emotionally. Health professionals are in the 'helping' profession and when they cannot help this can bring up difficult emotions. Staff should have good access to information about effective self care.

Principle A:

Individualised Bereavement Care

Bereavement care should be individualised to recognise bereaved parents' personal, cultural or religious needs. To deliver tailored bereavement care, time needs to be spent with bereaved parents to gain an understanding of their wishes.

Rationale

Many bereaved parents have reported to Sands that they did not receive individualised care that gave them the time and ability to make informed decisions about their baby's care (Sands 2016). Parents have expressed regret that they only found out about care options available to them once they'd already left the hospital – when opportunities for memory making, for example, had already passed.

Research has shown that when bereaved parents are able to have honest and open communication with informed, educated health professionals early on they have greater opportunities to participate in personal, cultural or religious traditions or rituals that are meaningful to them (Lang et al., 2015), which can make a large impact on their lifetime memory of their child. Health professionals should be aware that these practices can vary greatly between individuals, even from similar cultural or religious backgrounds.

Managers and staff should recognise that adequate time needs to be spent with each family to recognise and support them through their choices. Each baby who has died is unique and each family will be affected by that death in a different way. Staff should therefore be responsive to the needs of families and understand that those needs may differ within the family unit itself and that they may change over time.

When health professionals practice individualised bereavement care:

- They explain to parents how the relationship with their baby will change from one of presence to one of memory and support that conversation with the following questions:
  - What would you like to happen?
  - How would you like to be involved?
  - What is your greatest fear in doing that?
  - How can I support you in that fear?
  - Does your partner share the same view, or do they differ? How can we best support your partner?
- They initiate early conversations about memory making and normalise memory making practices. For example, instead of saying "Would you like to give your baby a bath?" they may say "Many families have found that they benefited from the memory of giving their baby a bath, would that be something you might like to consider?"
- They ensure that parents are consulted more than once about key time-sensitive issues such as memory making. They explain that grief can sometimes cloud our thinking and that it's ok to feel confused or to change your mind.

Principle B:

Good Communication

Communication with bereaved parents should be clear and honest. Consideration should be given to specific language to ensure it is empathic and sensitive. The term 'your baby (or babies)' should be used in all conversations (terms such as fetus, embryo, spontaneous abortion should be avoided). Trained interpreters and signers should be available for parents who need them.

Rationale

The death of a baby is a tragic experience that is unique for every bereaved parent. No one can be prepared for the devastating grief that follows. A family's dreams for the future with their child are lost and their heartbreak is immeasurable. The death of a baby or child is known to evoke one of the strongest grief responses in one's life.

Grief is incredibly complex, individual, and has real effects in terms of losses of normal cognitive functioning in some circumstances (Hall et al., 2014). It is therefore important that all interactions with bereaved parents have in mind the need for clear and consistent communication. Good communication increases the likelihood that parents feel informed, heard and respected and that their wishes for memory making and other aspects of care for their baby are delivered in the individual way they require.

Bereaved parents have reported to Sands, even many decades after the death of their baby, that good communication is vitally important and can have a significant impact on the choices they make. Bereaved parents have reported that they can still hear certain 'phrases' in their head many years later and that this can affect a positive memory of their baby. An example of this is a bereaved parent recalling the moment that their baby was referred to as a 'fetus that is incompatible with life'.

Health professionals should understand the long lasting impact their words and actions may have on bereaved parents and communicate with them in a sensitive and responsive way.

When health professionals communicate well with bereaved parents they:

- Avoid clinical terms such as fetus, embryo, and spontaneous abortion.
- Ensure that language or disability is not a barrier to memory making and other important decisions by ensuring trained interpreters or signers are available for key discussions.
- Ask parents for permission to call their baby by name, if the baby has been named, and ensure all staff continue to refer to the baby in this respectful way.
- Use intuitive questioning to really understand their position.
- Actively listen to parents to ensure their needs are being appropriately met (they don't just tick off a check box).
- Pay particular attention to the environment in which they deliver bad news or have difficult conversations, choosing private areas over hallways or common spaces, for example.

Principle C:

Shared Decision Making

Parents should be provided with full information into any important decisions to be made regarding themselves or their baby (babies). Parents should be given adequate time and information to consider all options available to them.

Rationale

Evidence suggests that shared decision making provides numerous benefits for parents, health professionals, health services and the healthcare system (Oshima Lee & Emanuel, 2013). Parent led decision making is found to reduce healthcare costs as well as importantly providing increased knowledge to parents, resulting in less anxiety about care processes and greater alignment of care practices with parents' values (Oshima Lee & Emanuel, 2013).

Bereaved parents have reported to Sands that when decisions about their baby's care have been taken out of their hands they feel like their parenthood is not being acknowledged (Sands, 2016). Conversely, when parents are encouraged to be a part of those shared decisions it provides an important opportunity for them to parent their baby (Sands, 2016). Given the chance, most parents report that they want to be involved in as many decisions about the care of their baby as possible.

It should be noted, however, that grief may mean it is difficult for parents to lead the decision making process and that health professionals may need to support parents when they feel confused or under pressure.

Health professionals can involve parents in decision making by:

- Using decision-aids such as Sands' range of information booklets to inform and empower parents to make informed decisions.
- Offering choices around what could happen next. For example, will baby leave hospital to go to the funeral home or will baby stay at the parents' home until the funeral?
- Providing opportunities for them to parent their baby. For example, by taking their baby outside into the natural light or for a walk in a pram.
- Suggesting they name their baby.
- Involving parents in decisions around memory making and the taking of photographs.
- Involving parents in decisions around autopsy consent.
- With the parents' consent, including others, such as family members or spiritual leaders, who may help them in their decision making.

When parents are encouraged to be a part of those shared decisions it provides an important opportunity for them to parent their baby.

Principle D:

Recognition of Parenthood

Recognition of parenthood and the role of memory making is vitally important and is thought to assist with the actualisation of grief and the slow transition of the parents' relationship with their baby from one of presence to one of memory (McCreight, 2008). One of the greatest regrets that bereaved parents report to Sands is the lack of memories of their baby.

Rationale

Memory making, as well as language, is thought to assist with the recognition of parenthood for bereaved parents. Within the many stories bereaved parents share with Sands each year is the recurring theme of regret – regret at not spending enough time with or making enough memories of their baby.

Information about memory making and care packages should therefore be given to bereaved parents early enough for them to take up those opportunities. All individual wishes, needs and cultures/religions should be respected but health professionals should also make provisions for future change of mind.

Not all bereaved parents may wish to see their baby (babies) and sometimes bereaved parents even within the same family have differing wishes. In all cases where parents express a desire not to see their baby (babies), medical staff should have a careful discussion with parents and assist with making memories on behalf of the parents.

If parents wish to have photos of their baby, encourage photos of baby wrapped, unwrapped, clothed and unclothed, hands, feet and face at a minimum. Some hospitals provide the option for photos to be stored on medical files should parents wish to view these at a later date, however not all hospitals have this facility. It is important that health professionals are aware of what is possible at their health facility.

Memory making opportunities should include photographs of the baby (including wrapped and unwrapped), videos, hand/footprints or casts, locks of hair, hospital keepsakes/name bands, delivery of a Sands Bereavement Care Package and extended time with baby through the use of a cuddle cot or the option to take baby home, if appropriate.

Parenthood is recognised when:

- Parents are encouraged to unwrap their baby and see all of their features, not just their face and hands. Many bereaved parents report they didn't see their baby's belly button, for example, or baby unwrapped (Sands, 2016).
- Photos and videos are taken of the baby. Take high-quality hand and foot prints and suggest parents keep a lock of baby's hair.
- Health professionals consider options that would enable bereaved parents to spend extended time with their baby, such as the opportunity to take them home for a period of time, if appropriate. This experience should be normalised for parents.
- Each parent is given ample time alone with their baby.
- Parents are given photos that "tell the story" – such as photos from throughout the labour, not just after baby is born.
- Health professionals handle the baby in the same manner in which they would handle a live baby.
- Parents are encouraged to name their baby if they wish and health professionals refer to the baby by that name.

Principle E:

Acknowledging a Partner's and Family's Grief

Recognition that a partner's and family's grief can be as profound as that of the mother and that their need for support should be recognised and met. It should be clearly communicated to both the mother, her partner and family that support services are available for them individually and that it is helpful to talk to someone if they require support.

Rationale

We know that grief is individual and that also extends to the experience of bereaved parents (Rosenblatt, 2017). It is very normal for partners and families to experience intense grief in a very different way to that of a mother. Often partners and families are looked upon as a pillar of strength that the mother can rely upon for support, however, partners, families and particularly other children grieve too. As stated by the Royal Children's Hospital Bereavement Service, supporting them is vitally important too (rch.org.au, 2017).

Consideration must be given to the different types of families including mother/father relationships, same-sex and intersex relationships and the different types of grief that can be experienced by bereaved parents. All types of relationships should be treated equally and respectfully. Support services should be offered to the partner and family as well as the mother.

Health professionals should steer away from traditional views of 'male' and 'female' grief. We now know that there are many different types of grief that can be experienced.

A partner's or family's grief is acknowledged when:

- Partners are involved in all discussions and decision-making processes.
- Health professionals have some time alone with the partner to talk through any issues they may have and to offer them the use of support services.
- Professionals normalise the fact that partners sometimes feel differently than the mother with regards to grief and decisions that need to be made.
- Health professionals acknowledge and work towards each parent's goals and hopes for the care of their baby.
- Parents are referred to Sands' range of support services.
- Consideration is given to how children or siblings are coping with grief.

All types of relationships should be treated equally and respectfully. Support services should be offered to the partner and family as well as the mother.

Principle F:

Acknowledging Grief is Individual

Recognition of the grief journey and that all bereaved parents will handle and react differently to grief. The intensity and duration of grief for each bereaved parent will be different. Recognition that is it common that even within the same family each parent may react and handle grief differently. Health professionals should make parents aware that different grief responses are normal and that there is no perfect way to grieve.

Rationale

It is important for health professionals to view each bereaved parent's experience as unique and to understand the significance of their role in supporting parents through one of the most personal and vulnerable times of their lives.

Many bereaved parents report the death of their baby as their first experience of the death of an immediate family member, meaning they are often inexperienced in dealing with grief and grief responses (Sands, 2016). Health professionals therefore have an important role to play in helping bereaved parents understand and adjust to their feelings, thoughts and behaviours.

Research shows that health professionals should aim to inform bereaved parents about the different types of grief and the grief journey early so that bereaved parents can normalise any differences in feelings that may occur (McGrath, 2003). They should also consider the experiences of siblings/children or other immediate family members in these discussions.

Health professionals should consider describing grief responses in the following way:

Intuitive Grief*

- Strong, affective reactions, waves of powerful emotions.
- Expressions that mirror feelings, more like an open book (Watson & Stella, 2009).

Instrumental Grief*

- More thinking than feeling (inward, quiet processes, less outward expression of emotions).
- Being physical, expressing grief through doing something. A practical example is 'I cannot fix my son, but I can fix this broken chair' (Watson & Stella, 2009).

This normalisation of different ways to grieve can assist parents in early decision making as well as help them understand each other's points of view if their responses differ.

When health professionals acknowledge that each family member's grief is individual:

- They educate and inform the parents and wider family, where appropriate, about the different types of grief commonly experienced.
- They spend time to get an in-depth understanding of what each bereaved parent requires.
- They acknowledge that this baby's death and the family's responses to it are unique.
- They consider using one of Sands' decision aid tools/brochures to help ensure that individual needs are met.
- They pay attention to how cultural and religious differences may impact on a family's experience and processing of grief.
- They acknowledge the involvement of the wider family in the grief journey, if that is what the bereaved parents feel comfortable with.

**please note these are not the only two types of grief response.*

Principle G:

Awareness of Burials, Cremations and Funerals

All babies, no matter the gestation, should be treated with respect at all times. Options for burial, cremation, taking baby home, home funerals and conventional funerals should be discussed before baby is born if possible, to give as much time to organise, consider and for all options to remain open. Health professionals should be aware of burial, cremation and funeral options available in their local area.

Rationale

Coming home from the hospital without your baby is a devastating experience for most parents. Mothers, in particular, often describe this as the hardest part of their experience. Bereaved parents say that having to separate themselves from their baby and walk away from the hospital is extremely difficult. Many say these physical actions went against a strong motherly instinct to be with their child and protect them.

No matter the gestation of the baby, parents should be given options for burial, cremation or to take their baby home.

Organising a funeral or similar service can be a very frightening and confusing experience for parents. Normalising this experience and providing resources that have been helpful for other families is something health professionals can do to assist bereaved parents during this process, including providing information about what services are available in the local area.

A funeral or memorial service is one of the only things bereaved parents get to do for their baby. Therefore, it is important that discussions are had in a timely manner to allow bereaved parents a full range of options for their baby. Bereaved parents, especially if they are unexpectedly a large distance from home, may need extra time to discuss their options for burial or cremation and make arrangements. Health services should encourage parents to take their time to make these significant decisions and be accommodating of this extra time.

Bereaved parents should also know that there are times, when appropriate, that they can take their baby home for a period of time and this should be normalised. It should also be noted that parents should be made to feel that it is ok if they also decide not to do this.

To inform bereaved parents of their options for burials, cremations and funerals health professionals should:

- Give parents options to take baby home.
- Let the parents know that they have options beyond the traditional.
- Be aware that some babies under 20 weeks can be taken home for burial (check state information).
- Have a very good understanding of services available in their area.
- Prepare bereaved parents for having the first conversation with a funeral director (if using). Funeral directors have a specific set list of questions that they have to ask, often by law (such as parents' occupation, mother's maiden name etc.) which may be difficult for parents to respond to. Funeral directors have reported to Sands that it is helpful from their perspective if the health professional prepares the bereaved parent for this initial phone call.

No matter the gestation of the baby, parents should be given options for burial, cremation or to take their baby home.

Principle H:

Ongoing Emotional and Practical Support

Bereaved parents should be provided with information and referrals to both professional support and peer-to-peer support services such as Sands. The concept of seeking support (professional or peer) should be normalised for the bereaved parents and encouraged. Bereaved parents who have accessed peer support services such as Sands have reported that they feel their grief was heard, understood, and validated and have greater prospects of hope for the future.

Rationale

Sands research indicates that at least half of all bereaved parents are not given information at the hospital about continuing support services (Sands, 2016). Ongoing support is an essential part of bereavement care and should be made available to all who want it, including during subsequent pregnancies.

All parents should receive information for both professional and peer-to-peer support services, such as Sands, before leaving the hospital. Details of the support services offered should be discussed with parents as well as detailed in handover documents to the bereaved parents' primary care GP or other allied health services.

Peer-to-peer support has been found to be especially beneficial in the normalisation of grief processes and in transitioning from the hospital to the home environment (Legere, Nemec & Swarbrick, 2013). Grief is lifelong and ensuring that evidence based peer-to-peer support is offered ensures that bereaved parents are supported even throughout subsequent pregnancies (if experienced) (Koopmans, Wilson, Cacciatore & Flenady, 2013). Bereaved parents continually report that the support received through Sands' peer-to-peer support model validates their grief and provides a place where they feel safe, heard and understood.

Health professionals should discuss the range of peer-to-peer support services available to parents, such as Sands' national phone support line, online live chat support, online resources, brochures and face-to-face support groups.

At this time, it is also helpful if other family members are directed to information about how best to support the bereaved parents. Sands' support services are also available for friends. Brochures specifically for family, friends and grandparents about how to be an effective support are available for free download at www.sands.org.au.

To ensure they provide parents with options for ongoing emotional and practical support health professionals should:

- Talk through the different options of continuing support (professional and peer support).
- Provide a Sands Bereavement Care Package, if hospital supplies and space permits.
- Provide Sands information brochures.
- Discuss the Sands live chat support service available online.
- Ensure that all bereaved parents receive a follow up call and/or visit from a maternal health or allied health professional in addition to the regular referral to their general practitioner.
- Acknowledge that while continuity of care can be challenging, it can be achieved through effective communication.

Principle I:

Healthcare Professionals Trained in Bereavement Care

All health professionals who interact with bereaved parents should be aware of the Sands Australian Principles and should aim to attend professional development opportunities on bereavement care to ensure that the goal of consistent bereavement care across Australia is achieved.

Rationale

Bereaved parents Australia-wide have reported widespread differences and disparities of bereavement care services both rurally, regionally and in metro services (Sands Forum, 2017). Sands believes this is mainly due to differences in education across the services, not access to services or resources. Education for health professionals of what exceptional bereavement care can look like is needed so that all Australian parents receive respectful, sensitive and, importantly, consistent bereavement care.

All bereaved parents deserve the very best in bereavement care. In order for this to occur, all health professionals should have bereavement care training (in perinatal loss). It is not acceptable to only have 'bereavement care specialists' to handle all bereavement cases. All maternal health professionals should be 'experts' in bereavement care. This promotes wider education in bereavement care and decreases the chances of burnout of midwives/nurses or doctors. Sands, however, acknowledges the wonderful work that all bereavement care specialists and midwives provide.

It is important for health professionals to remember that bereaved parents will carry the memory of the care they provided throughout their lifetime as it is intertwined with the very short time they have with their baby (babies). Investing in education, such as Sands low-cost online bereavement care training, will ensure all health professionals are equipped with the knowledge and skills they need to confidently and compassionately respond to bereaved parents.

Health professionals can prioritise training in bereavement care by:

- Undertaking Sands' online training modules on bereavement care (CPD points available).
- Engaging in informal discussions about bereavement care on their ward/unit/department. E.g. Discussing 3 ways you can improve bereavement care today.
- Encouraging interdisciplinary discussions in improving bereavement care at their hospital.
- Inviting a Sands representative to their maternity unit for an education session.

All bereaved parents deserve the very best in bereavement care. In order for this to occur, all health professionals should have bereavement care training.

Principle J:

Health Professionals with Access to Self Care

It is ok to not be ok after the death of a baby. All staff who care for bereaved parents before, during and after the death of a baby will be affected emotionally. Health professionals are in the 'helping' profession and when they cannot help this can bring up difficult emotions. Staff should have good access to support and practice self care.

When birth and death are fused together there is a confusion of thoughts and feelings, as well as a totally bewildering sense of unreality' (Kenworthy & Kirkham, 2011). If you are emotionally affected by the death of a baby and need support you are able to call the Sands national support line as well as other support lines.

Rationale

Many health professionals suffer from vicarious traumatisation, due to exposure to workplace stressors (Saakvitne et al., 2000). Vicarious traumatisation, more commonly known as 'burn out', occurs as a natural human response to exposure to abnormally sad, horrific events or unusual events (Saakvitne et al., 2000). Whilst prolonged exposure is an increased risk factor for vicarious traumatisation, it can commonly occur after one profound event (Saakvitne et al., 2000).

Many sufferers of vicarious traumatisation experience symptoms such as emotional numbing, social withdrawal or disconnection with loved ones, feelings of despair or hopelessness, no time or energy for themselves, difficulties making decisions, reduced productivity, increased illness and fatigue or increased fear for the safety of children and loved ones (Saakvitne et al., 2000).

One known method to help decrease the chance of vicarious traumatisation is to practice self care (Power & Mullan, 2017; Saakvitne et al., 2000). Power & Mullan (2017) state that practicing self care is a common strategy for healthcare professionals to assist with burn out symptoms, but best practiced regularly before burn out occurs.

Health professionals should be aware that self care need not be elaborate. Most effective self care methods take just 5-15 minutes a day and include simple activities such as enjoying an outside walk during a lunch break.

There are benefits in practicing self care, not only for healthcare professionals, but for the organisations that employ healthcare professionals (Power & Mullan, 2017). By adopting and promoting self care in their healthcare facilities, organisations help to lower absenteeism, burn out and associated costs (Leinweber et al., 2017) as well as assist their talented and valued health professionals to stay healthy and well.

Healthcare organisations can support good self care amongst staff by:

- Offering professional development in the area of bereavement. E.g. Sands Australian Bereavement Principles Training (online or in person).
- Encouraging staff to practice a self care activity each week.
- Having open discussions in their units/work about practicing self care.
- Conducting reflective practice.

References

About Us - Stillbirth CRE. (2017). *Stillbirthcre.org.au*. Retrieved 9 March 2018, from https://www.stillbirthcre.org.au/about-us/

Australian Bureau of Statistics, Australian Government. (2017). *Abs.gov.au*. Retrieved 9 March 2018, from http://www.abs.gov.au/

Flenady, V., Wojcieszek, A., Middleton, P., Ellwood, D., Erwich, J., & Coory, M. et al. (2016). Stillbirths: recall to action in high-income countries. *The Lancet, 387*(10019), 691-702. http://dx.doi.org/10.1016/s0140-6736(15)01020-x

Hall, C., Reynolds, C., Butters, M., Zisook, S., Simon, N., & Corey-Bloom, J. et al. (2014). Cognitive functioning in complicated grief. *Journal Of Psychiatric Research, 58,* 20-25. http://dx.doi.org/10.1016/j.jpsychires.2014.07.002

Herbert, D., Lucke, J., & Dobson, A. (2009). Pregnancy Losses In Young Australian Women. *Women's Health Issues, 19*(1), 21-29. http://dx.doi.org/10.1016/j.whi.2008.08.007

Information and communication about autopsy following stillbirth: meeting the needs of parents - Stillbirth Foundation. (2015). *Stillbirth Foundation*. Retrieved 9 March 2018, from http://stillbirthfoundation.org.au/information-and-communication-about-autopsy-following-stillbirth-meeting-the-needs-of-parents/

Kirkham, M., & Kenworthy, D. (2011). *Midwives coping with loss and grief* (1st ed.). London: Radcliffe Pub.

Koopmans, L., Wilson, T., Cacciatore, J., & Flenady, V. (2013). Support for mothers, fathers and families after perinatal death. *Cochrane Database Of Systematic Reviews*. http://dx.doi.org/10.1002/14651858.cd000452.pub3

Lang, A., Fleiszer, A., Duhamel, F., Aston, M., Carr, T., & Goodwin, S. (2015). Evidence-Informed Primary Bereavement Care: A Study Protocol of a Knowledge-to-Action Approach for Systems Change. *International Journal Of Qualitative Methods, 14*(1), 121-145. http://dx.doi.org/10.1177/160940691501400102

Legere, L., Nemec, P. and Swarbrick, M. (2013). Personal narrative as a teaching tool. *Psychiatric Rehabilitation Journal, 36*(4), pp.319-321.

Leinweber, J., Creedy, D., Rowe, H., & Gamble, J. (2017). Responses to birth trauma and prevalence of posttraumatic stress among Australian midwives. *Women And Birth, 30*(1), 40-45. http://dx.doi.org/10.1016/j.wombi.2016.06.006

McCreight, B. (2008). Perinatal Loss: A Qualitative Study in Northern Ireland. *OMEGA - Journal Of Death And Dying, 57*(1), 1-19. http://dx.doi.org/10.2190/om.57.1.a

McGrath, P. (2003). Living well with grief: insights on bereavement support. *Austral-Asian Journal Of Cancer, 2*(3), 225-233.Nemec, P., Swarbrick, M., & Legere, L. (2015). Prejudice and discrimination from mental health service providers. *Psychiatric Rehabilitation Journal, 38*(2), 203-206. http://dx.doi.org/10.1037/prj0000148

Oshima Lee, E., & Emanuel, E. (2013). Shared Decision Making to Improve Care and Reduce Costs. *New England Journal Of Medicine, 368*(1), 6-8. http://dx.doi.org/10.1056/nejmp1209500

Palliative care : Bereavement. (2017). *Rch.org.au*. Retrieved 9 March 2018, from https://www.rch.org.au/rch_palliative/for_health_professionals/Bereavement/

Power, A., & Mullan, J. (2017). Vicarious birth trauma and post-traumatic stress disorder: Preparing and protecting student midwives. *British Journal Of Midwifery, 25*(12), 799-802. http://dx.doi.org/10.12968/bjom.2017.25.12.799

Rosenblatt, P. (2017). Researching Grief: Cultural, Relational, and Individual Possibilities. *Journal Of Loss And Trauma, 22*(8), 617-630. http://dx.doi.org/10.1080/15325024.2017.1388347

Saakvitne, K., Gamble, S., Pearlman, L., & Lev, B. (2000). *Risking connection: A training curriculum for working with survivors of childhood abuse*. Lutherville, MD: Sidron Press.

Sands Australia. (2016). *Sands.org.au*. Retrieved 9 March 2018, from http://www.sands.org.au/research-and-statistics

Sands Bereaved Parents Research Survey (2016). *Sands Australia*.

Watson, W., & Stella, C. (2009). Patterns of grief following spousal bereavement: Intuitive and instrumental styles of coping. *Gerontologist, 49*, p360.

All bereaved parents should receive high quality care and support following the death of a baby.

Level 2, 990 Whitehorse Road
Box Hill VIC 3128
Australia
Phone: 03 8652 5020
Email: admin@sands.org.au
www.sands.org.au