



March 17, 2021

Thank you to House Government Operations Committee. My name is Heather Silver and I am a perinatal specialist. I work with families who suffer the loss of a pregnancy or infant, as well as provide perinatal hospice services. Imagine going to a sonogram appointment excited to get your first set of pictures, find out the sex, or see and hear your baby's heartbeat for the first time, only to hear those heart-breaking words; Something is wrong with your baby.

Perinatal hospice is a philosophy of family-centered care that addresses the intentions of families who choose to continue a pregnancy with a life-limiting condition. The goals are to anticipate, prevent, and relieve suffering, to preserve dignity, and to promote quality of life for baby and family, while honoring the parent's wishes for their baby's care regardless of length of life.

Perinatal Hospice focuses on creating a relationship with parents and guiding them in decision making and caregiving. After birth, the care also focuses on the comfort and well-being of the baby, with interventions to support quality of life for both baby and family. Parents must balance the dual experience of preserving hope with preparation for birth and eventual death—or of death and then the birth. It is creating a safe space with parents and understanding their goals. These goals shift and change over time. They go from "I hope the diagnosis is wrong", to "I don't want my baby to suffer", to "I want a peaceful death."

I have been involved in bereavement care since 2001 and it is heart-breaking that in 20 years we have barely advanced the movement of perinatal hospice. These services are necessary. They are special. They prove over and over again that they impact families mental health and well-being in a positive way.

Brochures highlighting these resources should be given to physicians because they are present when the diagnosis happens. These families choose their provider, therefore this would be a trusted source. This also helps a family have a place to start instead of going home and googling their diagnosis which can be packed with misinformation. Only 10% of information is retained after receiving traumatic news...leaving the office with resources in hand is vital. Families turn to the internet for information and the Health Department should provide this information so it can be the trusted source for these families.

I travel around and give presentations to OBGYN office, hospitals and clinics and its astounding how many doctors and other providers are not aware of perinatal hospice, not aware of what services are offered, and not even aware there are local resources for their patients.

Parents that utilize perinatal hospice are able to process their grief, they are able to have an advocate for their wishes, and they are able to understand their options. Let me give you an example of two sets of families I am currently working with.

The first family was sent to me by their doctor at the point of diagnosis, at about 20 weeks gestation. I was able to help the family process the baby's life-limiting diagnosis of a major heart defect.

We discussed all of their options, I worked with them to help with communication between one another, as well as managed their expectations and hopes. We planned for the birth and eventual death of their baby. We recorded their baby's heartbeat, we provided them with extra sonogram photos, and planned maternity pictures. We also planned a special baby shower where we did a belly painting and a belly cast to honor the family and friend's relationship with this baby. We organized a photographer for the birth, and did 3-D hand and foot molds after the baby was born. We worked with the baby's siblings, explaining death to them in a way that was age appropriate and did legacy building that honored their relationship with their unborn sibling, as well as helped the parents anticipate their grief needs. All of the burial and funeral plans were completed during their sessions. This allowed them to fully focus on the limited time they had with their baby after birth. They found great comfort in the baptism they had performed by their priest who came to the hospital when it was time, and being able to make meaning of the loss from pre-planning for the mom to donate her breast-milk helped her feel as though her baby continued to make a positive impact.

The second family came to one of my support groups approximately 3 months after their loss. Their baby also had a severe heart defect which resulted in a stillbirth at 38 weeks gestation. The hospital staff was compassionate. They took pictures with their own phones and were given a memory box with a special bracelet and special blanket. After birth while they were spending time with their baby they had to meet with hospital staff to discuss disposition options and make all of their plans. Would they like cremation or burial? What funeral home would they like to use? Did they want someone to bring a special outfit? Because it is up to various hospital staff that already have so much responsibility to have these conversations, things get lost. There is limited time to make these choices and most parents aren't able to process what each outcome would be. The mom was never told her milk would come in. Many mom's don't realize this is a part of loss and can be extremely traumatic when this happens. By the time they are able to access support they are extremely uncomfortable and it takes much more time and effort to stop this from happening.

At the support group this family was able to listen to the other family who had perinatal hospice involved from the start. This resulted in another round of grief. They now knew what they had missed and this turned into anger and resentment. This was pointed at their OB providers, their hospital, and the staff. It was too late. What could have changed their entire experience? What could have helped them plan and prepare for their baby's arrival and maximize their time with their special little one? A simple brochure with a list of resources.

This is a bill to empower parents to make decisions for their baby because they deserve a choice. They deserve information. They deserve your vote which honors their relationship with their baby and gives them control over something when they are swimming in a river of the unknown.

For these reasons I urge a favorable report on House Bill 1112. Thank you for your time and attention.

Sincerely,

Heather J. Silver, LCSW-C, CPLC