

## A Family's Experience with Perinatal Palliative Care

The editors of *AFP* welcome submissions for Close-ups. Guidelines for contributing to this feature can be found in the Authors' Guide at <http://www.aafp.org/afp/authors>.

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A collection of Close-ups published in *AFP* is available at <http://www.aafp.org/afp/closeups>.

It started with an unexpected diagnosis—our unborn daughter had a fatal genetic birth defect called trisomy 13. That moment began a five-month journey navigating tough issues most parents never have to address. We were told that our daughter's chance of a "meaningful life" was essentially none and that she might even die before she was born. Heartbroken, we turned to our faith for peace and understanding. We decided to continue the pregnancy, a decision some of our doctors found difficult to understand.

We spoke with our family doctor, who was also our perinatal care doctor. Although she had never handled a situation like ours, she said she would continue to work with us and support us. She helped us understand the decisions we had to make and helped us express our goals for the care of our unborn daughter. We wanted our daughter to have a comfortable life—for however long she lived—and a natural death. At the same time, we wanted as few medical interventions as possible to avoid unnecessarily prolonging her death or suffering. These were tough decisions to make, and it was helpful to have our doctor support us through the process.

After the birth of our daughter, the team of family doctors and nurses involved with her care allowed her to have a natural and comfortable death three short days later. Because of the care and support we received, our first and last moments with our daughter were full of love, comfort, and peace. We were able to celebrate our daughter's life and to create cherished memories in spite of the grief. On this difficult journey, we found that her short life helped us focus on the things that are most important to us—our family, our friends, and our faith.—N.F. and C.P.



### COMMENTARY

Being entrusted by the family as a partner in this experience was very meaningful. First, it was an example of how patient-centered care involves listening to patients' goals and helping them to achieve those goals. I felt out of my element at several points along this journey, but I focused on advocating for the family and their goals as my touchstone. Second, it reaffirmed for me the importance of family doctors providing maternity care. Caring for the mother and her baby helped me meet this family's needs by seamlessly participating in and coordinating the prenatal, labor, palliative newborn, and postpartum care. Third, I learned how helpful our state's Physician Orders for Life-Sustaining Treatment (POLST) form was in communicating the family's goals and wishes to all members of the health care team. Having a documented POLST and care plan helped unify the doctors, nurses, and family, and it allowed us to meet the family's wishes to have a peaceful birth, life, and death for their daughter.

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Photo courtesy of Jennifer Zila

### RESOURCES

#### For patients

Perinatal Hospice and Palliative Care  
<http://perinatalhospice.org>

#### For physicians

Catlin A, Carter B. Creation of a neonatal end-of-life palliative care protocol. *Neonatal Netw*. 2002;21(4):37-49.

Physician Orders for Life-Sustaining Treatment Paradigm  
<http://www.polst.org/>

Spoelhof GD, Elliott B. Implementing advance directives in office practice. *Am Fam Physician*. 2012;85(5):461-466. ■