

FIELD NOTES | SPRING 2020

## Cigarettes, Coffee, Cookies and a Good Rest

By Florence Gelo

Some time ago, Antoinette, age sixty, was admitted to the Vale Residential Care facility, which was her only option to avoid homelessness. She needed hospice and mental healthcare and could only access these subsidized services at Vale.

She was referred to me as a potential participant in a project I was doing to evaluate the use of paintings to help those at the end of life narrate their journey toward death. These art-based interviews with hospice patients create narratives that reflect on the importance of conversations with the dying to learn more fully about patient experience living at the end of life. What set these conversations apart from others is its unique focus on using art images to stimulate such discussions. Having had over twenty-five years of experience working with patients receiving palliative care as a former hospital and hospice chaplain, I was curious to see whether art had the power to stimulate or open up stories for those who are ill or suffering.

What would evolve during my get-togethers and conversations with Antoinette enriched the assumptions and objectives I initially had but also held surprises that revealed the real need for honest talk and engaged care that many patients desire and need.

The first step was an introduction and scheduling an initial get-together: Although Antoinette had given consent to hospice staff for me to contact her by phone, I made several appointments with staff, but she was never at the care facility when I arrived.

Subsequently I learned that early each morning, after showering in the middle of the night, Antoinette dressed, left Vale, and walked 1 minute (0.1 mi) around the corner to Sacred Heart Free Home, which provided care to "incurable cancer patients." The Home, owned and staffed by the Dominican Sisters of Hawthorne, is where Antoinette found true solace and where I found her.

During my first visit to the Sacred Heart Free Home, I was greeted by Sister Marie who introduced me to Antoinette. She offered both of us a cup of coffee, a package of Lorna Doone cookies, and a quiet place for conversation. I reminded Antoinette about the art-based interview process we spoke about earlier and explained I would begin by showing her five images of art works. I invited her to select an image that interested her, to look closely at it (with assistance if necessary), reflect and respond to a series of verbal questions (followed by prompts if necessary). The objective was to use art images to facilitate communication about her experience of dying, and for her to become aware of coping strategies she uses and has found helpful, as well as to better understand the role of spirituality in coping. She chose *Martha Hovenden and Her Dog* by Martha Hovenden.

When I asked Antoinette why the painting appealed to her she replied she "liked animals and little children." She then commented "I like the girl's outfit." I asked "Is there anything else in the painting that you like?" In a disinterested way, she said "All of it." It seemed she wanted an opportunity to talk, but not necessarily about the image.

Sitting in oversized chairs in a secluded space on the second floor of the Home, Antoinette told me her story. She was born and raised in a section of Philadelphia that "received a large number of European immigrants and was historically working class." She was raised Roman Catholic and attended parochial school. "I went there for 20 years. I got my communion and confirmation." Her matter-of-fact tone of voice grew excited. "I went to that church. They had quite a few, some nice priests. My church is Nativity in Port Richmond. We have an upper church and we have a lower church. The church is old. It's about 116 now, years old." Antoinette's pride and affection for 'Nativity' was evident.

Within moments, Antoinette's smile vanished. I asked "Do you miss not being able to go to church now?" She answered "Yes, I go here for Mass on Sunday at 10:30." I realized that to attend services at the Home would require planning, so I asked what motivated her. "To pray, I wanna hear Mass. I listen to Mass and I go to communion. It makes me feel good."

I wanted to understand more about her decision to walk from Vale each morning to Sacred Heart Free Home. I knew she had not chosen to live at Vale, but when Antionette clearly stated that attending Mass was crucial to her well-being, it became obvious what motivated her to leave the facility in the morning and walk to the Home.

Returning to the discussion of her faith and the importance of Mass, I asked Antoinette if she saw anything about God in that image. Antoinette dispassionately said "No." What she saw in the painting was "a girl and a dog." I asked again about the image. "Does the image say anything about where you are in your life right now? Is there anything you want to talk about?"

Antoinette was silent. She looked at the image, saw a dog and a little girl, both of whom appealed to her and I imagined it might have reminded her of her own childhood. She did not appear to be interested in the image itself. My invitation to look at art images likely appealed to Antoinette's curiosity and desire for interaction with others. Her interest allowed me to interview her and to learn how she managed a shielded awareness of the terminal nature of her illness. How Antoinette uniquely lived life in her last days was not revealed by looking at an art image. What interested her most, and resulted in her storytelling, was being asked questions by an active, engaged listener.

Abandoning reference to the art image, I asked Antoinette directly about her belief in God. She declared her belief. "Where is God in your life right now? I asked" Antoinette pointed to her heart and said "God is in my heart. He lets me put my feet, my legs on the ground in the morning." I replied "God lets you put your feet and legs on the ground each morning, but do you have thoughts about why you might be ill right now?"

A pained expression appeared on Antoinette's face and along with it, a free and unexpected flow of words. "I always say, 'why me'? Why do I have to suffer? Why did I get this way?" I

asked Antoinette what happens when she asks "why" and she replied angrily "Nothing." I asked again if she ever gets any answers about "why?" and again, an indignant "No."

This was the only time during our conversation that Antoinette stopped eating cookies and drinking coffee, both mine and hers. "You are trying to take care of yourself both body and spirit. And if you were going to tell me what makes your day good, what would you tell me?" Antoinette swiftly replied "My coffee. My cigarette."

"Your cigarette, your coffee; how about the cookies they give you?"

"The cookies too. And good rest."

Our conversation had become cordial, and the intimacy that had developed allowed Antoinette to name her "problem" directly. "I'm still not over having breast cancer."

"Do you think you will get over having breast cancer?"

"I don't know. I don't have an answer for that yet."

"What are you waiting for? What would help you answer that question?"

"If they would stick something right here [she pointed to her breast] to draw the excess liquid out. Cause I had to go to the medical center one night because I started bleeding and I got released the same night."

"You're looking forward to getting better and then what will you do?"

"What I've been doing, my usual."

"Which is? What is your usual?"

"My daily routine." By that, Antoinette meant visiting the Sacred Heart Free Home daily. I asked Antoinette "You seem to be friends with all the Sisters?" She replied, "About eleven or twelve of them."

Two months after the interview with Antoinette, I called the Home asking if it was possible to visit a second time. That's when I learned that Antoinette had applied to the Sacred Heart Free Home and was admitted. Antoinette required a higher level of medical care than Vale could provide. Then Sister Marie remarked that Antoinette had been coming to the Home regularly anyway. Application and admission were mere formalities.

Sister Marie granted permission for me to go to Antoinette's room and when I entered, I saw balloons floating on the ceiling. Birthday cards with warm wishes were neatly placed side by side on the bedside table, along with wrapping paper suggesting she had received a gift. Antoinette welcomed me and eagerly told me that the day before had been her birthday. She told me the Sisters baked her a cake; that she had coffee and cake a few times; and that she enjoyed the day. She was still smoking her beloved cigarettes she purchased at Walgreens where she was well known and liked. She appeared tired, so our visit was brief.

Two weeks after that visit, in a conversation with Sister Marie, I learned Antoinette died. I was told she had a child or children and family but did not want them contacted. She further remarked that Antoinette was very secretive about her life and shared very little: she had been a waitress and appeared to live a "normal" life until, at some point, had a "mental breakdown."

Sister Marie also recalled that a couple of nights before she died, Antoinette could no longer stand or walk. In keeping with her feisty nature, she tried and tried again to get out of bed and

roam as she had before. She had difficulty breathing and eventually accepted her limits and remained in bed. The Sisters sat at her bedside. She was never left alone. A couple of hours before her death, as one Sister sat vigil, Antoinette whispered breathlessly, "I've been a good patient, haven't I?" With the reassurance she had been a good patient, Antoinette died.

What can we learn from Antoinette's story? Her desires were simple: autonomy (to come and go as she pleased), independence (to make decisions about her healthcare needs and preferences), attendance at Mass (to experience the sustaining benefits of prayer), invitations for conversation (to confirm that others were interested in her and for companionship), and coffee, cookies and cigarettes (for sheer enjoyment). Spiritually informed care came naturally for the Dominican Sisters of Hawthorne who provided comprehensive care throughout Antoinette's illness and at the end of her life. Like an abstract painting, spiritually informed care, added texture, shape, color and value to Antoinette's living and to her dying.



Martha Hovenden and Her Dog, 1888, by Helen Corson Hovenden (Woodmere Art Museum: Gift of Ann and Roy Wilson)

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