

**Statement by  
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**Hearing Title:** "Empowering Patients and Honoring Individuals' Choices: Lessons in Improving Care for Individuals with Advanced Illness"

Good afternoon, Senator Whitehouse and distinguished Members of the Committee. Thank you for your time, and attention to my story. I am Dr. Gail Austin Cooney. I have spent most of my professional life as a physician working in the field of hospice and palliative medicine, on both a local and national level. Today, though, I am going to talk about my personal experiences as a patient receiving palliative medical care. I know that I would not be here today if it was not for the support of my palliative care team. Because this is a new concept for many people, I would like to begin by defining palliative care in a way that is most easily understood:

*Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age, and at any stage in a serious illness, and can be provided together with curative treatment.*

For me, the key message is that palliative care puts a focus on quality of life while pursuing curative treatments. Without excellent symptom control, education, and psychosocial support, I would not have been able to tolerate the treatments of my disease. Because I was able to tolerate the treatments, I am here to talk with you today – feeling as well as I look!

In 2008, I was asked to develop a palliative oncology program in West Palm Beach, FL, where I live. The program was scheduled to open in August. On the morning of July 27<sup>th</sup>, I walked into the office of one of the oncologists to ask her about the abdominal swelling I had noticed over the previous 2 weeks. Within hours, I found that I had Stage IIIC metastatic ovarian cancer. Two days later, I had extensive surgery to resect as much tumor as possible. The surgery is difficult. Ovarian cancer spreads wildly within the abdomen. I compare it to throwing a carton of yogurt at a black velvet painting, and then trying to clean it up.

I got through the surgery. My oncologist told me that I would next need intra-peritoneal chemotherapy. This involves injecting highly toxic chemotherapy into the abdominal cavity, trying to put the drug directly in contact with the remaining tumor in the abdomen – the remaining yogurt that's stuck to the black velvet. Only 40% of women are able to tolerate and complete this treatment. With it, about 1/3 of women survive for over one year. I wanted to be one of those women! But I knew that I would need help to tolerate the treatments.

Because of my professional experience, I knew that I needed the help of a palliative care team. Sadly, the value of palliative care delivered from the time of diagnosis is not well known to either the medical community or the general public. That is something I want to change, and it is why today's hearing is so important.

I actually became one of the first patients at the palliative program that I had just developed. My oncologist led my palliative care team. She is board certified in both oncology and hospice and palliative medicine. She helped me to develop a plan to control the symptoms, pain, and stress of my disease and of its treatment.

Nausea and vomiting were my biggest initial concern. Dr. McKeen prescribed medications to take – before, during, and after each treatment. She recommended acupuncture twice weekly, both for my nausea and to enhance my sense of wellbeing. My husband and I saw the team's psychotherapist and we learned how to talk about my disease with our children and how to support one another. We talked about our fears; I was afraid that I was going to die. I learned to take each day as it came.

As other problems arose, I had a structure to help address them. Even though I was a physician, I knew little about chemotherapy. Now, I had my palliative care team to help me identify solutions to the problems. I had my last chemotherapy on Christmas Eve in 2008. Two months later, my cancer was officially in remission.

Gradually, my strength returned, my hair grew back, and I went back to work, sharing my new perspective with the patients and families under my care.

And then, two years later, the cancer came back. I felt fine but it was back. My palliative care team again helped me to understand and sort out the treatment recommendations – chemotherapy, surgery, or both? In what order? I speak “doctor” and I still needed help to understand my options and my personal goals. This was even more difficult than my initial treatment decisions: with each recurrence, there is less and less “solid” data on what the next steps should be; the decisions become more and more dependent on the patient's personal goals. I needed help to sort those out.

Oddly, I know exactly what I want if I am dying; but figuring out what I want when I am living with a serious illness requiring complex treatment – I didn't know how to do that!

My husband and I decided on chemotherapy, possibly followed by surgery to “clean up” any residual tumor. This course of treatment lasted longer – 6 months – but because the chemotherapy was intravenous and not in my belly, it seemed like a piece of cake. I went back to my acupuncture physician, saw the oncology psychotherapist, and kept working. So far, so good.

Then there was the surgery: it didn't go quite as well. I had that surgery one year ago, on my 59<sup>th</sup> birthday. It's the last time that I will do that on my birthday! I had my surgery at MD Anderson Cancer Center, in Houston, by the best surgeons in the business. I still had problems. I developed infections and my kidneys shut down. I nearly died. Once again, I knew to ask for help. Luckily, I know some of the palliative medicine physicians at MD Anderson, so I called them up. They sorted out my pain. They helped both me and my husband to talk through our feelings about the complications I'd experienced. I made it home. I got sick again – more infections in my abdomen. But my local palliative care team was there again, too. This experience really shook me and my needs were even more spiritual than emotional. They helped me to find the resources I needed for support.

I am back at work again – still me, but different. With my patients and families, I have a new understanding of their needs and the difficult decisions they face. I also have a passion for sharing my experience with palliative care because I know that it is what people need when they are facing serious illness. I know this from personal experience.

As difficult as this journey has been I know I am lucky. I have a husband and family who love and stand by me. I have great health insurance and have not been bankrupted by this illness. And just as important, I have access to superb palliative care teams and expertise. Without their support I would not have been able to be here to talk to you today.

People with serious illness, me now and eventually each one of us- need your help to make this kind of care- this added layer of support- available to all Americans. To provide the Committee with additional information about palliative care I would like to submit in the hearing record an April 2012 National Institute for Health Care Management Expert Voices In Health Care Policy paper authored by Dr. Diane Meier, MD

Thank you, again, for making this discussion possible.