

CHANGING THE NARRATIVE OF PEDIATRIC DEATH AND DYING: THE STORY OF A BEREAVED PARENT SERVING AS AN END-OF-LIFE DOULA AND HOME FUNERAL GUIDE

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Pathima, mathima

Old Greek saying that we are supposed to learn from what happens to us.

Witnessing my daughter Angelica's final rite of passage reframed the experience of death and dying into a beautiful ritual of love and honor. The preparation for that moment made it possible for the acceptance of its reality to unfold peacefully. We surrounded her with the support she needed for the natural labor of dying. Cheering her on until the last breath at nearly 7 years old was a continuation of tapping into an intuitive energy. Thus, empowering my child to live fully with purpose since her first metabolic crisis at 3 days old. This is when my journey as an End-of-Life Doula (EOLD) began.



Angelica's life-limiting condition required the child-rearing responsibility of guidance to cross the threshold without fear. This pragmatic perspective recognized that my child needed to feel safe and understood. A holistic approach to nurturing her well-being powered our family through carrying the burden of anticipatory grief. There was an ever-present fear that today may be the last time we embrace her. I learned that control is what we make of it. Dignity and resilience provided the foundation for forging ahead into the path of unknowns towards a certain ending.

Children experience life with a wisdom that they may not be able to articulate. That is when holding space without judgement allows them to process and share how they feel and what they need in their own timing. Listening to what my child wanted did not always resonate with what I had hoped for. Caregiving is a sacrifice to personal thoughts of what should be.

Reflecting on the proving grounds of following my own child's wishes gave incredible insight into the delicate balance of diplomacy. Angelica rejected the idea of returning to invasive procedures after a harrowing final round of medical treatments. Subsequent doubt and confusion that caused my own intuition to waver came from outside pressure to consider saving her. I explained to her the choices and possible outcomes. She understood quality of life

and the implications of each scenario. The concise response of my primarily nonverbal child obligated me to honor the final phase. Her clear “NO” and knit eyebrows signaled the invitation of hospice care. Curative care was no longer an option for Angelica.

Angelica appeared well and continued daily activities with resilience in those final months. Changes appeared slowly at first, which frustrated her, prompting anger. A shift in parenting happened when I had to witness my child’s decline. She was dying and wanted companionship through new feelings. The distinct memory of sitting quietly beside her after a tantrum compelled me to instinctively hold space. Her anger subsided and she looked at me with such sadness. We sat together in silence with my arm around her. Then I spoke to her in Greek which she preferred for moments like this. “*Ela mou*, Mommy knows you are sad because you don’t feel good. You will not get better. I am sorry *agape mou*. Mommy will help.” This exchange was a pivotal experience as she approached the time of transition.

Parents need the same validation of acknowledgment for what is normal for them. They follow a similar route knowing that it will continue without the physical presence of their beloved child. The EOLD serves as a participant observer that provides non-medical and non-judgmental support for families to help them control their own narrative. Being present for what is most important to them involves coaching for what is to come. The EOLD advocates on behalf of their wishes and needs when strength is depleted or the focus elsewhere.

Becoming an end-of-life practitioner seamlessly blended into surviving as a bereaved parent. There was an undeniable force that gravitated me to this calling. The doula model of care encompasses the essence of palliative care to rely on intuition, poise, and empathy. Our role is to empower families by being proactive, creative, and solution oriented. Facilitating difficult conversations confronts the complexity of relationships and situations to connect with what is best for the child. An EOLD works together with other professionals by sharing our observations and expertise, bringing something different to the table.

The desire to keep Angelica’s body home after death was deeply rooted in my Greek heritage and her upbringing. I promised my daughter that we would take care of her until the end, meaning the disposition. Home funerals generally do not require embalming and encourage family participation for preparing the body regardless of disposition. Activating our family’s circle of support while she was actively dying allowed us to create a sacred space to give her full permission to let go. Angelica’s breathing plateaued into a delayed rhythmic pattern while she heard what a great job she was doing. The moment she crossed over we were prepared.

The EOLD skill set may include after death care as a Home Funeral Guide (HFG). Our family consulted an HFG that instructed us on how to take care of the body. That meeting was incredibly valuable and reassuring that we were capable. Our HFG reminded us that we could spend time with the body before the preparation. She also connected us with a local funeral director that would assist the process as Michigan law requires it. My own loving hands cared for the child that I had carried in the womb, enabling me to process the grief through the shock of entering a new reality.

The hesitation to share funeral plans with our families, healthcare providers, and hospital staff resulted from guilt of possibly declining life-saving measures. I had an Eastern Orthodox prayer book in Angelica's hospital bag. A laminated copy of the Resurrection icon marked the page of prayers for the dying. I wanted to be calm if she coded and to read the prayers over the body before calling the priest, knowing we would have to negotiate her transport home.

Families inquiring about a home funeral may change their mind or circumstances may dictate otherwise. That is established at the initial consult. It is our ethical responsibility to present choices and alternative scenarios. Especially for those that may not have social support or the logistic feasibility. Losses from early pregnancy, medical complications, or trauma may necessitate alternative considerations for the body preparation and vigil arrangement. Plans need to be flexible to accommodate fluid situations.

There was an intense confusion about how to include end-of-life wishes in Angelica's goals of care when curative measures appeared less viable in the last year of hospitalizations. It was refreshing to openly talk to those that would listen to my concerns for the dying process and after-death care. I researched during respite times about code status, hospice care, details of the dying process, and funeral planning. It felt like betrayal when browsing pine caskets on the internet while Angelica napped. This is not a criticism to standard protocols and practice. However, it offers a glimpse of the unnecessary anxiety and disconnect that may affect an equally important time for our children.

During an initial consult, the family story abundant with nuances, guides the conversation when we meet for the first time. The goal is to get a sense of their perspective and expectations. It also sets a tone for maintaining boundaries and emphasizes the importance of listening to them. They are safe and information is confidential unless given permission to share on their behalf. I can refer families to colleagues if we are not a good match and other organizations if their requests are outside of my scope of practice. A support plan is then created that may alter, adapting to changes. EOLD collectives such as the one I am part of assure back-up support or collaboration.

Journeying with a family from the diagnosis to after death reinforces the trusted companionship developed over time that fosters a continuity of care. This is an ideal outcome but not necessary. We can help at any stage, for various needs, and help families connect with how to honor their grief. Grief support is available as a separate service as well. Providing resources, creating memorial projects, teaching about ritual, and checking-in are common practice.

We must enter sacred space grounded and ready to take in the energy of the environment to optimize support. My first pediatric home funeral consult for 10-month-old baby Evey was one of crisis mode. The palliative care team diligently worked throughout the day to reach someone to help a newly bereaved mother take her baby home for a vigil before cremation. It was divine timing in how we connected.

The strength of a mother's grief and love welcomed me into the hospital room. There was an instant collaboration with staff. Our coordinated effort to navigate through policy, protocols, and partnerships gave precious time to a mourning mother devoted to nurturing her child the way she needed to. The family had a lovely four-day home vigil. They were able to spend time and make memories with Evey in familiar surroundings before the final farewell to her physical presence. Evey's story initiated a new dialogue about EOLD support, home funeral protocols, and the hospital body release policy.

Then came a first official referral from a Peds Palliative Care social worker. The family awaiting the arrival of baby Oliver wanted to bring his body home. Connecting with Oliver's mother throughout the pregnancy gave her the support to honor the inner wisdom of parenthood. My involvement as an EOLD was activated as needed. There were circumstances that changed the original plan for a direct transport to their home. However, conversations prior to his birth led to a seamless transition to an alternative scenario. Oliver's family welcomed him with reassurance that their wishes would be fulfilled. His body was held and loved by family in an intimate setting before the funeral. Oliver's story was used in a training to help EOLD students learn about the unique aspects and considerations of perinatal support.

I strongly feel my daughter's spirit in this work. Repurposing lessons learned from caring for her influences how I speak my truth and inspire others to find their own voice. As End-of-Life Doulas, it is our professional purpose to network, form partnerships, and collaborate with mainstream systems to complement existing services in the palliative and death care continuums. Advocacy parallels activism to validate and normalize the needs of the dying and their loved ones. A great love and respect for my child loss tribe and other dedicated end-of-life professionals is a beautiful relationship of reciprocity that naturally contributes to a positive approach to death, dying, and bereavement. Our collective motivation to seek understanding for achieving a meaningful final rite of passage is the process for a narrative of change.



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