Pandemic Grief Watch

Pandemic Grief Watch *Aisley's Bench*

March 26, 2021 By Sarah E. Shively

As many of you in the Brief Encounters community may know, Aisley Faber was born September 19, 2013. Two days earlier, she died. What you may not know is that one of 30 plus memorial benches at Portland's Crystal Springs Rhododendron Garden belongs to Aisley. As her mom, Sandy Faber, shared last November, "The birthday is the biggest thing. We go down there on her birthday and light candles. We had actually checked ahead to make sure it was open. It was supposed to be open—and we get there—and the gate's locked."

As part of a student journalism assignment for Fall 2020, I had the opportunity to interview four people to check in with all things grief and COVID. (I've started a master's program in Multimedia Journalism at UO's School of Journalism and Communications). Writing initially for an 'uninitiated' audience, I decided to make some updates and adjustments for this version given that the issue of infant loss is not taboo to this community and doesn't need as much explanation. Having perused the Brief Encounter's Facebook Group back in early November, I became aware that Sandy and her family were experiencing frustration at repeatedly losing access to the Rhododendron Garden and thought there might be a bit of a story there...

So, Aisley Cecilia Faber's birthday was September 19th, but on that day in 2020, The Garden was closed because of the wildfires—not actually COVID this time. Regardless, Sandy was losing patience. She even considered pulling strings—maybe calling someone from the organization, but she knew that "five minutes into that conversation, I'd be yelling or crying." While the wildfires prevented the planned visit to the Garden, they didn't stop Sandy from posting Aisley's photo to the Brief Encounters Facebook Group. Like others, after losing Aisley, Sandy attended support group meetings; now seven years later, she leads them. Unable to celebrate Aisley on her birthday at the Garden, Sandy found herself turning to the Facebook Group where her particular brand of grief is understood unconditionally.

These days, Sandy Faber is a lawyer working from home. Zoom calls are sometimes interrupted by a child (or two). Maintaining her special relationship with Aisley requires intention. As she explained, "Grief has a way of coming up when things are in chaos. To be disrupted from all your usual touchstones—it's just really hard."

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In Sammamish, WA, Ali Furtwangler echos the sentiment, "You grieve the loss of those traditions. It made me mad that I couldn't take cupcakes to the nurses this year—we want to share our gratitude with them because they were so important to us when we had Zachary."



Ali's son, Zachary was born November 10, 2011. Like Aisley, he was stillborn. Also like Aisley, his name is on a park bench plaque near a playground. Ali is both photographer for the worldwide organization Now I Lay Me Down To Sleep (NILMDTS) and their Volunteer Program Manager.

"You never know what you are walking into. I like to talk to the nurse outside the room to know what state the family is in. I was there

for a newborn session for a trisomy baby. The family had props, a tiara, angel wings and outfit changes. And then you walk into sessions where the family was completely blindsided. An hour ago they thought they were having a healthy baby and then they didn't."

The photo that Sandy posted on September 19th of Aisley was taken by a NILMDTS professional volunteer. NILMDTS brings photographers bedside for parents experiencing pregnancy loss, stillborn births and infant death. Owing to COVID, birthing mothers haven't always been able to have their partners with them. But many hospitals were quick to create a compassionate exception allowing bereavement photographers to be present. For the family members that were not allowed in, these photos are often all they have to remember babies that never came home.

Even though NILMDTS photos are beautiful, many people will not share out news relating to their dead children anywhere else but within private online spaces like Facebook groups. Those who share more publicly may face a chilling reception, as model and author, Chrissy Teigen discovered in September 2020 when she and spouse, musician John Legend, experienced the loss of their son, Jack, at 20 weeks into her pregnancy. She shared her harrowing experience on Twitter including photos.

After a series of nasty responses from people telling her that she should not have shared such intimate photos from the delivery, she addressed her critics from the blogspot, <u>Medium</u>, a few weeks later. She wrote, "I cannot express how little I care that you hate the photos. How little I care that it's something you wouldn't have done. I lived it, I chose to do it, and more than

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anything, these photos aren't for anyone but the people who have lived this or are curious enough to wonder what something like this is like."

As those who go through this are quick to discover, infant loss, while common, remains a largely taboo topic. As Ali put it, "It's a great way to stop a conversation—especially in 2020—no one wants to bring up the dead baby." For the record, 24,000 babies are stillborn every year in the US. 3,500 babies die suddenly and unexpectedly and as many as 15 out of every one-hundred pregnancies end in miscarriage. Ali continues with, "but people need to share. I'll keep pushing to have those conversations. Grief is healthy."

For the larger Seattle metro-area, Ali also serves as the President of <u>Parent Support of Puget Sound</u>. Like Brief Encounters, this organization provides support for bereft families. And like Brief Encounters, all the in-person meetings have gone on-line. Attendance is significantly down.

Famed Brief Encounters' founder, Pat Schwiebert shared with me a brief history: The bereavement support meetings many of us hold so dear to our hearts grew out of her years working in prenatal care and maternal education at OHSU. "In childbirth education we always assumed that we were training healthy women to be prepared for a healthy delivery. And most of the time that happened. But there are always opposites in our lives, good and bad, day and night. birth and death." For more than 30 years, these in-person meetings have been part of the regular flow of life at Peace House, the home of the Metanoia Peace Community. "You can feel the healing in the walls." Several years ago, I too attended these meetings in Portland after experiencing a miscarriage and numerous failed IVF attempts.

But conducting meetings online has impacted the delicacy of the healing space. Pat continues, "You don't get that from a Zoom meeting, sorry. It is a huge loss for me—and for them it is a loss, but they don't even know it." (Referring to newly bereaved families that have not been to Peace House for an in-person meeting).

As many of you will appreciate, membership into this community is desired by none but welcomed by all. Pat shares, "It was a surprise to me that people would walk into a meeting and these people would become their new best friends. Even though every story is unique, there is something that these families hold together and that is their precious child."

Fellow BE member, Shannon Stemm Patel is mother to baby girl Charlie who died on March 15, 2015 at the age of four days. She expressed the tremendous value in that connection. "Brief

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Encounters is the anchor, the mothership." Both Sandy and Shannon share news and baby pictures on the BE fb page. This safe space invites families to share knowing that no public criticism is allowed. And during the pandemic, while some of the numbers are down for Zoom support meetings, postings and support on the fb page is up.

In 2020, to celebrate Charlie's birthday, Shannon took herself to the March 11th Tool concert at Portland's Moda Center. The legendary LA rock band is a favorite and she fondly remembers laboring to their music during Charlie's birth. While at the concert, Shannon noted that messages from the Governor were beginning to circulate. Before April, Oregon went into a lockdown. Regular programing for support meetings temporarily ended, memorial events were cancelled and the Crystal Springs Rhododendron Garden closed.

Returning to Sandy's frustrations with the Garden, complications actually dated back to January 2020 when, due to construction, no one had access to Aisley's bench. With promises that the construction would wrap up by April, Sandy mustered up an uncomfortable patience. Then, with the shutdown, the construction came to a halt and so even after the Garden reopened in May, the area around the bench remained cordoned off. Finally, the construction wrapped—months behind schedule. It wasn't until August 4th 2020 that Sandy, her husband, Rick, and their two living children paid their first visit to Aisley's bench in more than seven months.

Sandy posted, "The renovations look great, and they power washed the bench. It is looking snappy and I think I will try to make it down there to do another guerrilla refinishing of it, which the garden tolerated last time. (I take an ask forgiveness rather than permission tactic on refinishing the bench myself)." But she also admitted, "It's been so hard not getting to visit for so long, I felt torn up inside about it."

For a bit of background, as a couple, Sandy and Rick struggled for years with fertility issues, but finally in 2013, Sandy was pregnant. When their daughter, Aisley, died two days before she was born on September 19, 2013—eight months into the pregnancy—they were forced to make a decision about a burial plot rather than an infant car seat. But most of the places they explored felt too stuffy. Then one day as they were driving near the Rhododendron garden, not far from their home, Sandy suddenly just knew, "what if we had her cremated and got a bench at the garden?"

Thanks to family and friends, Sandy and Rick raised the money for the memorial bench and became official Friends of Crystal Springs Rhododendron Garden. Visiting the Garden took on a vital role during the first couple of years after Aisley died. Now, seven year later, access to

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Aisley's bench may not be as critical on a daily basis but it is still very important. When the birthday visit was smoked out the following month in September, Sandy felt that loss intensely. Frustrated, she turned to her online community seeking understanding and support. Eventually, the smoke cleared and the Garden reopened. The birthday moment was able to be carried out, albeit a few weeks delayed. But what is difficult for people to appreciate outside of the grief community is that delaying that memorial celebration is not the same thing as delaying a birthday party for a living child so that you can schedule it on a Saturday rather than a Wednesday. The date is non-negotiable.

On November 18th, with plans to go the next day to refinish and weatherize Aisley's bench, Sandy got an email from the Friends of Crystal Springs Rhododendron Garden announcing another closure of the Garden due to the gubernatorial mandated 'freeze'. "I just collapsed." She acknowledges, "if we were three years out, I would have jumped the fence. It was a complete meltdown."

When I shared the classroom version of this article with Ali Furtwangler in Sammamish in December, she wrote back, "Makes me feel better knowing I'm as crazy as someone else about our bench." She continued saying, "We had to deal with construction during 2019, and I had the team make special plans to move the construction fence for Zachary's birthday. I know that wanting-to-jump-the-fence feeling intimately."

Managing infant loss and the grief that lingers has been particularly challenging throughout the COVID Pandemic. Proper grieving during more than a year filled with cancellations of memorial activities, support meetings and locked garden gates has exasperated bereaved moms like Sandy. As she put it, "I just want them to open the stupid gate." In speaking with her, Sandy further explained, I'm not going to kill myself for not doing the thing for my dead baby that I wanted to do, but there is another piece to it too, because that was what I wanted to do for me."

When grieving parents establish traditions and routines around their lost babies, those moments are deeply important and when control over those rituals is disrupted, it can feel like an affront. An irritation to another person becomes the nadir of a loss mom's day. As Sandy said, "Sometimes the bottom just falls out."

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On December 4th, Sandy sent me a text, "Garden reopened yesterday :"."



This little light of mine
The gift you passed onto me
I'll let it shine
To guide you safely on your way
Your way home
From 10,000 Days (Wings, Pt 2), Tool