



Homeless and ill. © Frank Windgassen.

## Caring for the invisible and the forgotten

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Illness isolates; the isolated become invisible; the invisible become forgotten.

—Elisabeth Tova Bailey<sup>1p132</sup>

I was recently asked to speak to the class of graduating medical students on the topic of humanistic care in medicine. Always after receiving those sorts of invitations I start fretting about what I can possibly say that will be meaningful, memorable, and maybe even a bit profound. On my morning runs, at night lying awake, and on my drives to and from the clinic, I propose, formulate, and discard potential topics based on what I think would be of interest to the group in attendance. This time I had the good sense to ask one of the student organizers what she thought would be of value to upper level medical students who were just a few months shy

of starting their residency training. “Just talk,” she suggested, “about your own work in medicine and what we might learn about patient care.” Following her advice, I began to think in a more deliberate way about my patients, and their struggles, and what they have taught me over the past several decades. I focused upon trying to describe what I have learned as a physician about patient care from persons whose illnesses have frequently driven them into the shadows of our society and, oftentimes, outside the web of human relationships.

For twenty-five years I have been providing care to patients whose illnesses contribute to the most devastating form of suffering: human and social isolation. Through my work as an academic community psychiatrist I have been given the somewhat unique opportunity, and privilege, to dedicate my full professional energies to caring for mentally ill persons experiencing homelessness. My patients are those who, for the most part, have received the bulk of their health care through safety net clinics, emergency departments, public

crisis units, jails, and prisons. They have been treated by a myriad of different unfamiliar providers, most commonly under rushed and less-than-caring circumstances. Over the years I have come to fully appreciate that they shoulder burdens most of us cannot begin to fathom. And they have taught me everything about the grinding pain that arises from human isolation and aloneness.

My inner-city clinic welcomes those who spend most of their days in solitary wanderings through our city streets, oftentimes wholly preoccupied with bizarre ruminations or engaged in conversations that only they can hear. Even though we have a medical street outreach team that tries to engage individuals experiencing chronic homelessness, most remain unseen and unnoticed, invisible to the many who pass by on their morning treks to work or on their way to grab a quick sandwich at the noon hour. For the vast majority of my patients, the clinic appointment is the one opportunity they have to be heard, to receive attention, and to know that their lives matter and have meaning. In those



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clinic encounters, or during the fleeting stop-and-greet meetings on the street, discussions about medications, treatment plans, and lab results are put on hold. Because the most common shared experience for most of my patients is one shaped by human loneliness and deprivation, my initial treatment intervention is nothing more than undivided attention and empathic listening. I fully believe my most important role as a physician is to show up and, by my presence say, very clearly, “I see you. I hear you.” It is always the first step to coaxing persons out of the shadows and back into the human community where many have come to believe they are unwanted and unwelcome. In fact, some have come to the conclusion they do not exist at all.<sup>2</sup>

A few months ago I was called to the front of the clinic to see a young woman who had wandered in from the streets where she had been living for several years. She was disheveled, malodorous, and seemingly oblivious to the efforts of our staff to gather the usual intake information. She was not one of our regular patients and no one in our clinic had ever seen her before this unexpected appearance. When I introduced myself and asked how I should address her, she reluctantly and guardedly gave her name: “Dead Girl.”

I invited her back to my office and sat with her. She began a long, detailed account of her nihilistic belief that her internal organs had rotted away and she had died many years ago following the suicide of her boyfriend. She had lived mostly on the streets over the years, but had become a “ghost” who was invisible to others. “No one can see my face,” she explained, “since I’m dead.”

As I often do during that tenuous slow dance of building trust, I worked hard to speak little and to listen much. I later learned that her name was Robin and she had experienced at a young age the sorts of horrifying trauma that can wound persons beyond repair. As a child she saw herself as being invisible to the family who was supposed to care for

her and, later, to the agencies that were supposed to protect her. Now, many years later, her illness made her invisible to those who walked by her every day. Instead of interpreting the chronic social ostracism as human rejection, she had developed the delusional belief that she was no longer a living being who could be seen. Obviously, it was much more acceptable for her to believe that she was invisible rather than ignored and forgotten.

Then there is Willie, a middle-aged gentleman who suffers from the ravages of rheumatoid arthritis and schizophrenia, who we seek out every couple of days through our medical street outreach team. Gaunt and drawn from years of being battered on the beach by the sun and wind, he hides beneath layers of blankets and tarps. Several trash bags filled with his personal belongings surround his living space and stand like sentinels that silently warn others away. Each time we make contact with Willie it takes many minutes before he peeks out from beneath what he perceives to be his cloak of invisibility. He almost always acts surprised that we have been able to find him because he fully believes that he is unseen underneath his makeshift cover. And in many ways he is “invisible” since he is surrounded each day by a crowded beach teeming with swimmers and surfers, bikers and walkers, who seemingly are incapable of “seeing” the mentally ill person who is sharing their public space. The contact with our medical outreach team appears to be the only tether to the human community Willie has remaining to remind him he is not invisible and he is not forgotten.

The fundamental acts of relationship and human connection in medicine can be healing and restorative, as underscored by the physician Richard Gunderman, MD, when he eloquently describes what patients most need from the doctors who care for them:

They need us to be genuinely curious about them and take a sincere interest in their lives, not just with

a view to arriving at a diagnosis or prescribing a therapy, but simply to share their experience. Everyone will get sick. Everyone will die, even the doctor. Medicine may turn the tide for a time, offering a reprieve of months, years, or even decades of life. But the end is always the same, and every human being, even a doctor, needs someone with whom to share it. There are times when our patients need us to be human beings first and experts second.<sup>3</sup>

My patients who struggle with chronic homelessness have been exemplary teachers when it comes to understanding the therapeutic value in medicine of an empathic presence, other-directed attention, and human recognition in the slow work of healing. They have taught me that physicians must always be willing to recognize those patients who, because of the depth of their illness and suffering, are isolated and alone, unseen and forgotten, whether they are living on the streets of our cities, occupying an ICU bed within a teaching hospital, or sitting alone on the edge of a bed in a skilled nursing facility. And, as physicians, I would hope the initial impulse and response that begins the process of healing will always be, “I see you. I hear you. You are not invisible.”

### References

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