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Understanding and Treating Cancer Fatigue

By Judith A. Greenfield, PhD, RN

Jane Poulson[1], a general internist and palliative care physician who taught communication skills to undergraduates and oncology fellows, thought she knew a lot about cancer and cancer patients. After being diagnosed with breast cancer, however, she realized that knowing a lot about cancer did not mean she knew about having the disease. She could not, she said, "…believe the extraordinary difference in feelings between being the doctor and being the patient in the same clinic".

Chief among her physical complaints was fatigue, which by far exceeded the fatigue she had experienced in her hitherto active, athletic life. Nothing relieved it – not even the things she had typically advised her patients to do. Her experience of cancer fatigue (which she found both physically and emotionally trying) has since led her to campaign for investigators to consider, and study, fatigue as an important symptom of cancer.

For now, however, the question is: what can healthcare professionals do to help their patients deal with cancer fatigue? One answer is to direct patients and their families to visit http://www.cancerfatigue.org/, the website of the Oncology Nursing Society (ONS). Although the site's offerings are targeted to patients, professionals can also benefit from the information contained therein – some of which includes information about rating and managing fatigue as well as listings of times and dates for free educational teleconferences. Last, but not least, offering a sympathetic ear to patients' complaints of fatigue, and validating the reality of it, can help lessen any emotional downslide it may evoke.□

[1] Jane Poulson, "Patient Perspective: The High Cost of Wisdom", *Medical Encounter* 15(3): 8-9 (Summer 2000).

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Adrienne's Voice

By Dennis Novack, MD

In 1991 I published a story entitled "Adrienne" in Medical Encounter, telling about my relationship with a young woman patient who died of breast cancer at the age of 33, when I was a senior resident in medicine. But before her death, Adrienne had spoken for herself and I am lucky enough to have the tape of what she said.

She was an assistant professor of English literature at a local college. She felt that medical professionals could do much better in communicating with their patients with cancer, and offered to talk with our staff. She agreed to be part of a panel discussion that also included her oncologist, a nurse, a minister, and me. It took place on December 6, 1973. I advertised it for all hospital personnel, and about 200 people attended. It was an extraordinary and moving event.

A few weeks ago, as part of our first year clinical skills course at MCP Hahnemann, I was supposed to interview a colleague with metastatic cancer in front of the class. My colleague begged off, and, looking for a good substitute, I remembered that I had taped that panel discussion with Adrienne. I sent students a copy of the "Adrienne" story, which was re-published in revised form in the Annals of Internal Medicine 1993:119, 424-425. During the class, I played the recording of Adrienne's opening comments, which students were also able to read on a Power Point slide presentation while she spoke. Adrienne's remarks about the experience of having metastatic breast cancer, and the communication issues involved, were moving, valuable, and enlightening 25 years after her death. (After the students heard her comments a panel discussed the issues that she had raised.) Below is an edited version of her remarks. I would be glad to make copies of this audiotape and Power Point presentation available at cost for those who might want to duplicate this kind of teaching session.

"I wouldn't be a doctor, your kind of doctor, for all the tea in China. I think being a doctor or a nurse is an extraordinarily difficult profession. You spend endless hours on your feet, you never have time to eat, or watch television, or make love. Everything gets crammed into corners and you spend endless time filling out stupid forms. You have patients who never come when they should and others who come too often and won't stay away. You are called on to be eternally patient, eternally understanding, always good-tempered. I think it's extraordinarily difficult, and I sometimes wonder why it is people become doctors and nurses.

One reason, of course, is that it gives instant respectability. Another is that you really do want to help people. You are concerned that people are ill. You want to help them out with their pain. There is another side of this, however. I think one of the reasons that some people go into the medical profession is because it is the ultimate power trip. You're on the side of the gods. You have the power over life and death. In the profession of teaching one also has power. Unfortunately, in teaching, the correlation between what people learn and what you did to make them learn isn't nearly as obvious as giving someone a pill.

I think there's a fourth reason people go into the medical profession, and this is perhaps the one that is the most difficult. This is that you are terrified of death yourself, and one of the things that happens if you put yourself on the side of the gods is that maybe you can stave off your own illness, your own death. The problem, I think, that the medical profession faces when it hits someone like me is that I am the "F" student. I am the kind of person who is not going to get better.

Some people just run away. Running away can take the form of seeing a patient as little as possible, not answering the bell, running in and doing your thing and running out again as quickly as possible, trying not to get too close to this person and turning them over to somebody else, putting them on another floor, finding another doctor for them; anything so long as you don't have to cope with it. That's one possibility, and it's a possibility I've seen. The second possibility, I think, is to become very authoritarian. There is an inbuilt uncertainty, I think, in your profession in that you have to deal on a statistical basis, but you've got no real idea exactly how any given drug or treatment is going to affect any given person, and that is very insecure-making for you. And your authority is being threatened by the fear of failure. So that one way out of your fears is to become very authoritarian indeed, lay down the law, say, "you must do this;" "this is what's good for you; no questions asked."

Fortunately, I think there is another alternative, and that is the doctor who is willing to admit that he or she is a person, that he or she is afraid of the same kinds of things that patients are afraid of and is willing to treat the patient not as a case, not as a statistic, but as a person. It seems to me that the greatest failure in the medical profession is those who ignore the responsibilities that their power gives them and try to treat patients as if they are cases that you talk about in the hallway, and talk about the appendix in room 420, and the mastectomy in 421. I've heard these conversations. I know the degree to which it is very easy and, in fact, even necessary for you to behave as if the illness is something separate from the person.

My Own Reactions

Perhaps my own emotional reactions can be some kind of guide. I think the first reaction I had when I was told that that funny little lump in my breast was yes, a cyst, but goodness gracious, there was a cancer underneath, was sheer disbelief. You can't do that to me, there must be some mistake. I am not that kind of person. You know it's other people who are sick, it's other people who have cancer. You're in a kind of catatonic state of shock, incredulity, and I think this is the point at which you often encounter the people in the hospital. I think one problem that you have is assuming that people want to talk about things. There is a certain period in which it's just not possible for a patient to talk. The point at which one can start to verbalize comes rather later on. The initial reaction is simply shock.

For me, the second reaction was a sense that my whole life had been changed in some way, that all of the things that I thought about myself had suddenly come to a point of discontinuity. I felt I was being cut off from my past and so uncertain about the future that there was no sense that I was still the same person all the way through. I think this sense of discontinuity is very strong. It goes along also with a sense of real impotence. I think one of the problems about cancer is that, unlike a number of other diseases, it's so metaphorical, it's something, somehow attacking you. There's a real sense of something invading you from outside and destroying your integrity.

The problem with being in a hospital, is that you're flat on your back. You have absolutely no power of any kind. You can't control what time your lunch comes, and you have a minimal choice about what you are going to have for lunch. It's extremely difficult for a patient to keep any sense of what they really are. You are, for the most part, talked to as if the beginning and end of your life is in the hospital. You are a patient in there with something, once you move out of the hospital then presumably you take up your life. But that has no relevance to your being in the hospital for the most part. I think this is a very distressing feature of hospitals.

One of my healthier reactions was pure fury. The first time I was in the hospital I spent most of the time in a complete rage, which I regret to say I think I took out on the medical staff, who were very patient with me. After the first operation, after the mastectomy, because it appeared so statistically improbably that this would metastasize, I was lulled into a period of saying I have had cancer so I've lost one of my breasts but now I'll go on, and I'll go back to where I was. I think a mastectomy is one of the most humiliating and depersonalizing operations in the world. One's self-image is very much tied up with one's physical self-image. If your physical self-image becomes radically changed, then who are you? Are you a different person? How do you relate to the person who originally had two breasts? I don't think one ever adjusts to having only one breast. I've talked to much older women who've had mastectomies 10, 20, 30 years ago, and they still haven't adjusted either. It's something one copes with, but it doesn't ever go away.

When I found that the cancer had metastasized, I had some of the same original reactions – shock and horror and disbelief and anger. But there is a new problem in self-identity: I now had to say I am not a person who has had cancer. I am a person who has and will continue to have cancer. I am a cancer person. More obviously, I had to deal with the fact that the probability of my dying of cancer is extremely high. There's still a chance given the number of people in this room that one of you is going to die before me. My big advantage is that I know it, and you don't. I think that there has been an ongoing process of adjusting to a whole new image of myself and rediscovering those parts of me that are in continuity; and this is where I think I'd like to go into the question of what the hospital staff can do, hospital medical staff can do.

What Hospital Staff Can Do

To combat the complete impotence and lack of control that I suspect is true for most patients and most diseases, hospital staff can allow choices as far as possible. There are a number of areas, which to you may appear trivial, but I think to patients can be very important. I personally dislike intensely that for the most part, hospital personnel never ask me how I want to be addressed. Now I am sometimes called Professor Lockhart, I'm sometimes called Dr. Lockhart, I am sometimes called Mrs. Lockhart, I am sometimes called Adrienne. And it seems to me that all of those represent certain aspects of me. But if I were given a choice in the hospital as to which name I were being called, I would have some sense that I had an element of control. I think that being automatically called by your first name is humiliating, particularly when the person who is addressing you happens to be 15 years younger than you. It's a very small thing but it's something that symbolically is important to patients.

One of the complaints that almost all patients I know have is that if they're in for longer than a week they can't wash their hair. This is not, I think, a trivial thing. For most people their whole sense of being themselves is tied up with being able to wash their hair at regular intervals. If you have been lying in a hospital bed for two weeks and your hair is in strings and you just lost a breast, it’s pretty hard to regain any kind of respect for the possibility of your appearance.

The most difficult part for you is that in order to treat the patient as a person you have to know something about them. You have to know what are the kinds of things that matter to them. Where are their real interests? What are the things that would provide continuity? Are they people who are family people? Are they people who are professional people? Are they people who are terribly interested in the arts, or something? If you know that kind of information I think you have a basis for encouraging the patient to maintain a sense of continuity, which will go a tremendous way towards making you not feel isolated, not alienated, not a patient. I am not a patient, that’s not my image of myself and if I’m constantly treated as if that is the beginning and end of my life, then it’s very hard for me to cope with my feelings of discontinuity and impotence.

But it means a lot of time on your part. It means a lot of patience. It means a lot of sensitivity. You obviously have to be aware that one of the reasons that you don’t ever do that – or don’t do it very often – is that you’re very afraid; and I think you should be as aware as possible of the degree to which it’s your fears, finally, for yourself, rather than my fears for myself that are getting in the way. Patients may or may not want to talk about this. I think the people in the hospital who have helped me most are very often those who haven’t been at all verbal. The nurse who came in and said, “you have pretty hair, would you like me to brush it? It’s hard for you to brush it with your arm in the state that it is.” A charming student nurse who came in and simply talked to me about my work and asked perfectly honest questions, was willing to admit that she was curious. Obviously, people are curious. There are a number of you who are sitting there trying to remember which side it is that I don’t have a real breast. I find that curiosity perfectly normal and not at all offensive.

I think what I want to say in the final analysis is that for me the whole process has been, finally, a positive one. If I can accept my own death, there’s not much that anybody can do to me. I’m invulnerable to normal kinds of threats in a way I never used to be, because I have that kind of perspective. I also do more things. I do things that I want to do instead of saying when I’m 50, I will. I am doing it now, and I’m simply enjoying life a lot more. Because I’m aware that being a cancer patient is being a minority, I think I have a much greater understanding of other minorities. Particularly elderly people, for example, with whom I now have more in common. And, I think to go right back to the beginning, it’s given me a much greater understanding of the medical profession and how difficult it is. I find learning to treat you people as people, is finally very rewarding, because on the whole, you are very nice people. And there are things I think that I as a person can do for you as people since, finally, we’re now on opposite sides of the table or the bed as the case may be, but we are working in the same area.”□

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The Importance of Treating Persons

By Judith A. Greenfield, PhD, RN

The test of a system of medicine should be its adequacy in the face of suffering.
Eric J. Cassell, MD in *The Nature of Suffering and the Goals of Medicine*

One message that Adrienne seems to be sending is that a large part of her suffering stemmed from a sensed loss of identity. This sense of loss, as she describes it, arose in large part from the fact of her illness. Where once she was a person of good health (in all her different aspects), now she was not. For her, as for many others, this loss of identity extended well beyond the physical.

How can healthcare professionals help patients with such debilitating, life changing, perhaps even fatal, identity-stealing conditions? What can they do, when nothing can be done to change the physical effect of these conditions? If Adrienne's voice is to be heard, the simple act of seeing and relating to patients as persons, not diseases, would be immensely helpful.

Cassell makes the same argument. In *the Nature of Suffering*, he builds a strong case that getting to know and treat patients as persons goes beyond leaving them more satisfied with encounters. It can, he claims (as did Adrienne), help patients regain positive self-identities. This, in turn, can serve:

> *…to heal the sick; to make whole the cured; to bring the chronically ill back within the fold; to relieve suffering; and to lift the burdens of illness (p. 69).* □

Judith A. Greenfield is contributing editor of the *Healthcare Communication Review* and President of the Healthcare Communication Project, Inc.

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