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It's Complicated: Having a Family Member Die on Hospice Not-of-Covid-19

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As the world has rightfully focused on COVID-19 people have continued to die of other things, and their needs and the needs of their loved ones have been overshadowed by the pandemic. My mother died of stage IV pancreatic cancer on April 25, 2020 in New York City (NYC). This was the peak of COVID-19 in NYC, when emergency rooms were overloaded, and nursing homes and hospitals had refrigerated trucks in the streets to deal with the dead.

My mom's story begins well before COVID-19, with a diagnosis in February 2019. When she was diagnosed, everyone- friends, family, medical providers- was supportive. Mom did not want visitors but people were available when she was ready. Things were "normal" in the world: friends helped my husband with the kids' activities and co-workers lightened my load so I could travel to provide care. In my family, I was the experienced one. I am a social worker, with expertise in gerontological social work and macro systems. I knew to anticipate family obstacles like navigating caregiving with a sibling and helping my dad adjust to his new normal. I knew about getting a wheelchair, connecting with home care, activating long term care insurance, and so on. Mom's oncology social worker proved to be an agile communicator and an expert connector. We emailed regularly when I was back home, three states away, as she helped me manage the details.

Mom improved. Once she settled into an every-other-week chemo routine she felt stronger. It wasn't easy- formerly very active, she was more tired, and for the first time that I can remember, took naps! Her brother died during that time, very quickly, from a different cancer, but his death gave her the will to fight her own. She started socializing with friends again, going to the movies and the store, and in August, went on a delayed but long-anticipated trip to Paris with her granddaughter. Throughout the pre-COVID part of her cancer, Mom had palliative care, at my insistence, and she had a great team. She talked to her chaplain regularly.

She joined a walking group led by her oncology social worker, and joined a meditation group. The palliative care social worker checked in with me periodically for my perspective on mom's needs but also to see how I was doing.

We knew Mom's stability wasn't going to last and it didn't. At Christmas 2019, we were all together, but mom was more tired and developed a persistent cough. She had lung metastases, but her breathing had been better for a while and it wasn't anymore. Her oncologist started talking about giving her body a rest from eight months of chemotherapy, and the alternatives. Mom decided to try "the other treatment," a harsher cocktail of chemotherapy drugs. This infusion took longer, she had wear with a pump that continued to infuse the medications over 48 hours, and was rumored to come with a host of terrible side effects. It lived up to its expectations- it was much harder. After one dose and ten days of feeling terrible, mom told our family she was done. Done meant being done with treatments and being done with fighting for quantity of life at the lack of quality. My professional background had prepared me for this. I had been anticipating and dreading this moment from the minute I heard her diagnosis. I was ok with it, because it was her choice, and it was true to form. She hated being sick. As hard as it was, I was determined to make sure she got what she wanted.

This is where COVID-19 comes to the forefront of the story. This was March 2020, in NYC. When I arrived on St. Patrick's Day, the streets were empty. The grocery store had no toilet paper, no bread, and few of the limited things mom would eat. We were to meet with the palliative care team to discuss next steps but the medical building cancelled in-person visits. We held this critical meeting via telehealth. As a gerontological social worker, I knew how the meeting should go. As a daughter, I knew my family did not. My goals for that meeting- a MOLST [Medical Orders for Life Sustaining Treatment] form and a hospice referral- were likely

different from my family's, but I don't know. I didn't ask. I left that to the professionals because I knew my mom had rapport with them, and I knew my parents saw me as their daughter. The palliative care team, the attending physician, mom, dad, and I, and my sister were all in different rooms. The meeting had many of the technological challenges we have experienced in COVID-19: the physician's connection kept dropping off; the sound from the palliative care team was inconsistent; and what was already a challenging conversation was disjointed, with more attention on technology than content. More than once I had to step into a social work role, clarifying points that were lost in technology challenges before stepping back into being a daughter. This was distracting, and to me, interfered with the connection I hoped for in such an emotionally challenging conversation.

The hospice nurse came in-person to the house do the intake, and her nurse and social worker came in-person the following day. But every day COVID-19 brought new complications. As the governor and mayor traded barbs on the news my dad watched constantly, we learned that NYC was implementing a stay-at-home order. Since I live out of state and my sister lives in NYC, we decided that my sister would shelter with mom and dad and I would go home. When I got home, my state had a mandatory 14 day quarantine for people traveling from NYC. Back in New York, mom and her caregivers were dealing with shortages, trouble getting groceries delivered, and little in-person attention from hospice. The nurse and the physician were available by phone and the nurse came once a week. But after the first week, the social worker could not come in-person. She called regularly, but as mom weakened, mom could not engage in these phone visits. Mom had already stopped talking on the phone to her grandchildren, and if she wouldn't talk to them, she wouldn't talk to anyone.

COVID-19 complicated other things too. I considered every day whether to go back to New York, but my questions were different than in a non-COVID situation - things like “If I go back to care for mom will I be able to come home?”, “Is travel into NYC permitted?”, and “Am I a COVID-19 risk to my parents?” I talked to the hospice social worker once about my concerns- while juggling a school-from-home video call for my seven-year-old- but at that point in COVID-19, she didn’t have any more answers than I did. After my 14-day quarantine my husband continued to shop so we could minimize the risk to my parents.

As happens with dying, mom’s health deteriorated and she needed more help than other family members could give. My husband and I agreed that the needs outweighed the COVID-19 concerns. I packed masks, and prepared to depart. I live along Interstate 95, and in each state I entered there were dire messages about unnecessary travel. It made a fraught situation more intimidating and during the whole drive I just wanted to get there.

During mom’s last week, our contact with hospice consisted of daily phone calls with the physician and nurse and two visits by the nurse. Symptoms were addressed promptly and we had the medications we needed. What we did not have, due to COVID-19, was aide service, social work visits, and more frequent nurse visits. My parents were reluctant to accept aide service due to infection risk, and by the time the need outweighed the fear, we could not access the service before my mom died. Finally, we would have had visits from family and friends for help, company, or support.

My mom died just before 1:00 AM. The hospice nurse came to the house to pronounce her death. At that point the COVID-19 challenges got worse. The first funeral home I called was not able to tell me when or if they could pick my mom up. I had never dealt with a death at home before, but the nurse was clear that it shouldn’t work that way. I called them back, and

they suggested we call the medical examiner. We were adamant that we were not sending mom to the New York City medical examiner in the middle of a pandemic. We thought we would never find her again. At nearly 2:30 in the morning I talked to the on-call social worker about options. Three funeral homes later we found one that was able to come- the next morning at 10 AM. The nurse left and we tried to sleep.

The funeral home came, and later we went in person to make arrangements. The funeral director explained because the Environmental Protection Agency (EPA) limits daily cremations, her cremation wouldn't happen for three weeks. There were no calling hours, and no funeral. I went home two days later and have not seen my New York family since. COVID-19 has left this feeling unfinished. My immediate family and I created our own remembrance but we have not had any of the social sanctioned mourning rites. Some days I have to remind myself she's gone. While the social worker in me knows that is a normal part of grief it is worse because of the absence of ritual. So, for now, I'm just Nancy, whose mom died not-from-COVID19.