Foreword:
Giving the Story Back

The medical encounter is, fundamentally, the creation and exchange of stories between patient and doctor.

It goes something like this: The patient experiences something – we can call it a symptom – and develops his own story about that experience. That story may include elements such as where he was or what he was doing when the symptom began; what it felt like; what he thought of it; and why he chose to seek medical attention. He may then bring that story to his physician. She may then add to it with additional questions and possibly a physical examination; she may order some tests and include those results. It is the physician's job to then reshape that story and give it a name, a title, a diagnosis. She may even add a glimpse into the next chapter – the treatment and prognosis.

Having created a new edition of this patient's story, the physician must give that story back to her patient and to do it in a way that allows him to try it on and, if it seems to fit, to incorporate this new version of his story back into the bigger story of his life.

As physicians, most of what we learn focuses on the first part of that process: how to add to the patient's story, how to reshape it, and how to rename it. We get all kinds of training in making the diagnosis, and in treating the disease captured within the diagnosis, but this whole business of giving it back was for years relegated to the "art" part of medicine and until recently wasn't even taught to doctors. And yet it is one of the most important parts of our job. Done well, the patient has a

sense of what is happening to them, what is going to happen to them, and what can be done.

And we do this all the time. As Jutel acknowledges, when we take something we've experienced to a doctor, we expect a diagnosis. We demand a diagnosis. It seems natural and inevitable. A patient comes in with a fever and sore throat, cough, and body aches during flu season. We swab the back of their throat to confirm what we already suspect – this is the flu – and give them a prescription for Tamiflu. It's an almost invisible transfer of the story from patient to doctor back to patient. But there are other stories that are harder to give back, harder to tell. And those are the stories we never forget.

In my second year of training, I reviewed the chart of a 55-year-old man I'd never met but was supposed to see in clinic at the end of the day. He was a patient of one of my fellow residents and was coming to get the results of a recent CT scan. An unusual reason for an appointment, I thought, until I read the radiologist's report. It was bad. A large mass in the head of the pancreas. So large it was partially blocking the upper part of the intestines. Other masses were seen in the liver as well. The diagnosis was suggested by the radiologist: Pancreatic cancer that had spread to the liver. A biopsy was needed to confirm it. My job, as I could see it, was to let him know that this was probably a malignancy and get him to both the cancer surgeon and the oncologist.

I considered what I'd been taught about breaking this kind of news. We'd had a lecture on it in med school:

First you find out what the patient knows.

Then you give a hint that the news you have isn't good.

Then you tell them what you know.

Then you address their feelings.

Then you get them to see the specialist.

Five steps. Easy.

Because I'd never met this patient, I wasn't at all sure what to expect. From reading his chart, I could see that he was a guy who didn't see the doctor often. His thin chart carried only his insurance information and notes on the two visits he'd had with my colleague the week before. He'd come to see a doctor because he was vomiting any time he ate anything. They tried medicines and when that didn't work, he had the CT scan. And now he was coming back.

He was the last patient on my schedule, and I was grateful. Breaking this kind of news, I thought, could take a while. I had the patient's chart in my hand as I entered the small exam room. I introduced myself

to the patient and his wife and sat down. The patient was very thin and moved restlessly in his chair as we spoke. The mild jaundice from the way this mass blocked the liver made him look suntanned, though there was still snow on the ground. His eyes were nervous, darting. His shirt hung loosely from his thin frame and I could see he'd lost a lot of weight. "Tell me what you understand about what's going on," I said, trying to keep my tone level.

"It's cancer. It's cancer." He jumped up and strode to the window. Turning to look at his wife, he exclaimed, "I told you, it's cancer. If it was anything else they wouldn't have told us to come here today." He glared at me, "I mean, why couldn't you just tell me over the phone?"

Not going the way I expected.

"So hang on," I tried. "Let's not get ahead of ourselves," I said, my voice cracking.

"It's the liver, right, doc?" he turned to his wife. "I told you." Then he turned back to me, "How long do I have?"

"There was a mass seen on the CT scan," I tried again to frame this story in a way that allowed the possibility of hope, of next steps.

Cancer, right?

I tried to explain that a diagnosis wasn't possible based on the CT alone but that was certainly a possibility. The next step was for him to see a surgeon and an oncologist, and I had already made the referrals and had the phone numbers.

"More doctors?" he asked, as if I had suggested some crazy course of action. "I think I've seen enough doctors. Let's go." He motioned to his wife. "I told you this would be a waste of time." He strode out of the room. His wife gathered her coat and purse and followed. I trailed behind trying to slow him down, to have the conversation I'd rehearsed in my head. Near the door he turned to me, "Look lady, I don't want any of this." He waved his hand indicating the exam rooms and clinic. "If I'm dying, I sure ain't doing it here. And if I'm not, no offence but what do I need you for?" And with that he put his arm around his wife and strode out.

It's been 15 years since I met that patient. Though he is long dead by now, I suspect, he lives on vividly in my memory. I've replayed this encounter countless times. Certainly, I could have handled it better. And the set-up was clearly a problem. He'd been stewing about this since he had received the call to come in.

We think of the diagnosis story as our story, the doctor's story. The patient has the symptoms, the questions, but we have the answer, the

diagnosis. But, actually, it is never really our story. It is always his story. In this case, it was a story he'd shared reluctantly. And in the end, he decided to take it back. I don't know how much we might have done to change his prognosis. I'd like to think that, at the very least, we could have made the remainder of his life a little better. But that's not how he wanted his story to end.

In the years since the afternoon of that terrible education, I have seen countless patients, received their stories, done what I could with them, and given them back, as best I could. And yet, for the most part, this leg of the story, this transfer of the story from doctor back to patient, remains murky territory.

Thus, this volume, dedicated to the exploration of that murky territory, is a welcome addition to the scholarship and to understanding diagnosis. The stories I describe above – the patient story before and after and the doctors version in between – are not the only stories at play. These stories have been shaped by other stories: there are those we were taught in school; those we heard others tell before us; those we watch in the news on TV or read in novels or biographies. The stories of diagnosis are everywhere. And they are important. These stories have power to shape how we think, how we feel, how we act. And they have the power to shape the world around us: how we are seen, how we are understood, and how we are remembered. Indeed, the diagnostic story can have power that far exceeds the concrete reality beneath – the actual disease that prompted the story in the first place. The diagnostic story can reveal important aspects about medicine and health, but in *Diagnosis: Truths and Tales* Jutel demonstrates that these stories reveal even more about the world we live in, the roles we inhabit, and the creation and transformation of identity.

This examination of how the doctor and patient see, shape, and understand their respective stories is an important and untold aspect of medicine and society. And long overdue.

Lisa Sanders, MD, FACP