



Building a legacy of hope

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The team asked me to meet with you to discuss hospice. Your illness was serious, and they weren't sure that you "got it". My first impression of you was vastly different than expected. You were as sick as described, surrounded by medical equipment and wound dressings. However, I soon forgot that I was in the hospital and instead felt that I was meeting you, an accomplished and respectable businessman, over coffee. I asked you to share your story.

You talked of your ambition—before the pandemic, you had a steady, well-paying job. When that opportunity crumbled, you never imagined that you would be left jobless. You never thought that you would burn through your savings or lose your apartment. While this string of events would have left anyone else disheartened and disillusioned, you became only more motivated to change the system. I expected to hear about your illness and how it impacted your life; instead, I heard of your plans to lobby the local government and apply for new jobs.

I found myself struck—and, honestly concerned—by how you talked about the future. Shouldn't you be thinking more about what you would want your final days to look like? Is it realistic to be planning to apply for a new job? "The team must be right—he really doesn't seem to get it..." I thought to myself as I prepared to deliver my headline. "I'm worried that you're dying". You looked at me, contemplative. You quickly shifted the conversation back to your plan to work and study at the local university.

In this moment talking with you, I felt acutely aware of the conflict between the life you were envisioning and the life you were living. Because of circumstances out of your control, you were committed to managing serious illness

without much social support, healthcare resources, or safe lodging. You struggled to keep up with your medical care—both because it was hard to take medications without safe storage and because you faced judgment and shame from your providers. You are not alone in this experience. People experiencing homelessness are more likely to have serious illness and are more likely to die young than people with stable housing (1).

People like you who are experiencing homelessness deserve high quality palliative care, but there are so many barriers (1). It's challenging to seek care when your immediate priorities for survival are finding food and shelter. It's hard to have adequate symptom management when many shelters have restrictions against certain medications, when it is unsafe to carry medications with you, and when stigma and bias deter doctors from prescribing appropriate therapy. And, it's nearly impossible to work with hospice teams when you are moving between the street and various shelters. Because of these and other barriers, your serious illness became just another part of your life where you were stripped of autonomy and control.

This came into focus when we discussed moving you to an inpatient hospice unit—described by many as heaven on Earth compared to the cramped, shared hospital rooms. You surprised me when you refused. "The food is good here. I feel safe here in the hospital", you said to me. You helped me to understand how three consistent meals and a warm bed allowed you to feel a sense of security you haven't felt in months. I came to appreciate how important your independence is to your identity and how losing that independence challenged your sense of safety.

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As you described your hopes for the future, I heard the strong sense of meaning you found in your life. You shared that you weren't afraid to die. You talked of reconnecting with loved ones and making sure that they would be okay without you. You described your faith, how it brought you strength, and how you believed that each of us have our own purpose. We discussed your fears around death and dying; more than the uncertainty around the dying process or life after death, you worried about whether you had done all you could to help others. I realized that it wasn't that you "just didn't get it". You "got it" more than any of us; you had a true appreciation for your mortality. "I know I'm going to die. I'm not saying you're wrong, but I just don't think it will be right now. I still have a purpose in this world", you confided.

In maintaining what I would have initially called "hopeless optimism", you were working to create a legacy for yourself. If you couldn't control your living situation or your job, you could control the way that people remembered you. Through your last moments, you continued to hold hope by building your legacy. In caring for you, I found myself reflecting on the idea of hope. Heartbreakingly, it was your steadfast hope that made me so uncomfortable in our initial conversation. In retrospect, I wanted you to accept your impending death. I hoped to afford you power and control in the form of knowledge and understanding. However, I admit that I also wanted to absolve myself from the question of whether I was able to effectively be honest with you; I didn't want you to be upset with me when you got sicker.

I am humbled to realize that by trying to impress my own views upon you, I was taking more control away from you. And, I was blinding myself to the true message you were trying to convey. It became clear that, like so many others (2), you found hope in positive thinking, your sense of connection to your community, and your desire to make a difference in the world. Although archaic, a definition that fits your version of hope is a "feeling of trust (3)". Through building a legacy of shared wisdom and advocacy for the underdog, you reclaimed your independence and cultivated a feeling of trust in yourself that you were living out your purpose. In planning your future, no matter how unlikely, you were doing all you could to prepare yourself to peacefully accept whatever may come.

As I write this, I hope that I am honoring that legacy you created. I remember you sharing your perspective on the learners on your care team—"if anyone can learn

something from my life and use it to make things better for someone else, then it's a good day". While you were never able to interview for that job at the university, you were able to teach countless nurses, medical students, residents, and fellows. You challenged our perspectives. In the face of homelessness, you showed us how to maintain generosity, faith in others, dignity, and independence. In confronting serious illness, you showed us how to create hope in even the most dire circumstances.

I expect that I will be in similar situations again when I feel the urge to make sure my patients "get it". I have faith that in that moment, I will remember our first meeting and allow space for hope. Because aren't they almost interchangeable, maintaining hope and building legacy?

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