

Keynote Address: *When Breath Becomes Air*— As Physician Becomes Patient

Presented by Lucy Kalanithi, MD, and Heather Wakelee, MD; moderated by Robert W. Carlson, MD

Abstract

As part of the NCCN 22nd Annual Conference: Improving the Quality, Effectiveness, and Efficiency of Cancer Care, Lucy Kalanithi, MD, wife of now-deceased best-selling author Paul Kalanithi (*When Breath Becomes Air*), and Heather Wakelee, MD, Paul's oncologist, discussed—for the first time together in a public forum—Paul's experience of going from a neurosurgery resident to a patient with cancer with a terminal diagnosis. Robert Carlson, MD, moderated the discussion.

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When Breath Becomes Air is the best-selling memoir written by Stanford neurosurgeon Paul Kalanithi, MD, about his experience of living while dying of stage IV lung cancer. Much has been written about this exceptional book. For the first time on a public stage together, Paul's wife, Lucy Kalanithi, MD, Clinical Assistant Professor of Medicine, Stanford School of Medicine, and his treating oncologist Heather Wakelee, MD, Associate Professor of Medicine, Stanford Cancer Institute, discussed Paul's remarkable life and experience as a physician-turned-patient. Robert Carlson, MD, Chief Executive Officer of NCCN, moderated the discussion.

Dr. Wakelee explained that she had worked at the same hospital, but she didn't get to know Paul until he was her patient. "It is a different interaction when a colleague becomes a patient. He faced his cancer in a brave manner. In his book, he captures the concept that even though he was dying, he really lived life fully for the time he had his disease. This memoir can help us communicate with our patients about that concept," she said.

Balancing the Personal and the Professional

In discussing the balance between Paul's life and his work, Dr. Kalanithi noted that a *New York Times* review of the book stated that Paul had "postponed learning how to live while pursuing his career in neurosurgery," but that she felt Paul might say that was not accurate.

"He was living while he was a resident," she said. "It was the meaning of his life. It was also a liability to be so passionately involved in medicine, and in the book, he accurately describes the tensions inherent in a dual-physician marriage," she told the audience.

For Dr. Wakelee, an important aspect of Paul's book is the value he placed on treating his patients as people. Even when exhausted or frustrated, he focused on connecting with the patient as a person. "His book brings up the idea of finding the right balance between work and personal life. We need to set aside time for family and time for ourselves, and then always remember that the patient interaction is about the patient, and have the energy to give to them," she said.

Dr. Carlson noted being struck by something Paul wrote about his first encounter with Dr. Wakelee, when she said to him and his family, "I'm sorry this is happening to all of you." Dr. Carlson found that "remarkably simple but powerful."

"Each family is different, and each patient is different," Dr. Wakelee replied. "Cancer can happen to anyone. I try to communicate with each person in terms of where they are coming from and not use the same words every time. It is critical to try to put ourselves in the patient's shoes." She said that she tailors the conversation according to the way patients and their families react to what she says.

Doctor–Patient Relationship

“How did you experience Paul’s transition to being a patient? Were there specific encounters that helped solidify the doctor–patient relationship?” Dr. Carlson asked.

Dr. Kalanithi explained that Paul attributed weight loss and back pain he experienced during his residency to working long hours. Then a chest x-ray showed nodules in his lungs, and he was diagnosed with stage IV disease. “It was an intense transition for him to become a patient,” she said.

“When Paul was my patient, we focused on his living, not on Paul as a physician,” Dr. Wakelee commented. “I never talked with him about being a physician. He and I shared the same philosophy about communicating with patients.”

“When training doctors and nurses, I focus on the importance of continued communication with the patient and the family. You may not remember the patient well in a month, but the family will likely remember your conversation with the patient forever,” Dr. Wakelee added.

After Diagnosis

Dr. Carlson asked about how Paul’s diagnosis affected his sense of time. “Paul wrote about how planning for the future was eclipsed by the urgency of the moment,” he said. “There is a ‘time warp’ when you are diagnosed with a terminal illness. How did this affect Paul’s behavior?” he asked.

“Time stood still and sped up at the same time, especially when he was getting sicker,” Dr. Kalanithi explained. “He said that time used to feel like linear progression, but now it feels like a space.”

“The benefit was that we focused on our family right now without thinking of the future. Paul was goal-directed, and his identity as a chief resident was wrapped up in the future. He wrote, ‘the future I had imagined evaporated.’”

He was able to work as a resident for a year while he was on erlotinib, but when the treatment failed, he had to recalibrate, Dr. Kalanithi noted. “At that time, he got the book deal and started writing. Stage IV cancer disrupts your identity and purpose. Paul’s writing kept him rooted and participating in the world. He knew his book would outlive him. His book saved him in a way,” she said.

Physicians in the Family

Dr. Carlson noted that Paul’s wife, father, and brother were physicians. He asked whether being in a physician family was helpful, harmful, or neutral. Both Dr. Kalanithi and Dr. Wakelee agreed that having physicians in the family was a plus.

“I think having doctors in the family is a blessing,” Dr. Kalanithi said. “We had no illusions about a lengthy prognosis, but our being physicians helped us make decisions. The healthcare system can be confusing to people, and being physicians removed layers of stress. It was still unbelievably challenging,” Dr. Kalanithi told listeners.

Dr. Wakelee added, “It’s a smoother conversation when your patient and spouse are physicians. Oncologists understand that there are things we do not know: How long someone will live? Will the medication work even if it is supposed to? I’ve had patients who were engineers or venture capitalists who believe that every problem has a solution. It is easier to have a patient like Paul who (inherently) already understands that there are things that are unknowable.”

Dying in the Hospital Versus at Home

Dr. Carlson asked about decisions made during Paul’s final days, when he was aware that time was short. “How did you make decisions about intubation, withdrawal of support? Would you make the same decisions again?” he asked.

Dr. Kalanithi noted that the experience of Paul being in the intensive care unit (ICU) was positive in that he had a lot of support and was comfortable. “End-of-life care for a patient with metastatic cancer is sort of a quality measure. He had to choose between a clinical trial or hospice, and he chose the trial. We knew there was a chance he would have a disease flare when he had to stop the [medication] during the washout period. He did have a flare and experienced respiratory failure. He was rushed to the hospital with all respiratory parameters worsening. We made the decision not to intubate when it was clear that he might be mentally compromised and would not be able to write, and also it was likely that he wouldn’t come off the ventilator.”

“He died in a situation that made total sense. He was on comfort care. The signs, sounds, smells, and noises in the ICU were familiar to him as a neuro-

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surgeon. The staff made us feel comfortable. I had imagined that Paul would die at home. I am almost glad he didn't die at home. I will never read the sentence 'he died peacefully surrounded by his family' the same way again, because the emotional experience for all of us in the room was so intensely painful, even though it was peaceful," Dr. Kalanithi acknowledged.

Dr. Carlson was interested in the decision the Kalanithis made to have a child after he was diagnosed with a terminal illness.

"We raised a lot of eyebrows by doing that," Dr. Kalanithi said. "Paul wrote, 'I knew a child would bring joy to the whole family, and I couldn't bear to picture Lucy husbandless and childless after I died, but I was adamant that the decision ultimately be hers.' The pain and joy were magnified. Meanwhile, I have to help Cady understand where she came from. She will have the pain of not remembering Paul," Dr. Kalanithi responded.

Meet the Panelists

Robert W. Carlson, MD, moderator: Chief Executive Officer, National Comprehensive Cancer Network, Fort Washington, Pennsylvania.

Lucy Kalanithi, MD: Clinical Assistant Professor of Medicine, Stanford School of Medicine, Stanford, California. Dr. Kalanithi is the widow of the late Dr. Paul Kalanithi, author of *The New York Times* bestselling memoir, *When Breath Becomes Air*, for which she wrote the epilogue.

Heather Wakelee, MD: Associate Professor of Medicine, Stanford Cancer Institute, Stanford, California. Dr. Wakelee was the late Dr. Paul Kalanithi's treating oncologist.

Dr. Wakelee noted that she did not participate in the Kalanithis discussion about having a child and did not think that the family should have consulted her. "It was the right decision for them. It wouldn't have been for a lot of people," Dr. Wakelee said.

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Curriculum*

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| 7:30 – 8:15 AM | Breakfast and Registration |
| 8:15 AM – 2:15 PM | Module I: Ensuring Development and Access to Innovative Therapies |
| | Module II: Meet the NCCN Guidelines Panel Experts |
| | Module III: Patient Advocacy Update: Policy, Programs, and Effective Collaborations |
| 2:15 PM | Closing Remarks |

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