POLICY FORUM

Embracing Patients’ Wishes—and Stories—
As the Basis of Serious Illness Care

Introduction

At heart, we are all storytellers. Many of the articles in this issue wrap science and best practice around a kernel of heart-moving, soul-changing story. All too often, our practice has had to catch up to what the heart and soul already felt.

We’ve seen, we’ve listened, we’ve witnessed, we’ve cried, and we’ve yearned to make the experience of death and decline more dignified, more sensitive, something that belonged to the patient and the family, not bound by a process or a system.

We all have these stories—or we will, as clinicians, sons, daughters, mothers, fathers, friends, and family. We once hid behind our clinical expertise, until the wise pioneers of hospice and palliative care told us this is clinical practice. This is what our patients and families have yearned for us to hear—that their wishes are the basis of practice. What we might have uncomfortably turned away from to seek a diagnosis or write a prescription, we can now approach with awareness, empathy, and best practices. What we missed, we can now listen for and see differently, with mind, heart, and soul, knowing there is much to do. We can honor our patients’ control of their lives and their deaths in practice, record those decisions in writing, and protect those decisions in public policy.

We will practice differently, no longer thinking the most important part of our visit is the treatment plan; recognizing, as has been true, that the story is the most important part of any visit, that listening is a gift, and hearing is the best gift we can give to our patients as illness takes hold of their lives in unspeakable ways—unless we provide a space for words to be spoken, and stories to be heard, witnessed, and taken to heart.

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