

At Empty Arms we:

--->Help bereaved parents get the help they need to survive the death of their baby.

—Help the family and friends of bereaved parents become more knowledgeable about what the grief process is like.

--->Help professionals who care for bereaved parents have the resources they need to do their jobs well.



Stillbirth and Infant Loss Support

Miscarriage Support

Termination for Medical Reasons Support (5 monthly groups)

Pregnancy after Loss Support (Subsequent Choices)

Parenting after Loss

Loss of one Twin Support Group

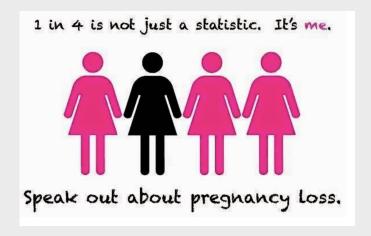
Dad's Group

POC Support

LGBTQ+ Group

Spanish Language Support Group

Loss is an Expected Outcome





Dad hugs newborn baby Anna, who was unexpectedly stillborn at term in 2019. No cause for her death was ever found.



Mentalization

- The relationship with baby begins before birth. As soon as one learns they are pregnant, they may begin imagining a life with a child.
- The loss is about a future imagined and expected
- The grieving process is made all the more challenging because there are no or few memories of the relationship

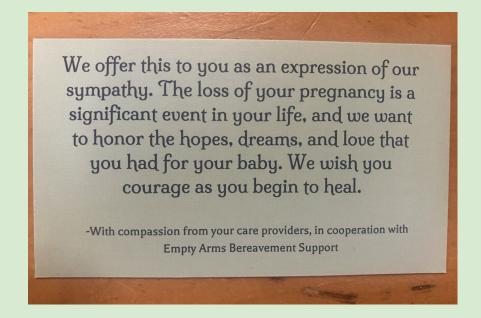


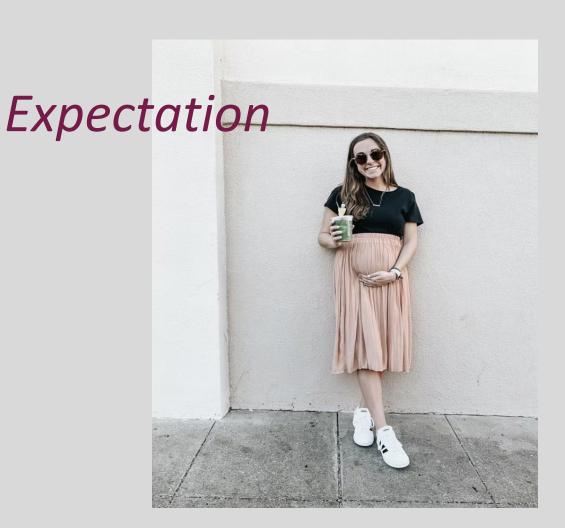
Megan and Tommy with their three living children and the silhouettes of their triplet girls who died in January and February of 2018.



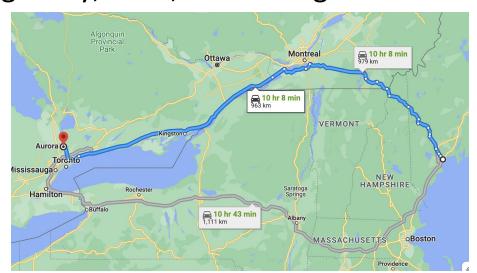
- Each of these people has transitioned from a state of expectation to a state of loss— each of their futures has been altered so that it longer includes a baby (at this time)
- None of these people was handed a roadmap in advance for how to manage loss, though many of them over time have put together a relatively decent roadmap for what to do and how to proceed during pregnancy, birth, and
- Each of these people will have experienced moments, days or hours as they are interacting with the medical care system where they are confused, not sure how to proceed, or even paralyzed with indecision.
- Each of these people will have challenges as they navigate their social world (friends, family, colleagues, etc) following this loss.

They have all transitioned from a state of expectation to a state of loss—each of their futures has been altered so that it longer includes a baby (at this time)





None of these people was handed a roadmap in advance for how to manage loss, though many of them over time have put together a relatively decent roadmap for what to do and how to proceed during pregnancy, birth, and raising an infant



Schema: what our brain does to make things easier



Each of these people will have experienced moments, days or hours as they are interacting with the medical care system where they are confused, not sure how to proceed, or even paralyzed with indecision.



Lead with Compassion

Follow with science

I'm so sorry this is happening to you.

No but.

No at least.

No anything else.

I am here to help you...

...and you will help me to know that that means.





Language

- Listen for and mirror clients language when they refer to their baby
- If you are unsure, you can ask:
 - "What language do you use when you are thinking about your loss? I want to make sure I am using the right words."



Do you have any questions about what has happened so far

–Do you feel like you've been given enough information about what happens next?

–You can ask again. We know you have no map for how to navigate this

The Collective vs the Individual

- Changing patient's perspective: you are part of a collective and this can be part of the process
 - Try to include loss in all your conversations from day 1 to normalize it as part of the process
 - Use "many families" or "most people" when offering decision making
 - Validate range of emotions using same language
 - Validate the possibility of re-traumatization

Miscarriage

I am so sorry this is happening, and I want you to feel as if you're in the driver's seat as we decide what happens next.

- Explain what the options are
- Why people choose them
- What they might be like
- Please ask me again

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Poor Prenatal Diagnosis

Honor the decision - do not ask any questions that could imply that you are questioning their decision

Lead with the facts

Offer options within a context and explain the medical risks and benefits within a human context using laypersons language

Stillbirth or Inevitable Loss at Birth

- -Most people have no idea what this might look like or what could possibly help
- -Going to share with you some thoughts of things that have helped people in the past— what I share may be surprising
- -You don't have to do, or stick to, anything—at every step of the way you are going to call the shots and you can change your mind at any time. We want to support you in this opportunity to be a parent to your child in a way that feels comfortable to you.
- -We may circle back and remind you of your options, because this will be your only chance and we want to make sure you feel comfortable with your decisions

Our social norms bump up against what we know is often best for parents.

It is not intuitive for anyone - not for you (yet!), not for parents.

THEREFORE Parents need your help and permission to follow their own instincts









TOP TWO:

- Define time together offer the range!
 - for some people they are overwhelmed after 30 minutes and ready to say goodbye
 - For others, they stay curled up in bed together for 3 days
 - We have no expectations but want you to just do what feels right for your family— will probably fall somewhere in the middle of those two examples!

 Offer choices wherever possible—blankets, clothes, hats, bathing, and always frame in terms of what other people have done!

What do parents want?

They want their baby affirmed They want to have zero regrets They want to be able to make decisions They want to have their wishes respected They want to have their grief validated They want to know "I'm not crazy" They want to know "I'm not alone"



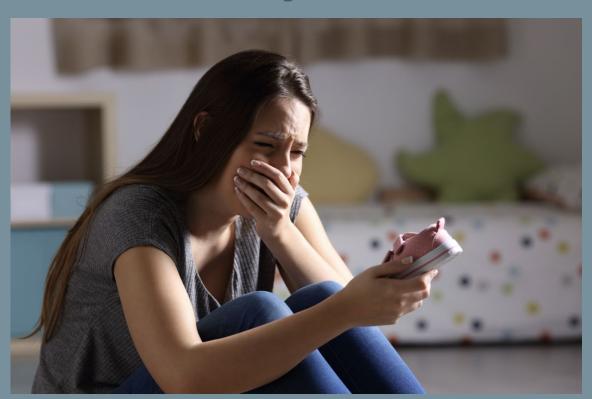
Guilt and Shame

It felt hard for me to share that I had experienced two miscarriages because the way I felt about my body was that it was broken. I didn't want to tell

People that, I was embarrassed. But I needed them to know because I was suffering. So it was a hard balance.

It was shocking to me how humiliating it felt to be the only person I knew whose baby didn't live. Why did everyone else get their live baby and mine had to die?

Identity



Next Steps

- -Regardless of type of loss people may ask about next steps (*this is not a topic you should raise, but should respond to with detail)
- -Reassure that thinking about next steps is expected and universal because you want to be a parent (or a parent to 2 children, 3, etc)
- -Know that next steps will be a repeat of a previously traumatic event— with little to no tools to ensure a better outcome
- -Know that whatever surveillance measures you can offer will be appreciated regardless of their ability to truly ensure a better outcome

Each of these people will have challenges as they navigate their social world (friends, family, colleagues, etc) following this loss.



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I am with you, not standing in opposition to you

I am listening to you AND I hear you, I am not cancelling out your words

I am speaking the same language as you are

You are not a body, you are a person

We are working together with all the tools available to us, and we are making rational decisions





Serving Vermonters by providing peer support for pregnancy and infant loss.



Peer Support Groups

- PREGNANCY AND INFANT LOSS GROUP (2nd Wednesday of the month)
- **EARLY PREGNANCY LOSS GROUP** (4th Tuesday of the month)
- PREGNANCY AFTER LOSS (3rd Thursdays of the month)
- TRYING TO CONCEIVE AFTER LOSS (2nd Monday of the month)
- PARENTING AFTER LOSS (1st Tuesday of the month)

- Groups are peer-facilitated, open, and free for anyone with a loss during pregnancy or within the first year of infancy.
- Meets virtually on Zoom
- www.emptyarmsvermont.org/support



More Services...

- Miscarriage Support Bags for OBGYN offices
 - Contact <u>chelsea@emptyarmsvermont.org</u> if your practice is interested in learning more.
- Monthly yoga classes designed for grief & loss
 - Sangha Studio or live virtually
- Helpers in Healing Discussion Group
 - 3-month sessions for friends & family supporting someone through pregnancy and infant loss
- Weighted teddy bears for late term loss



Remembrance Night

October 7 Shelburne, VT 5:30–7:30pm (RSVP online)













Aundi Kolber, Therapist+Author @aundikolber

Perhaps one of the most validating things someone has ever said to me as a trauma therapist + survivor is this:

I just want to honor everything it cost you to know what you know.



Black, Beth Perry, Wright Patricia Moyle, and Limbo Rana <u>Perinatal and Pediatric Bereavement In Nursing and Other Health Professions</u> New York 2016: Springer Publishing Company

Bohn, Jessalyn When Words Fail: "Miscarriage," Referential Ambiguity, and Psychological Harm *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*, Volume 48, Issue 3, June 2023, Pages 265–282,

Boyden, J. Y., Kavanaugh, K., Issel, L. M., Eldeirawi, K., & Meert, K. L. (2013, October 1). "Experiences of African American Parents Following Perinatal or Pediatric Death: A Literature Review". Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/24666143

Brosig, C.L., Pierucci R.L., Kupst, M.J., Leuthner, S.R., "Infant End-of-Life care: The Parents' Perspective".

Journal of Perinatology. 2007 Aug; 27(8): 510-6.

Caccitore, J., Froen, J. F., & Killian, M. (2013). Condemning self, condemning other: Blame and mental health in women suffering stillbirth. *Journal of Mental Health Counseling*, 35(4), 342-359.

Carter, Brian S. and Levetown, Marcia: <u>Palliative Care for Infants, Children and Adolescents: A Practical Handbook</u> 2004 Baltimore: Johns Hopkins University Press

Centers for Disease Control and Prevention. Data and Statistics: How Many Babies are Stillborn? https://www.cdc.gov/ncbddd/stillbirth/data.html Accessed March 10, 2022

Davis, Deborah L. PhD https://www.psychologytoday.com/us/blog/laugh-cry-live/201904/reflections-perinatal-bereavement-care
Ely, D. M., & Driscoll, A.K., (2020). Infant Mortality in the United States, 2018: Data From the Period Linked Birth/Infant Death File. *National Vital Statistics Report* 69(7)

Côté-Arsenault, Denise, et al: "Pregnancy as a rite of passage: liminality, rituals & communities". Journal of Prenatal and Perinatal Psychological Health

2009; 24(2):69-87.

of Women's Health, 25(3), 263-269.

Davis, Deborah L. PhD IPBC Conference 2018 Presentation

Flannigan, A. Y., Cultural Meanings of Death and Dying. E-Course. Retrieved from

https://www.netce.com/coursecontent.php?courseid=2231#bibl.evidencebased Accessed March 10, 2022

Health Psychology 24(I) 65-78

Gold, K. J., Leon, I., Boggs, M. E., & Sen. A. (2016). Depression and posttraumatic stress symptoms after perinatal loss in a population-based sample. Journal

Gandino, G., Bernaudo, A., Di Fini, G., Vanni, I., Veglia, F. (2019) Healthcare professionals' experiences of perinatal loss: A systematic review. Journal of

Gold, Katherine J. Gold MD MSW MS Presentation IPBC 2018

Harris, Darcy L. and Bordere, Tashel, <u>Handbook of Social Justice in Loss and Grief: Exploring Diversity, Equity and Inclusion</u>. 2016 New York: Routledge.

Heustis, Jane and Jenkins, Marcia: Companioning at the time of Perinatal Loss: A guide for nurses, physicians, social workers, chaplains and other bedside caregivers. Fort Collins, CO 2005: Companion Press.

Jonas-Simpson, C., Beryl Pilkington, F., MacDonald, C., McMahon, E. (2013) Nurses' Experiences of Grieving When There Is a Perinatal Loss. Sage Open April-June I-

Kavanaugh, K. and Hershberger, P. "Perinatal Loss in Low-Income African American parents" <u>Journal of Obstetrical Gynecology and Neonatal Nursing</u>. 2005 Sep-Oct; 34(5):595-605.

Kavanaugh, K., "Parents' Experience Surrounding the Death of a Newborn Whose Birth is at the Margin of Viability".

Journal of Obstetrical Gynecology and Neonatal Nursing 1997 Jan-Feb; 26(1):43-51.

Kavanaugh, K. Robertson, PA., "Recurrent Perinatal Loss: A Case Study". Omega (Westport). 1999; 39(2):133-47.

Keene, E. A., Hutton, N., Hall, B., & Rushton, C., "Bereavement debriefing sessions: An intervention to support health care professionals in managing their grief after the death of a patient". 2010 <u>Pediatric Nursing</u>, 36(4), 185-189.

Kendall-Tackett, K.A.. "Addressing Racial and Ethnic Health Disparities in Infant Mortality: Additional Barriers to Care". 2014 Clinical Lactation, 5(3), 83-85

Macpherson, C.F., "Peer-supported storytelling for grieving pediatric oncology nurses" <u>Journal of Pediatric Oncology Nursing</u> 2008 May-Jun;25(3):148-63. E pub 2008 Apr 15.