



international
stillbirth alliance

ISA

Peer Support Guidance

January 2025

Purpose and Intended Audience

This document was created by parent members of ISA who requested informal guidance in helping other parents, their peers through the grief journey of perinatal bereavement. Although intended for peer support, anyone who wants to support parents may find this informal document to be useful.

Writers and reviewers of the document

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What is peer support?

- People with similar backgrounds, such as bereaved parents who have experienced stillbirth, providing emotional, social or practical support to each other.
- Understanding another's situation empathetically through the shared experience of emotional and psychological pain. An example might be "It sounds like you did everything that you could."
- Shown to have a positive impact upon a bereaved parent's sense of isolation, reduce grief symptoms, and promote greater personal growth and hope.

The peer support role is valuable and one of the most important parts of the role is being able to *Hold Space* for others in allowing them to grieve in the way they need to grieve. One should not try to fix or minimize the other person's feelings by changing the topic when feeling uncomfortable or by offering advice. When wanting to share information or advice, ask yourself the following questions: What purpose will this serve? Whose benefit is this for? Am I being alongside or trying to lead? An example of trying to fix another person might be a statement like "You can always have another baby" or "I felt better a few months after my baby died and I am sure that you will too."



What is grief?

- Grief can be described as one's reaction to different types of loss.
- Grief is an experience that we all know in varying degrees and will certainly know over our lifetimes.
- Grief is a normal human response to loss and is very different for each person.

Grief is as unique as the fingerprint
of the loved one that you lose



As they touch and then leave their unique
imprint on your soul

How does grief affect us?

Feelings: Feelings of shock, denial, disbelief, numbness, overwhelming sadness, anger, loneliness, and guilt are all commonly expressed by grieving people. These feelings may develop at any time and may occur in any order. A number of professionals, like Dr. Kubler-Ross, describe feelings of grief that can include shock, denial, anger, bargaining, depression, testing and acceptance.



Thoughts: Thoughts can include “this can’t be real”, “this is a bad dream that I’ll wake up from”, “why and how could this be happening to me”, “what did I do wrong?”

Physical bodies: Feelings of fatigue, decreased appetite, disrupted sleep, impaired concentration, suppressed immune system, and an inability to relax are common complaints of people who are grieving.

Responses: Responses such as crying, screaming, rejecting, hyperactivity, apathy, and substance abuse may be displayed by grieving people.

What are some of the tasks for bereaved parents?

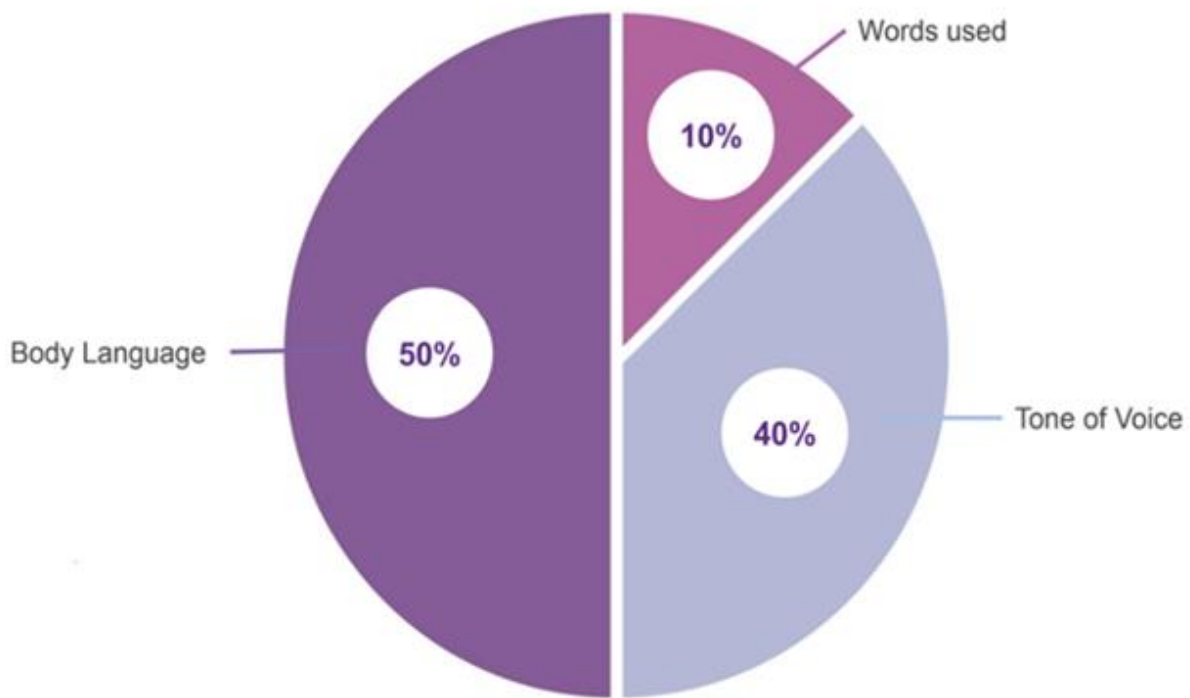
- Accepting the reality of the loss.
- Processing grief related to the loss such as through allowing others to share the grief and being with others who grieve.
- Meaning Making when the world you expected to have has been shattered. Parents may need to incorporate this grief and loss into their lives in different ways. Some may need to understand why this happened in order to find meaning in the loss or accept it.
- Figuring out how to be in the world without their baby; asking themselves, “Who am I now? How has our future changed? What do we do now?” Mothers may not understand why they are not being cared for as they would have been had their baby lived.
- Remembering their baby or child and integrating the baby into their lives in a way that pleases them. Some families honor their baby by doing acts of kindness while others celebrate their baby’s memory on the anniversary of death or anniversary each year.

Communicating with grieving families

Effective Communication

Body Language and Tone: A very large part of communication is attributed to body language so when we are providing support over the phone and can’t see the person, we must listen intently and be fully present. We have to be mindful of tone, both the tone of the bereaved person and our own tone, because whatever the *content* of the things we say, our tone communicates what we’re feeling when we speak. Mirroring the bereaved person’s tone helps in building rapport.

Words: In providing peer support, it is best practice to match the terminology of the bereaved person. If they use the term pregnancy loss instead of miscarriage, we would use the term pregnancy loss. If they use the word partner instead of husband or wife, we would use the word partner. This is the bereaved person's story. They are navigating and making sense of the loss in the way that they are experiencing it.



What are Key Components of Peer Support?

Creating a safe space means creating an environment where parents feel safe to express their emotions, thoughts, and pain without fear of judgment or pressure. Is the bereaved person able to share and explore what they are experiencing and express their feelings?

Active listening is listening without judgment or the urge to “fix” things.

- Invitations to speak such as: 'it's okay, take your time' or 'I'm here'



- Use silence; let the grieving parent pause and wait for them to continue. It is not about filling every painful moment with words.
- Normalize their feelings. Remind them that it is okay to feel whatever they are feeling.
- Use short phrases such as: “uh huh”, “hmm”, “oh ok” or “tell me more”.
- Do not ask questions unless necessary; listen and let the grieving person tell their story. Let them lead the conversation and do not push them to share more than they are comfortable with. Sit with them even when expressing strong emotion.

Barriers to active listening

- Comparing: Comparing the bereaved parent’s story to your own or others you have heard.
- Mindreading: You are too busy jumping to conclusions and pre-empting what will be said next.
- Rehearsing: You are busy worrying/thinking about how you are going to respond
- Impressing: Wanting to impress with how much we know on a grief topic.
- Judging: Pre-judging (prejudice) or stereotyping stops us from fully listening because we believe we already know what they will say.
- Dreaming/Identifying: Something triggers a memory within your own loss/life.
- Derailing: You may feel uncomfortable with a particular topic, so you suddenly change the subject topic.
- Placating: Any response that starts with “at least” will be placating and dismissive to the person you are supporting.
- Advising: You offer a suggestion of how you believe the bereaved person can resolve their pain or make a decision.

Empathy, not sympathy is putting oneself in another’s shoes without comparing or diminishing their experience. Peer supporters should avoid phrases like “At least....” or “You should...” .

Helpful phrases you can use:

- “I am so sad that you are experiencing this heartbreak; this must be devastating for you.”



“

- Sounds like it has been so tough for you”
- “If I’m hearing you correctly...”
- “Let me summarize what I’ve heard you share with me today...””

Follow versus lead

- Being alongside and receiving the other. Be still.
- Share your experience; do not rescue, have an agenda, or be an expert
- Learn from others, do not teach them, except by example
- Bear witness to another’s struggles without directing them
- Respecting another person’s confusion and not imposing our own logic or values

Values

Our values inherently shape our world view and our interactions with others

It is not possible to be completely objective and value free

BUT

Peer supporters have an ethical responsibility to ensure they do not impose their values on to the person they are supporting

The ethical code promotes the need for peer supporters to ensure they respect the family’s values and autonomy



Personal boundaries

Personal boundaries are the invisible lines we draw for ourselves in ensuring a separation between what belongs to us and what belongs to others. It is crucial, as you do peer support work, to know that you are going to be hearing stories and experiences that may clearly mirror our own grief experiences or perhaps be hugely different and challenging. It is essential to understand what is ours versus what is theirs to ensure our own wellbeing and the wellbeing of the bereaved parent. It ensures we can provide strong, non-judgmental and inclusive support and importantly, that we can then separate from the grief and stories shared when the support ends. Sometimes our boundaries become blurred and we may feel we have over-shared or perhaps that we've struggled to avoid judgment. These are the times you need to debrief with someone and get support for yourself.

Self-care

Loss is a profound experience and supporting grieving families can trigger our own feelings of loss. Take a step back if needed to support yourself. Providing support is emotionally draining; please know that tears are ok when supporting a grieving family. It is good practice to seek support from others and also recognize the impact of your work. Journaling, mindfulness practices, and sharing your story with other peer supporters may be helpful.

Self-care means:

- Being mindful of your boundaries
- Maintaining good physical health and using relaxation techniques
- Engaging in enjoyable activities that are personally rewarding
- Catching up with friends and family
- Having a sense of humor and self-compassion.



Recognizing Red Flags

Be equipped to recognize when someone might need professional help, such as in cases of prolonged or complicated grief, severe depression, or suicidal thoughts. Have a suicide line available for referral, as well as a therapist that you can recommend.

International suicide hotlines: <https://blog.opencounseling.com/suicide-hotlines/>

Resources

ISA parent advocacy toolkit

<https://www.stillbirthalliance.org/parent-voices-initiative/advocacy-toolkits/>

Global Guide

<https://www.stillbirthalliance.org/global-advocacy-and-implementation-guide/>

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