



## Why, Where & How Perinatal Loss Parents Grieve Online

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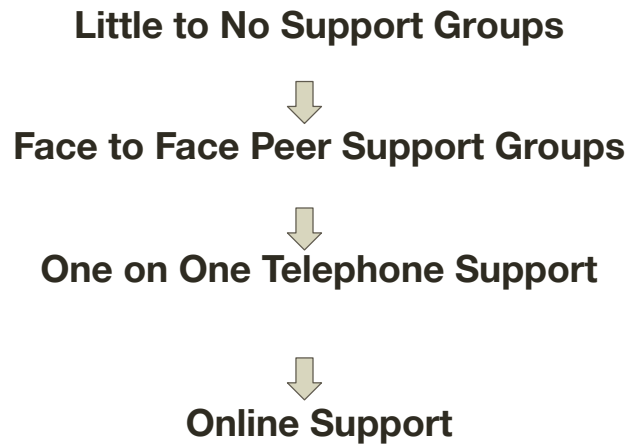
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# The Evolution of Group & Online Perinatal Support Over 35 Years

Carlson, R., Lammert, C. and O'leary, J. M. (2012)



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*“The telephone  
can’t reach the  
deceased but the  
internet can.”*

*~ unknown*

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9 in 10 Americans use the internet (Pew Research Center)



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Technology



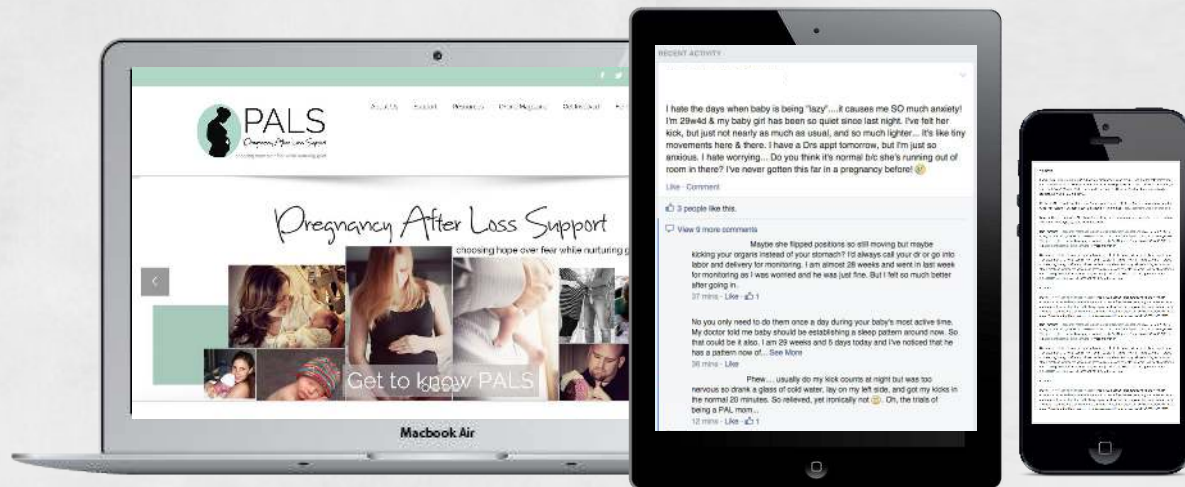
Thanatology



Thanatechnology

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# Who Grieves Online



Pregnancy After Loss Support

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## Who Grieves Online (Varga 2018)

### No Internet Use:

- Grief is private
- Not in need of support
- Disrespectful



### Limited Internet Use:

- Grief online use okay in moderation
- Access memorials and remembrance sites
- Private groups
- Posts on special dates
- Lurkers (people who read but do not post) (Pector, Hsuing, Van Uden-Kraan)

### Vast Internet Use:

- Acceptable to grieve online find it supportive
- Death announcements
- Grief and mourning tasks completed here
- Continued bonds - talking directly to deceased



## Perinatal Loss Parents Who Grieve Online

- Women
  - White (concerning due to African American women are twice as likely to experience pregnancy loss)
  - Well-Educated
  - Have Insurance
  - Mothers more than Fathers
- (Pector 2012 & Gold, Normandin, Boggs 2016)



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## Where Perinatal Loss Parents Grieve Online



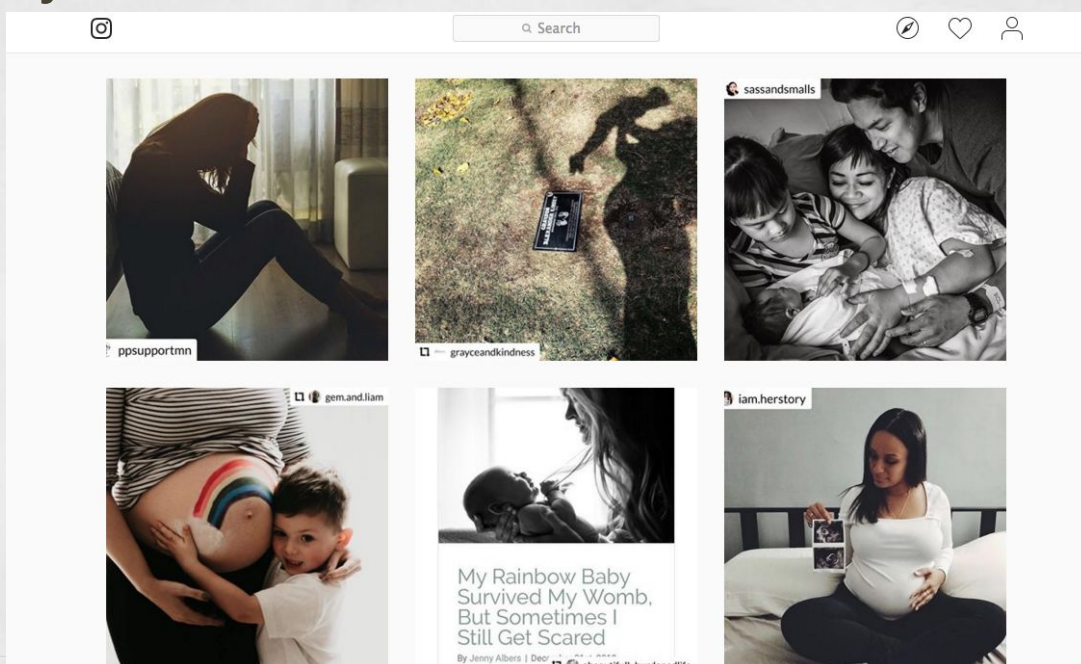
# Where Grieving Happens Online

- **Static Content** (Varga, 2018)
  - Information (websites)
    - ex: Still Standing Magazine
- **Synchronous Support**
  - Online & Offline (real time)
    - ex: Star Legacy Foundation virtual groups
- **Asynchronous Support**
  - Forums, Memorial Sites, Blogs, & Social Media (24/7)
    - Twitter #babylosshour
    - Instagram #lhadamiscarriage
    - Facebook - Pregnancy After Loss Support
    - Apps - S.O.B.B.S.
    - African American Loss Mom Specific - Sisters In Loss



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## Why Perinatal Loss Parents Grieve Online



Pregnancy After Loss Support

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# Why Grieve Online

## All Types of Grievors

- Seek Information & Support
- Express Emotions
- Engage in Grief Work & Mourning Tasks (Worden)
- Continuing Bonds with Deceased (Varga 2018)



*“Online world provides a place of others who validate, normalize, and provide a place where grief is accepted.” (Varga 2018)*

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## Continued Bonds Online for Bereaved Parents

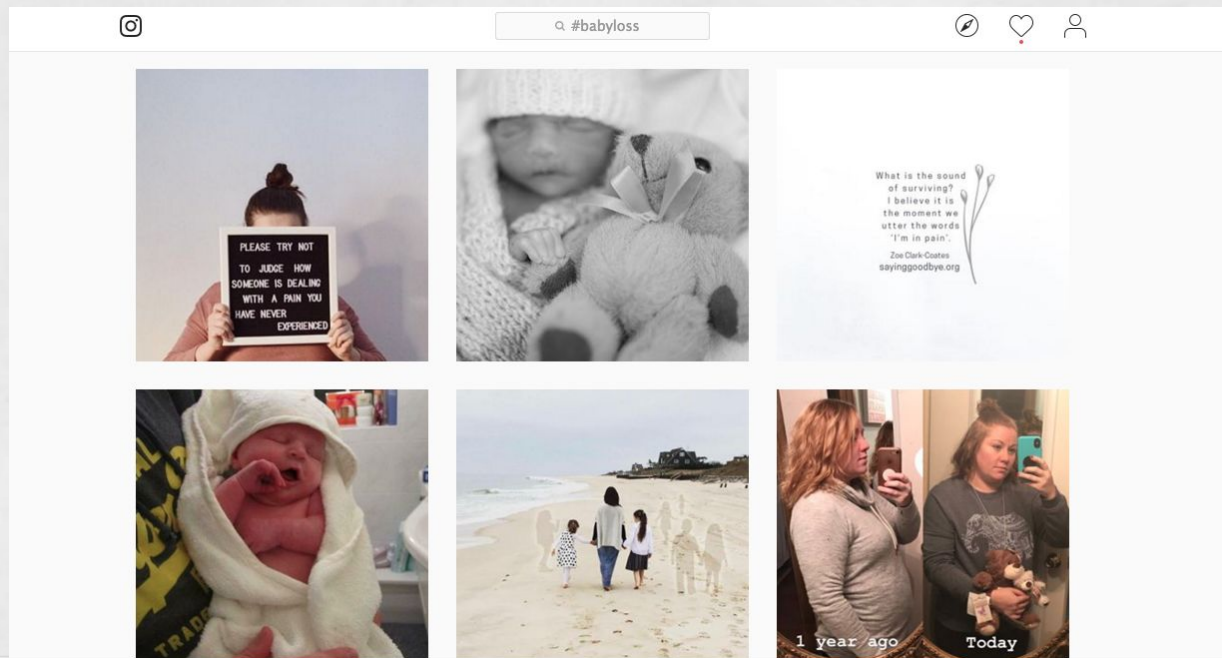
- Sharing Memories of Deceased
- Speak Directly to the Deceased (Varga 2018)
- Declaring Identity:
  - As a Parent (Capitulo 2004)
  - Completing Parenting Roles/Tasks
  - Making New Memories with Deceased



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# How Perinatal Loss Parents Grieve Online






Pregnancy After Loss Support

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## Asynchronous Support

### Symbols:

-  - Angel baby or baby that died
-  - Rainbow baby or baby born after
-  - Sunshine baby or baby born before

### Hashtags:

#stillbirth, #miscarriage, #infantloss, #babyloss, #stillborn, #SIDS, #TFMR, #bereavement, #lifeafterloss, #pregnancyloss, #1in4, #griefjourney, #StillbornStillLoved, #Ihadamiscarriage, #rainbowbaby, #pregnancyafterloss

### Sharing Memories & Emotions:

Photos, stories, momentos, helping others

## How

- Instagram
- Facebook
- Twitter
- Personal Blogs
- Collective Websites
- Memorial Sites
- Apps
- Virtual Groups
- Online Grief Courses
- TalkSpace





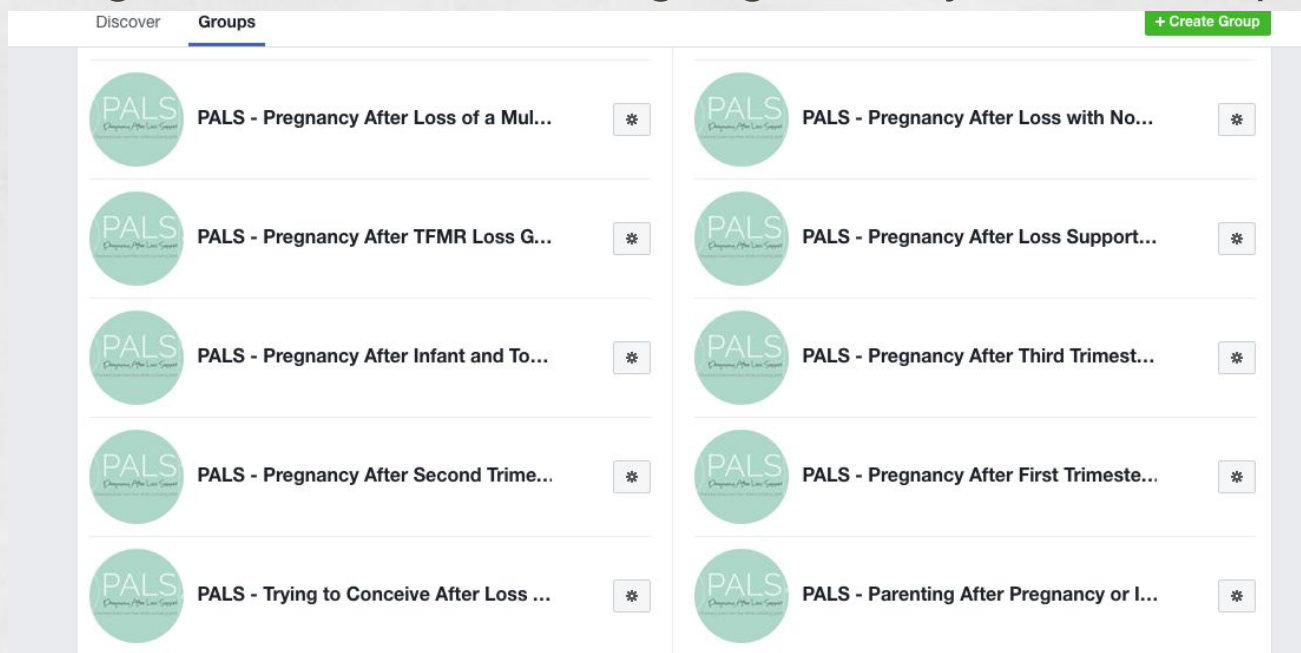
## Synchronous Support (real time)

- \*Facilitated same as if it was in-person
- \*See faces for emotional impact on others
- \*Everyone gets a chance to talk
- \*Sometimes others in background dad, sibling, grandparent



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## Signs of a Well Functioning High Quality Online Group



# Signs of a Good Online Group

Non-judgemental

Active

Caring with a sense of community & helpful support from multiple participants

Moderators

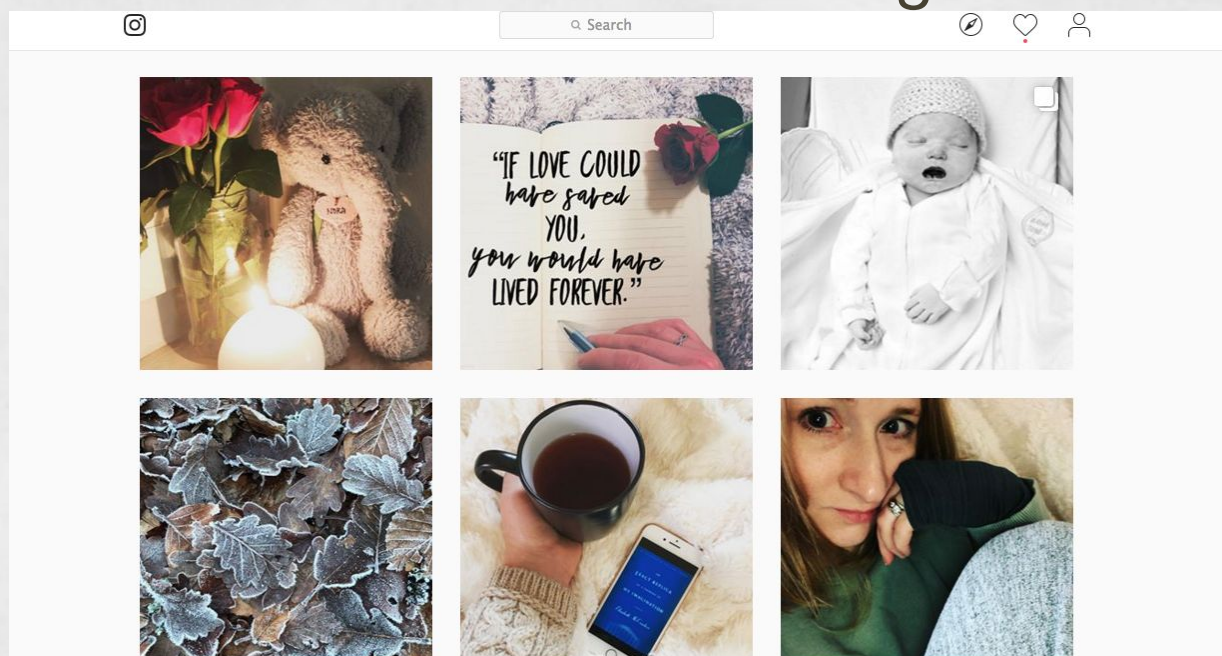
Stable core membership (Pector 2012)

Loss specific (Varga 2018)



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## Benefits & Risks of Grieving Online



## Benefits

Increase access to support  
Increased access to shared experiences  
Increases to validate experiences (Varga 2018)



Remedy for disenfranchised grief (Pector 2012)

Empower members to access info  
Convenient

## Risks

Safety  
Lack of site control (varies)  
Online social norms  
Knowledge where to find support (Varga 2018)

Misinterpretation


Anger


Fraud

Difficulty to manage crisis

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## Beyond Grief




After Loss Support | About Us | Support | Resources | Online Magazine | Get Involved | For Professionals | 


### Private Support Groups Available

Pregnancy After Loss Support (PALS) moderates 13 private Facebook groups:

- Pregnancy After Loss Support Group
- Trying To Conceive After Loss Support Group
- Parenting After Loss Support Group
- Pregnancy After Loss Support Group for Dads
- Pregnancy After First Trimester Loss
- Pregnancy After Second Trimester Loss
- Pregnancy After Third Trimester Loss
- Pregnancy After Infant and Child Death
- Pregnancy After TFMR Support Group – You must apply to join
- Pregnancy After Loss with No Living Children
- Pregnancy After Loss of a Multiple
- Pregnancy After Loss Family Support Group – Grandparents, Partners, & Friends
- Pregnancy After Infertility and Loss
- Newly Bereaved



### Rainbow Babies



Hudson David, October 16, 2013

SUBMIT YOUR RAINBOW

These groups are peer-to-peer support and have moderators (meet the moderators).





# Pregnancy After Loss & Parenting After Loss

Evolution of loss groups (Carlson, Lammert, O'Leary 2012)

“The Majority of today’s parents search for birth information and social support on the internet.” (Plantin, Darebrak 2009)



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## Online vs. In-Person Support





# Online vs. In-Person Support in Perinatal Loss

- No difference in outcome or those who participate (Gold, Normandin, Boggs 2016)
- Psychological benefits over measurable change in grief process citing Yalom: (Pector 2012)
  - Major Therapeutic Factors Operative in Groups
    - Universality
    - Cohesiveness
    - Catharsis
    - Interpersonal Learning
    - Helping Others

These factors occur as effectively online as in face-to-face settings  
(Pector and Hsiung 2011)

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## Current Resources

- [Resolve.org](https://www.resolve.org)
- [Starlegacyfoundation.org](https://www.starlegacyfoundation.org)
- [Pregnancyafterlosssupport.com](https://www.pregnancyafterlosssupport.com)
- [Missfoundation.org](https://www.missfoundation.org)
- [Stillstandingmag.com](https://www.stillstandingmag.com)
- [Firstcandle.org](https://www.firstcandle.org)
- [Compassionatefriends.org](https://www.compassionatefriends.org)
- [Sands.org.uk](https://www.sands.org.uk)
- [Petals.org](https://www.petals.org)
- [Storiesofbabiesbornstill.org](https://www.storiesofbabiesbornstill.org) - App PARI-P
- [Ericammcafee.com/community](https://www.ericammcafee.com/community) - Sisters In Loss

- [#Ihadamiscarriage](https://twitter.com/#!/hadamiscarriage)
- [@Ihadamiscarriage](https://twitter.com/#!/hadamiscarriage)
- [#Babylosshour](https://twitter.com/#!/hadamiscarriage)





Thanks!

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“Grief must be witnessed to be  
healed.” ~ Elisabeth Kubler-Ross

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