

# Compassionate Care: Social Workers Navigate Baby Loss with Parents

by Michelle Valiukenas, J.D.

**PAIL (Pregnancy and Infant Loss) Awareness Advocate, Founder and Executive Director, The Colette Louise Tisdahl Foundation,**

**Mom to angel babies Sweet Pea and Colette Louise, and rainbow baby Elliott Miguel**

In a society that does not like to talk about death or grief, the loss of a baby is particularly uncomfortable for us to handle. Parents who have lost a baby, whether during pregnancy, at birth, or within the first year of their child's life find themselves lost, confused, isolated, and shunned from society.

For generations, these losses happened but were hidden, with families never mentioning children with the rest of the world and often even within their own families. More recently, parents who have lost a baby are sharing their babies' stories, including them in their families, and making sure all their children, even those who did not survive, are recognized. As a result, practices have changed, but the challenge of how to best support loved ones who have lost still remains. In this article, we will look at the uniqueness of baby loss, from the immediate period before and during the loss, how loss parents experience the world in general and through various stages, highlighting suggestions that social workers and other healthcare workers can put into practice to provide trauma-informed care for loss parents.

## Background: My Story

Before delving into this topic, I would like to briefly share my history with loss and my journey to parenthood. My husband Mark and I struggled to

get pregnant, ultimately leading to a diagnosis of infertility of unknown origin. We tried intrauterine insemination (IUI) for several rounds before proceeding to IVF. I got pregnant on our first round of IVF in April 2017 and everything seemed good until 7 weeks gestational age when I started bleeding. We went into the doctor's office for an ultrasound where we were told that Sweet Pea as we affectionately named our little one was gone — there was no baby, just a gestational sac, and that they expected I would miscarry naturally. I had blood drawn with a phlebotomist that clearly did not know anything about us, bounced in with her Friday afternoon energy and asked about our weekend plans. I returned Tuesday to draw more blood, finding elevated levels. On Wednesday, at an ultrasound to determine if I would need a D&C, they found a heartbeat and told me to go back to being pregnant. That night, May 17, 2017, after bleeding profusely, I was told in the emergency room that I miscarried, gestational sac included.

We were devastated and the complexity of that loss, especially after infertility, took a toll on us individually and together. We entered couples counseling, something I consider a must for all couples who lose a baby. I wanted to jump right back into things and so at the end of July 2017, we transferred another embryo, this one genetically tested. That transfer failed and we found a new doctor.

A fresh start, our second doctor took much better care of us, and after an egg retrieval and third round of IVF, I was pregnant with our daughter Colette. We made it past the scary first trimester and breathed a sigh of relief, one that unfortunately would not last long. I had long discussions with her, sang her songs, and

although that pregnancy was tough, I was so excited to welcome this little girl into our lives. I had vivid dreams of a young girl with long, blond hair who ran through fields of daisies ahead of me. Even though we did not find out the sex of the baby, I was so sure she was a girl that I refused to choose a boy name.

On May 8, 2018, at 21 weeks pregnant, after a standard OB appointment revealed a blood pressure of 188/110, I was hospitalized with severe preeclampsia and told I would stay in the hospital until I delivered, with my due date being September 7. From one minute to the next, our world turned upside down and my primary job became keeping Colette inside as long as possible. Just over three weeks later, a repeat ultrasound led to doctors' recommendation to deliver because there were now more interventions they could do on the outside. So, on May 23, 2018, at just 24 weeks and 5 days, via emergency CC-section, Colette Louise Tisdahl entered the world, at just barely over a pound, and immediately emitted a tiny, but powerful squeak, defying all that we had been told about being too tiny to make noise.

Colette was whisked off to NICU, to her first and later, only home, where she valiantly fought for nine days, before that spirit that defied odds grew bigger than her tiny body could contain and she gained her angel wings on May 31, 2018. Losing a child completely changed my life in so many countless ways, a lot of which I will dive into deeper throughout this article, but I will say that it is the most isolating experience I have ever had.

Unique in baby loss and the accompanying grief is that while we were grieving, we still very much wanted to have a baby at home and given that I was already over 35, there was no time to wait. But, when it came to



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getting answers and solutions, there were no magic potions, elixirs, or medical causes that could guarantee or even begin to explain why. We were told that there was no reason why we couldn't have a baby that came home, but also that there was no cause they could identify, let alone a plan that would ensure a baby coming home. So, we tried again, first naturally, and then another round of IVF. March 19, 2019 was the day we found out that the transfer had failed and as I stood in the kitchen hugging my crying husband, I realized how relieved I felt. I had that feeling and the accompanying guilt for several weeks, afraid to say it aloud, taking time to do research and think. Finally, I admitted to my husband that I was absolutely terrified of being pregnant and that I wanted to look into surrogacy.

After we both did our research, we decided using a gestational carrier was our best chance of bringing a baby home. Our agency found an incredible woman who got pregnant on the first transfer. We were so excited! Then, just a few days after finding out, the loss of carrying our child coupled with memories of being pregnant with Colette hit me full force and I sobbed, telling my partner that we made a mistake. I feared not having a connection with our baby, that he would resent me, and that I had failed. Our agency was great and connected me with a mom whose baby was born via gestational carrier. Our phone call lasted about two hours and I hung up feeling so much better. I still struggled with the guilt,

self-doubt, and self-blame throughout the pregnancy. But, our gestational carrier was amazing and carried our "LL Cool T," until his arrival on July 14, 2020. About two seconds after he was handed to me, all the worries about bonding went away. I instantly felt like he was mine and that first night in the hospital, I barely slept, watching in awe as he slept. We took him home just two days later and he remains the amazing little man that he is today.

We do not know what type of parents we would have been without our experiences of loss, but I can tell you that our losses of Colette and Sweet Pea affect our parenting and our world every day. I will also say that I have learned a lot throughout this journey and in parenting all three of our kids. I would not have known how to handle these situations before, but experience and knowledge has taught me so much.

That is a point I want you to take from this article. We are human and we will make mistakes, and say or do the wrong thing, but it is how we handle that mistake that matters. A few years ago, I came up with the idea that every time something hurtful or triggering is said to me, I will throw a general I'm sorry out into the universe just in case I ever did or said something harmful before I knew better. So, please do not take anything in this article personally or feel like you failed as a parent. In the words of Maya Angelou, "Do the best you can until you know better. Then, when you know better, do better."

Let us work on knowing and doing better.

### **General terms Definitions [there are no definitions for types of loss, definitions below for other terms]**

To get us on the same page, these are the definitions and terms that will be used throughout the article. The general terms of loss, perinatal loss, pregnancy loss, or baby loss will refer to one of the following types of loss:

- Miscarriage
- Ectopic pregnancy
- Chemical pregnancy
- Other pregnancy losses, such as molar pregnancies
- Termination for medical reasons (TFMR)
- Selective reduction in cases of multiples
- Stillbirth
- Neonatal death
- Infant death
- Sudden Infant Death Syndrome (SIDS)

"Loss parent", or "loss mom/dad", is the term that will be used to be inclusive and encompass the spectrum of baby loss, as well as parents who have experienced multiple losses. The term "loss parent", encompasses the breadth of these experiences, emotions, and stages of grief.

"Rainbow" and "rainbow baby" are terms that have come to be widely used to refer to children born after loss, to signify that the baby represents light and hope after a dark time. While I love this term and use it all the time, some loss parents do not use it for various reasons. So while I will use the term within this article, please remember when talking to loss parents to let them lead with the terms they most prefer and use those in turn.

Similarly, I use the term "angel baby" because that feels right to me and my journey, and because I lack a better term. However, not everyone believes in a heaven or in angels so it may not work for some loss parents.

### **Statistics**

In the U.S., about 1 in 4 pregnancies ends in miscarriage and about 1 in

160 pregnancies results in a stillbirth. (Henke, 2020). The Centers for Disease Control and Prevention (CDC) reports that the infant mortality rate is 5.6 deaths per 1,000 live births, with the neonatal death rate accounting for 3.58 of the deaths and post-neonatal rate accounting for the remaining 2.02 deaths. (Ely & Driscoll, 2023)

Of women who experience a loss, about 50 to 80% will get pregnant again within 12 to 18 months. (Henke, 2020). This means that loss parents are not only experiencing the loss at the time and the immediacy, but will have to face another pregnancy filled with triggers with very little time to properly grieve and process.

### Before and During the Loss

This stage is when we first encounter loss parents, who have received terrible news, whether it be that a heartbeat has stopped, that a diagnosis has been given, or a change in outcomes expected. Experiences vary from parent to parent, dependent on personality, support system, and experience, but there are "intense emotions, being in a state of shock, and feeling as if the world had collapsed around them." (Berry, 2022).

The experience that parents have with healthcare professionals during this time is key to their grieving process. Berry highlights that interactions that were classified as "cold and clinically detached" had a negative effect. (Berry, 2022). These cold, clinical approaches often come about when policies and procedures dictate professional behavior and individual providers do not feel equipped to either stray from the policies or to address them straight on and provide context to parents and families.

One loss parent describes how before her D&C procedure, she was required to take a pregnancy test and decide what she wanted to do with remains. "I was an emotional wreck after reading that because no one prepared me and I felt like I should have put more thought into it. I had awful nightmares after because of this question and just wish I would have known." (M.L., personal communica-



tion, March 2023). Informing parents of the decisions they will have to make and providing information and support would have made an already traumatic and tenuous situation less traumatic.

Conversely, healthcare workers "who were supportive, guided parents through the decision-making process, and discussed the potential consequences of each decision" had a positive effect on parents' overall experience (Berry, 2022).

One loss parent describes her positive experience when a nurse gave her photos, handprints, footprints, and the blanket her son was wrapped in for photos: "She [nurse] said 'I am so sorry that you didn't get to spend time with your baby. I know this is not the same thing, but here is what I have for you.'...To this day, I cherish those few things I have.'" (K.N., personal communication, March 27, 2023).

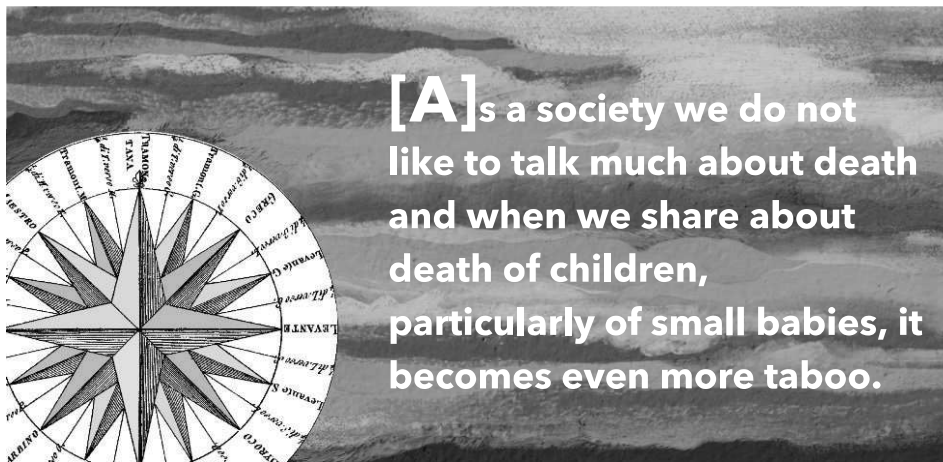
During this time, it is key to focus on words used, on being honest, not mincing words, but also in a kind and thoughtful way. Parents typically want a balance of direct words, not euphemisms, but not in a cold, sterile manner. In the moment, the focus is on letting parents feel what they are feeling without judgment or shame, to give them as much time as possible, to avoid platitudes, and most importantly, to follow parents' leads.

If this is not their first loss and if they have gone through struggles such as infertility, special attention should be given because they may feel

completely helpless at this point, dealing with an intense, compound grief. Use the terms "parent", "mom", or "dad" with them because they are parents, regardless of whether they have living children. Be honest, empathetic, and kind. They may have heard platitudes previously so it is even more important to avoid those.

While restrictions on visitors makes sense, especially in a post-Covid world, allowing for exceptions during the loss has huge benefits in the grieving process. The American Academy of Pediatrics sets forth this as a recommendation as well. "The family may benefit from a private space and additional time to remain with their child and welcome loved ones (such as siblings or grandparents) after the death." (Weaver et al., 2023)

Another best practice when working in a team of providers is the consistency from provider to provider with each family. If one provider offers help or support, that offer should be documented and other providers should comply. When loss parents are going through this and have to work with different providers, if the message is not consistent, they feel lost adding to the isolation. As one loss parent shared, "One social worker told me over the phone that they had a relationship with a funeral home that could cremate our baby's remains, and that her office could provide the necessary form to arrange it. When I was at the hospital to begin the procedure, her colleague told me that they no longer provided the form, but all I'd have to do was call



the funeral home." (E.B., personal communication, March 2023)

As the loss parent moves towards discharge or the end of the official relationship with you, it is key to provide useful resources for funeral and memorial plans, if applicable. No parent ever intends to plan a funeral for their child and offering connections to area funeral homes helps a parent navigate decisions they never expected to make. Merely going through formalities of discharge without any guidance is unacceptable as one loss mom detailed her experience. "She [nurse] said, 'In the folder is a list of funeral homes you can call to see if there are support groups or something for you.' Well, none of them really had anything to help me navigate these untraveled waters. I cried day and night, every day, all day long. I had nowhere to turn. I called a few places, a few churches, a few funeral homes. No one had any information for me. They didn't know where to tell me to turn to for help." Rather than sending loss parents out with little to no resources or places to turn, taking time to plan, offer resources, and support is immensely helpful to loss parents.

Also, provide resources for therapy and support groups, and any other resources available in your area. Do not leave loss parents with nowhere to turn, like in the case of one loss parent who wanted to find a support group and was given no resources and was forced to call the hospital herself: "They transferred me to the NICU. I could hear babies in the background and no one knew what I was talking about or how to help me." (D.A., per-

sonal communication, March 2023)

Communications should also include a reminder to parents that you are there for them if and when they need additional help and then a follow through on that promise. Providing a list of resources is not enough. Loss parents describe having to call a bunch of places and being rerouted; others say resources may be out-of-date and not accepting new patients or clients, or in cases of support groups, no longer meeting.

#### Few Weeks to Few Months after Loss

For early pregnancy losses, there often is not a memorial or a ritual available for the baby. "Generally, the possibility of saying goodbye after the loss of a significant person is assumed to have a positive impact on the bereaved person." (Kersting & Wagner, 2012) Not being able to have any sort of goodbye "may complicate the grieving process and increase a sense of isolation for the parents." (Kersting & Wagner, 2012)

For those who had a baby who lived for a short time as well as those who delivered stillbirths, they may choose to have a memorial or funeral service. These are events that most people know how to show up and, for the most part, what to say.

For those who experienced the loss early in the pregnancy or when some time has elapsed after a memorial service and people stop showing up, there can be a sense of isolation and loneliness for parents. It is important for there to be a continual presence of supportive family and friends. As one

mother shared in a study, "Be there when the person needs you even if you can't bring back that person that died. Just let them know that you are there for them." (Kavanaugh et al., 2004)

For healthcare providers, showing up even after your relationship has ended has a huge impact on parents. "Numerous studies pointed out that healthcare professionals' attitudes and communication skills, when adequate, might positively impact parents' decision-making, resilience, and long term well-being. Conversely, inadequate care might exacerbate an already difficult grief, hindering the parents' process of healing." (Gandino, 2019).

On a positive note, I still remember my daughter's NICU nurse who sent a beautiful card in memory of Colette as well as an acknowledgment of my husband and I being the very best parents we could have been. The simple card has an incredible impact on a family struggling with grief, shame, self-blame, anger, just to name a few emotions.

Your team should look at how they could send cards and/or make phone calls to just check in, to say that you are thinking of them and their baby. Using a baby's name or nickname, if you know it, is also very helpful for loss parents. One loss parent describes the impact she felt after loss: "About a week after my procedure, I got a sympathy card in the mail from the nurse and the team at the hospital. I'm not sure anyone has ever acknowledged both me and my angel babies so completely ... Never did I expect to be treated with such care and understanding. Forever grateful for that glimmer of light in a really dark time." (K.A., personal communication, March 2023)

Reaching out combats feelings of being left behind and alone. "The absence of social support and follow-up care required parents to actively seek help following their loss, which contributed to feelings of being alone and abandoned and often prevented parents from receiving the psychological support they needed." The reach out with a specific ask about what a parent may need and offering recommendations allows the loss parent to be vulnerable, to think through what

it is that they are feeling, and what support they may need goes a long way for the parent's emotional journey. If a loss parent asks for or accepts the offer of counseling, support groups, or other resources, it is important to do the work ahead of time to offer warm handoffs instead of merely packets of information with resources that may be out-of-date, places to call with no connection, or the worst, no help at all.

Further, it is important to address on a global scale, but also with individual families, what steps could be taken to avoid triggers. Some loss parents shared that they would still get reminders from the hospital to register for delivery or of upcoming appointments. Other loss parents commented that reminders of where they should be in a pregnancy or with a newborn from outside apps are hurtful to receive. For healthcare providers, it is key to avoid the possible triggers within the healthcare system such as the reminders and, when possible, to offer help with the outside systems.

Some ideas for things to think about as a team to best support loss parents:

1. Could you put into practice a system-wide update that automatically removes reminders of a due date and/or upcoming OB appointments from the patient portal when a loss occurs?

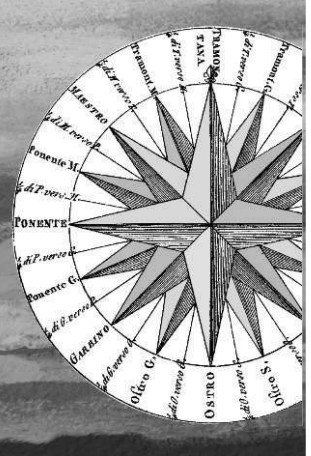
2. If the automatic removal is not possible, can a member of your team offer to take the steps on parents' behalf to remove these triggers from the system?

3. Could you offer to call a company or do some research as to how to stop alerts from an app related to pregnancy, a baby registry, or other similar resources?

Loss parents often felt like the connection to other loss parents was particularly helpful. "Sharing grief with another bereaved parent was always seen by the parents as positive. Parents appreciated the care, understanding, and advice that was given to them by someone who had had a similar experience." (Kavanaugh et al., 2004) Consider providing links and resources to other parents who have experienced loss.

One of the best examples of this

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practices that I have seen comes from Sue Villa, a nurse at Endeavor Health in Illinois. She and her team create baskets full of comfort items that are given to loss parents as they leave the hospital. One of the best additions to these baskets are notes written by parents who have previously experienced loss. The loss parent has something tangible to read and reference if they want and they leave already a little less isolated because someone else has experienced a similar loss.

### What Life Is Like for Loss Parents

It is at this point that I want to provide context to the world that loss parents navigate. First, a loss parent has to live their lives in a manner that is against all that we learn about the circle of life. "The process of living with the grief of losing a child has been described by bereaved families as learning to live with an empty seat at the table and a hole in the heart." (Weaver et al., 2023)

Secondly, as a society, we do not like to talk much about death and when we share about death of children, particularly of small babies, it becomes even more taboo. Loss parents often are given the message of "don't talk about that," or "it's time to move on." However, all the research tells us that this is very much not the case. "Family members cannot be expected to 'move on' or 'get over' the death of a child; instead, families benefit from receiving compassionate and comprehensive support as they attempt to adjust to the physical absence of their child while

maintaining a sense of continued connection." (Weaver et al., 2023)

Furthermore, the world around them does not know how to navigate and deal with a parent going through the grieving process. Loss parents often feel like they are told how they should be feeling rather than others meeting them where they are at. "Women were told that they should be grateful for their surviving children or that they could try to have more children. Men's feelings were often discounted, and they were told to be supportive and strong for their wives." (Kavanaugh et al., 2004).

These constant messages — that it is not okay to grieve, that their loss was not the major loss they feel it was and continues to be, that it is time for closure and 'moving on' — add to the enormous isolation, guilt, self-doubt, and self-blame that loss parents feel. One study talks about how parents would recount the often strange behavior of their loved ones to them, "such as being avoided, or experiencing sudden silence when they entered a room in which family and friends were conversing." (Kavanaugh et al., 2004).

The unique nature of baby loss means that parents themselves, much less the rest of the world have little to no concrete memories to share. Unlike adults who have lost loved ones and can engage in storytelling, laughter and tears ("Do you remember when?") loss parents rarely have any of those memories and when they do, they are very limited. This adds to the feeling that you are constantly fighting a world that does not recognize your child. "Parents also

reported that it was difficult when family and friends did not understand or acknowledge their feelings of loss and dismissed their infant's death as insignificant." (Kavanaugh et al., 2004).

Further complicating the battle that loss parents have is that very often, they do go on to try for another child and well-meaning individuals will say things that while intended to be helpful are not actually helpful. Statements like "at least you can get pregnant" or "just try again" or even suggestions such as "try this one thing because it worked for so-and-so" add to the grief, pain, and fear of trying again. "One doctor patted me on the back and said go home and try again. This was after losing three babies to miscarriages." (M.S., personal communication, March 2023)

### Types of people

In an effort to explain the people surrounding a loss parent, I created broad categories to describe what type of interactions a loss parent might have.

- **The Denier** This person does not want to talk about the child, the grief, the experience, and they will make this clear. Loss parents will find that when they encounter this person, it may feel as if their words fall on deaf ears. Deniers typically will get flustered or agitated when the topic arises and will quickly change topics, getting frustrated if it is again brought up.
- **The Martyr** This person makes everything about them, taking on the feelings that are experienced by the loss person. They will blame themselves for asking, for bringing it up, for not "doing the right thing." They will clearly exhibit emotions intensely and may cry outwardly. Often, when encountering this person, loss parents end up comforting them.
- **The Cheerleader** Every stereotype of the bubbly cheerleader comes out in this person, who is the true embodiment of toxic positivity. The cheerleader will say things like "everything happens for a reason" or "God has a plan for us all," putting a positive spin on everything. They also

believe you should feel the same way, so are likely to say things like "you just have to stay positive" or "you should be grateful for."

### Alternative approaches

My recommendation of what to be in place of any of these stereotypes is to "Be a Colette." What does this mean? Let us break this down:

- **C = Comfort, don't fix.** Loss parents become so used to a world that does not want to include their babies who have died that merely including all of their children or acknowledging their loss when warranted goes far. "We're all conditioned to be fixers, offering pep-talk platitudes and tidy solutions when someone we love is hurting — but anyone grieving a loss needs people close to them to bear witness to their pain." (Marisa Renee Lee, 2023). Fear of saying the wrong thing tends to make people freeze or try for platitudes. "I'm sorry" is good, but also name it by saying "I have no words" or "I don't know what to say." There is nothing you can say or do to fix the situation and the honesty of that simple acknowledgment lets loss parents know that you are an open, helpful resource.
- **O = Offer resources and strategies for coping and remembering their baby** As we stated earlier, offering resources to help, such as support groups, therapy (individual, group, and couples) in a warm, easy manner goes a long way. Being able to talk to a loss parent, hear what they really need, and then offer the warm handoff can make all the difference. Forcing parents to just go out and find it on their own leads to parents hitting brick walls, racing all over to get no after no after no, or feeling even more alone. Be aware of possible triggers and help the loss parent navigate those. If the loss occurred in a room in an area that they may need to access again, ask the parent if they would prefer to use that room or not use that room. Would a different doc-

tor or nurse feel better? Maybe the same would be best. Include their losses wherever possible. Mentioning their child's name, remembering if they have a stuffed animal, photos, or flowers, etc. that they use to remember their child, and including that wherever possible goes a long way.

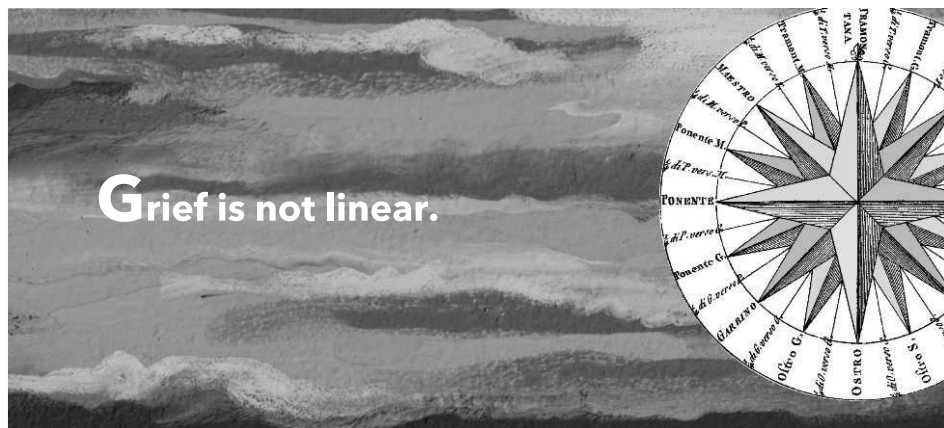
- **L = Listen and let parents lead.** Understand that grief is an evolving journey. The way a loss parent may act, look, or engage may not be what you would expect. Unless there is a concern of immediate risk of harm to themselves or others, whatever a loss parent is feeling is what they are feeling. Trying to put time limits on it or to say don't say that or you cannot think that way just adds to the isolation loss parents already feel and signals to the loss parent that you are not a resource for them. Ask questions and really listen to answers. Ask if they feel like they have everything possible to navigate the here and now. Ask if they would like to talk about their child. Ask for their child's name or nickname. Ask if they use a flower, an animal, something to commemorate their child.
- **E = Educate yourself, your team, those outside of your team.** Baby loss has been occurring for generations, but more recently, loss parents are stepping forward to tell their story and share their baby with others. As a result, we are all playing a bit of catch up. It is important to learn about loss and grief, to educate yourself not just through the formal methods, but also by what you can learn from loss parents. If you have a new thought or experience working with loss families, chances are that others on your team would benefit from the same lessons and awareness. Similarly, listen to loss parents. Are they consistently telling you about the same problem with an individual in a system, to a department, a certain procedure? Can you provide education outside of your team to minimize future issues?



If you witness something that you know is triggering or problematic, can you call it out in the moment or privately talk with the particular individual?

- **T = Think through your policies and procedures.** Think about policies regarding visitors and see if exceptions can be set out regarding loss parents. For example, could you allow for additional visitors? Is there private space where a family could go? Could time restrictions be lifted or less strictly enforced? Think about any paperwork or steps a loss parent has to take and consider if there is space to modify those. For example, if a procedure such as a D&C or a D&E is happening due to loss, could you perhaps forego the usual standard of a pregnancy test before such a procedure? These types of examinations and questions take time, but challenging them and changing them where possible is key to providing the best, most trauma-informed help to loss parents.

- **T = Time to grieve, to process, to be with their baby, to remember**  
When the loss is about to occur or already has happened, advocate for parents to have as much time as they want with their baby. Consider seeing if your institution could invest in products like the Cuddle Cot which would give parents more time by keeping baby cool. If they are in a private space, ask if they want to be left alone or if they would benefit from a chaplain or other people in the room. Long after the loss has happened, be the calm source, the supportive person who gives them all the time in the world. Because in our go-go-go world, it is easy for a loss parent to feel the rush, the hurry that the rest of the world may have for them. We like quick fixes, magic elixirs, automation and that is felt by loss parents both internally and externally. Be the person that does not rush them, that knows grief is lifelong.



- **E = Embrace the messiness of each loss parent, loss family.**

There is no one way to grieve and grief looks different on each person and within each family. While the societal view of grief tends to be one stage and then the next, "this process is rarely linear and instead occurs via a waxing and waning of experiences and an evolution of emotions over time." (Weaver et al., 2023). Some families are very open about death and for them, talking about their baby who passed may feel very natural; other families tend to stray away from talk about death and so they may not know how to talk about their baby. Additionally, because grief is not linear, the loss parent you see today may be completely different than the loss parent you saw yesterday. Depending on dates, times of year, what has happened recently, any triggers that they feel, a loss parent may seem like a completely different person. Do not judge. As we will dive into later on parenting after loss, loss parents have fears and worries that may seem overreacting or illogical, but a loss parent fears losing another child. While many parents can hide that fear, a loss parent cannot and lives, expecting the other shoe to drop. So it is important to acknowledge that the fears are understandable and to avoid sugar coating dangers and risks.

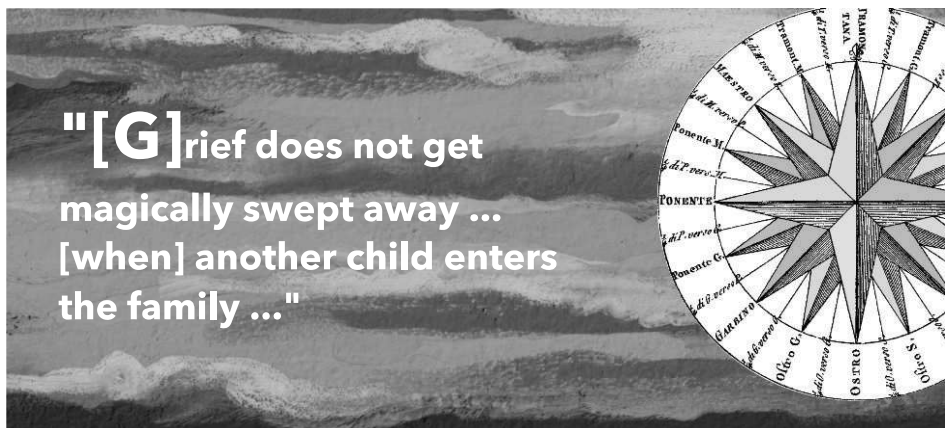
### Secondary Losses

Colette's death and Sweet Pea's loss are hands down the two worst experiences I have ever had, a sentiment that most loss parents would share. But, the secondary losses really sting hardest and still continue to accumulate even years after loss. Some secondary losses include loss of innocence and joy, and loss of family and friends who are not supportive of the loss parent's grief journey. "One of the most shocking things to me in the aftermath of Colette's death was how many people stayed mute and still, almost five years later, have never even acknowledged my daughter let alone my loss. I also mourn those relationships and what I thought the relationship was." (Valiukenas, 2024)

### Trying Again

It is important to understand and acknowledge that fear of trying again and of being pregnant is totally normal; avoid trying to say "don't be scared" or making promises that cannot be guaranteed. Additionally, recognize that the time between a loss and trying to conceive or being pregnant again is often very short, with a majority of loss parents being pregnant within the year after loss, so "it is likely that these women may be experiencing juxtaposing emotions of grief and simultaneous joy in their subsequent pregnancies." (Donegan et al., 2023)

If nothing else is taken away from this article, then please remember



**"[G]rief does not get  
magically swept away ...  
[when] another child enters  
the family ..."**

this: Remove the words "at least" and "just" from your vocabulary. There is no comfort and only pain to be derived from platitudes such as "at least you can get pregnant" or "you were just x weeks along." Removing those words from what you are saying goes a long way to avoiding triggering. Think of it this way, a few years ago, my grandmother died and no one at her services or in the following months said, "at least you had a grandmother," or "you can always have another grandmother." Those statements after any other loss sound absurd so treat any such statements made after a baby dies the same in your mind.

Acknowledge previous losses, but in a very sympathetic, trauma-informed manner. Do not do as one social worker who worked with me when I was hospitalized with Colette and said something along the lines of, "So I see you miscarried last year. How was that experience?" All that did was cause tears, trigger the self-blame talk inside of my brain, and make me uncomfortable. Instead, say things like "I know that you lost [insert name if you know it], I want you to know it is your decision if you want to talk about it or not and I'm here to listen either way."

Understand that there are triggers throughout trying again and a subsequent pregnancy. It may be the negative pregnancy test or the dreaded beginning of a menstrual cycle. It may be the positive pregnancy test that triggers memories and fears. It may be certain weeks of a pregnancy when the loss occurred or when

things started to go wrong. It may be certain dates, months, or seasons of the year that remind them of the past. For example, both of our losses occurred in May and so May for me is a very difficult month. At one point in our journey post-Colette, I joked with a doctor that if I were pregnant again in May, I wanted her to put me into a coma for the whole month. For those who do go on to be pregnant again, keep in mind that depending on timing, they may be experiencing those first anniversaries or previous due dates during a subsequent pregnancy.

Do not use a cookie cutter approach to all loss parents. What works for me may not work for the next person, what provides comfort for my husband may trigger me, and so on. Plus, even when you do figure out what works with a particular loss parent, that is subject to change. Ask me today how I feel about things and I guarantee what I say and feel is different than it will be next week. The success of your interventions comes from recognizing that it is meeting a parent where they are at on that particular day, being open and honest, serving as a resource, acknowledging their loss, and working with them on whatever they need help with.

### Having the Rainbow

Not every loss parent will go on to have a rainbow baby and not every rainbow baby goes home with their parents. But, for those of us blessed to bring a child home, it is difficult

because most of your outside world will assume that you are healed or over your grief. I remember shortly after my loss, overhearing my grandmother say "I just hope she gets pregnant soon and then with the baby, it'll be better." That sentiment is felt by many surrounding loss parents. But, no baby will ever be able to stop the grief. "Because losing a child changes you forever, having a baby after loss can bring healing, but it does not take away all the pain." (Schultz-Saindon, 2023) The reality though is that the grief and triggers that come from bringing a baby home after loss are often even tougher than it was prior to the baby. "The grief does not get magically swept away just because another child enters the family, and in fact, a lot of the trauma and the reactions to that trauma are reactivated and retriggered as another child comes home." (Valiukenas, 2023)

Navigating the emotions of how to keep your angel babies close while actively parenting another baby are complex and difficult. "Birthdays never to be had by one child but met by another. Milestones achieved by the living baby but never to be achieved by the deceased. An empty chair beside your living child that should be filled but never will be. It will always be present and a part of your life." (Henke, 2016)

The birthing process itself can be very traumatic, especially if it is the same hospital or birthing center. Regardless of where, there are bound to be moments throughout the process that trigger memories of the loss. One thing to try to address as early and as quickly as possible is minimizing the potential triggers. For example, if the delivery of the baby who died occurred in a specific room, is it best to choose a different room or is it comforting to be in a room associated with the angel baby? If the family is very open about their loss and includes their babies who have died in their family, then it is helpful to ensure no one will say anything to trigger the family. Is a sign on the door of the room stating this is a rainbow pregnancy or a pregnancy after loss something parents want so as to



avoid anyone making comments like oh is this your first?

At the hospital where we delivered, everyone did a very good job of recognizing that we had a history of loss. This was in part because the team knew us, but also largely because I was proactive. Some things that made a difference: we had a sign on the door that we had a history of loss, we also brought our Coco bear in memory of Colette who sported her very own t-shirt saying "Big Sister," as well as a picture of Colette. Helping parents by providing resources like the sign that we personally brought or a space in which to remember is vitally important. Having space and support to include Colette in her brother's birth meant a lot to us and we were glad we had the support of the hospital to do that. But, what was even more important was that right before Elliott came out, one of the nurses stopped by the Coco bear and the picture and said, "Are you ready to be a big sister?" That will always be held close to my heart, both as a mom and as a big sister myself. It took two seconds and a kind thought, but it meant the world to me.

## Parenting After Loss

Parenting after loss is a very unique and difficult experience. While the rest of the world will only see your living children, loss parents are parenting their babies who died just as well. I love this quote although I would change the term mother to parent. "When a child is born, it is the mother's instinct to protect the baby. When a child dies, it is the mother's instinct to protect the memory."

Parenting after loss carries trauma, fear, and grief. A parent who has experienced loss is not having a "normal" or "typical" parenting experience. We will dive into just a few of the ways parenting after loss is different.

1. Fear of losing another child. When you have lived the worst imaginable experience, it's hard not to think it'll happen again. Many loss parents report that they have had what most would consider irrational fears, but that they feel very real to them. I personally remember getting a check-in call from my son's preschool

on his first day and being terrified. "I pick up with trepidation because the thought that runs through my head is, 'They're calling to tell me my son is dead.'" (Valiukenas, 2023)

2. Making sure that your baby or babies lost are remembered within your family and also to others. Especially for a family that brings home babies after loss, less people remember the losses as the years go by. So, that first birthday may be filled with messages and reminders from everyone, but there are likely significantly less each year. Loss parents' biggest fear outside of losing another baby is that their babies will not be remembered, especially as other kids are present and able to be seen.

3. Trying to balance sharing and including the babies who have died with your other children while not putting the baby that is not there on a pedestal of perfection. "It is a nearly impossible balance to strike...to have healthy conversations about siblings who are not there while also making sure that your kids do not become consumed and overly fascinated by death, to hold your trauma in check while also listening to your gut, to want your living children to spread their wings and fly while also worrying about what happens if the wind does not stay stable enough to fly." (Valiukenas, 2023)

4. Balancing the emotions of joy and gratitude with your living children while also grieving your other babies. "While rainbow babies are beautiful miracles their mere presence does not erase the hurt and pain of loss. Grief and joy can coexist when parenting a rainbow baby." (Anderson, 2021)

5. Grieving the image of what your family should and/or could have looked like. I love being a boy mom, in ways that I could have never imagined. But, that was never what I saw in my family as I always thought I would have two girls. So, while I love parenting a boy, I grieve the experience I thought I would have and that I will never be a girl mom in the traditional sense. I also grieve having only one living child and that he will not have a sibling in the traditional sense.

Feeling like parenting, especially after loss, is not something you get to complain about, even when it is

totally justified. "You are so grateful that you finally have a living, breathing baby, in your arms, and that doesn't make parenting a newborn any easier for you than it is for anyone else. Just because you know it could always be worse doesn't mean it isn't hard. It's still hard, and you have every right to seek support and express your frustration about the hard parts." (Schultz-Saïndon, 2021)

Being exhausted all the time. Sure, parenting is exhausting regardless of loss, but when you add to it that you never escape grief, it becomes all-consuming and exhausting. "The one thing that follows me and the thing I can never take a break from is the grief. It feels like there is always some annoying bird on my shoulder, reminding me that it is there, telling me that there is a missing part of our family, saying that your daughter died. Although I have tried many times to run away from that piece, to leave the grief at home so I can do something else, I cannot." (Valiukenas, 2022)

## Summary and Suggestions

That was a long rollercoaster of information and there is still so much more I could dive into on this topic. But, I would like to leave you with some suggestions and recommendations on concrete actions and plans you can put in place individually, as a team, and as an institution.

A. Education. It's key. Make copies of this article or the sources used, read, share, discuss. Talk to loss parents who may have had time out from their loss about what was most helpful and most painful. Ask them what they wish had been done differently, listen and learn.

B. Choose your language and your words carefully. Take the words "at least" and "just" out of your vocabulary when it comes to loss parents. If you feel yourself saying them, take a breath and figure out how you could use them differently. If you know you say something using these phrases or if you do not know what to say, reread the article and then feel free to reach out to me or to someone else familiar in this field.

C. Create links to area resources for loss parents. These include funeral homes, cemeteries, support groups, therapists, and more. Then, when a parent needs them, you can do the warm handoff.

D. Look into how you can connect loss parents as they lose or shortly after loss with loss parents who have some time out from the loss. Could you connect with loss parents willing to write a few notes to give out to loss families? Could you start a support group of your own? Could you host a memorial on a yearly basis and invite loss families to join and be able to share about their babies?

E. Help parents create memories of their babies and include them wherever possible. If you can make footprints or handprints, do it. Take photos if appropriate. Create or purchase a pin or other memento that you give to loss parents. When parents are back, especially as they are trying or having a new child, include their babies who died. Ask them if they have a bear or other stuffed animal to represent their baby. Use the baby's name (or nickname) if you know it. Is there a flower, a song, a scent, something that makes them feel connected to their baby who died? Allow it to be used as long as it is possible.

F. Review policies and procedures for all the steps that a loss parent might have to go through and make recommendations and changes if possible. If certain things cannot be changed, develop a process to limit the triggering nature of the procedures.

G. Identify ways in which triggers may pop up and have a plan to combat the triggers you can think of. For example, if being in the same room could be triggering, what plans do you have in place if a parent tells you for the first time as they are in labor?

Finally, be kind to yourself. You are human, you are going to make mistakes. The important thing is to catch yourself quickly and then take ownership of what you said or did, apologize, and rectify.

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