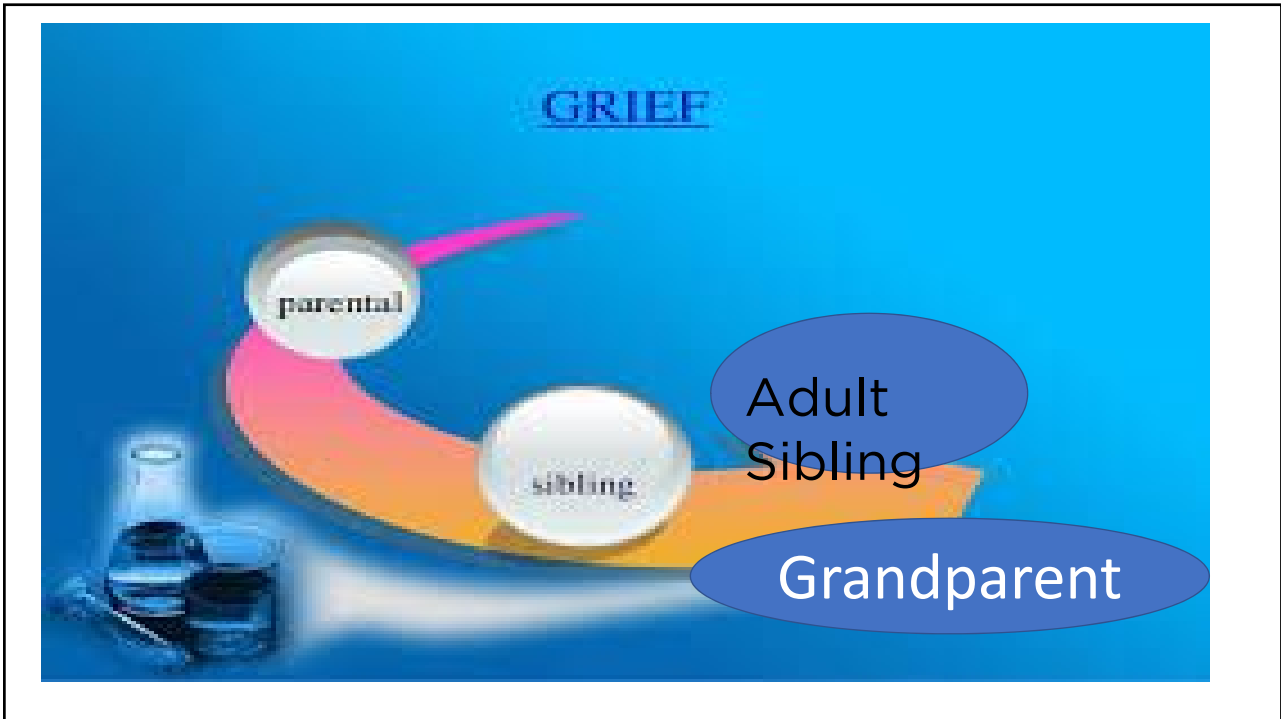


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Forgotten Mourners: Grandparents & Adult Siblings

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Presentation Objectives

- Explore what we know from the research on the impact of grandparents who experience the loss of an infant/grandchild
- Gain knowledge on ways to support extended family members when there is a perinatal loss in their family.
- Identify models of in-person and internet grandparent bereavement support groups

Stating the Obvious

- We are aware of many different spiritual, ethic and individual traditions around loss.
- It is the responsibility of staff to assess where each person is in their beliefs. These principles may fit many but we need to consider the individual as you care for families.
- This presentation will cover our work where the majority are families with a spiritual belief of a continued bond with a deceased baby

How Many

- 160,000 grandparents experience the death of a grandchild each year
- 34,000 are child and infant death
- 72% under one year of age (Youngblut, Brooten, et al, 2015)
- Currently little information on adult siblings

Experience Multiple Losses

- Loss of grandchild/niece or nephew
- Cannot fix adult child's/siblings pain
- Carry their own grief

What does the literature tell us?

- Is their grief legitimate?
 - Disenfranchised
 - Silenced
- Forgotten by others (O'Leary, et al. 2017)
- Helpless in supporting the bereaved parents
 - Expressing their own grief may be a burden
- Grandparents risk for health issues (Youngblut, et al., 2015)

The Bereaved Parents Perception

- Can feel responsible for their parents
sadness
- May hold back information
- Conflict in grandparents not talking
about the deceased baby

O'Leary, J., Wendland, J., & Parker, L. (2017). Bereaved Parents' Perception of the Grandparents' Reactions After Perinatal Loss and in the Pregnancy That Follows. *Journal*

Themes Discussed in Groups

- Hearing the news
- Boundaries
- Keeping the memory alive
- Finding support for self
- Coping with milestones
- Changed Relationship

What do Bereaved Parents Want

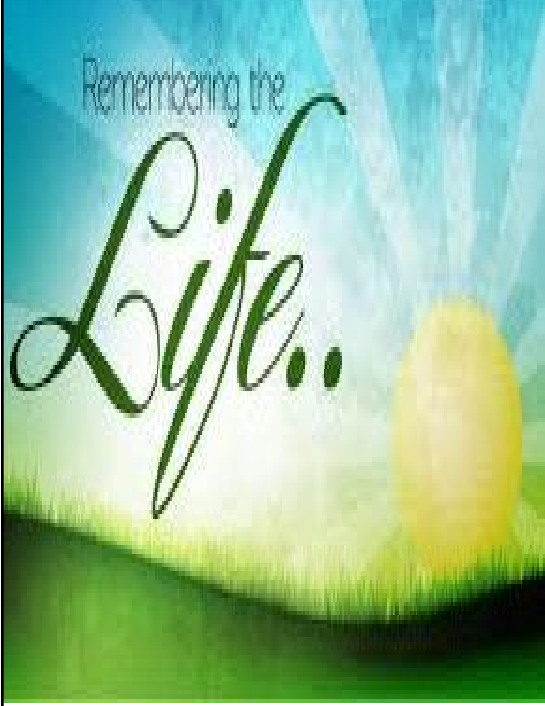
- Acknowledge the deceased child as part of the family
- Keep pictures of deceased child visible in the home just as other grandchildren
- Appreciate the deceased child as a continued family member **in the pregnancy that follows**

Strategies to Help without Burdening Parent

- Identify resources
- Handouts at hospital
- Grandparent support group
- Self care

One Grandfather's Quote

**“You may feel helpless but you're not
hopeless”**



Remembering the
Life..

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- Lighting a candle at family gatherings
- Memorial walks
- Donations:
 - Toys for Tots
 - Volunteering at Ronald McDonald
- Starting a non-profit
 - To help pay medical expenses
 - To help pay mortgage

References

- Carlson, R. (2012). Helping families create keepsakes. *International Journal of Childbirth Education*, 27(2): 86–91.
- Côté –Arsenault, D. (2013). Focus groups. *Routledge International Handbook of Qualitative Research*, 307-318. Alington, Oxon UK: Routledge.
- De Montigny, F., Verdon, C. & McGrath, K. (2015). Perinatal Death and Grief in Canada. In : Caccitore, J. & De Frain, (pp. 179-208.
- O’Leary, Parker, & Wimmer, (2017). Bereaved Grandparents: We didn’t know our Part. *Journal of Community Medicine & Public Health C*
- O’Leary, J., Warland, J., & Parker, L. (2011). Bereaved Parents’ Perception of the Grandparents’ Reactions After Perinatal Loss and in the Pregnancy That Follows. *Journal of Family Nursing*, 17(3), 330-356. DOI [10.1177/1074840711414908](https://doi.org/10.1177/1074840711414908)
- Youngblut, J., Brooten, D., Cantwell, GP, del Moral, t. & Totapally, B. (2013). Parent health and functioning 13 months after infant or child NICU/PICU death. *Pediatrics*, 132(5), e1295-e1301. doi:10.1542/eds.2013-1194.
- Youngblut, J., Brooten, D., Blais, K., Kilgore, C. & Yoo, C. (2015). Health and functioning in Grandparents after a young grandchild’s death. *Journal of Community Health*. 40:956-966. doi 10.1007/s109000-015-0018-0
- Resources for Grandparents
- <https://www.compassionatefriends.org/product/the-grief-of-grandparents/>
- http://griefwords.com/index.cgi?action=page&page=articles%2Fhelping16.html&site_id=7
- http://www.healingheart.net/articles/grandparents_grief.html
- <http://www.northsidepnl.com/grandparents-and-grief.html>