A Family’s Experience with Perinatal Palliative Care

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 prenatal 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.