

Letter to a Patient's Doctor

As a journalist who has written about the care of the dying (*Life Support: Three Nurses on the Front Line*. Little, Brown; 1997), I recently received a letter from a reader, Mr. Richard J. Arthur, whose wife had just died of breast cancer. After some discussion, Mr. Arthur sent me a copy of the following letter, which he had mailed to the physician who had cared for his wife.

Dear Doctor:

First of all, let me state that this letter is being written with love and respect, not as a complaint or anything remotely close to an accusation . . .

Let me go at it this way.

When you met with Donna and me last March to review the results of the latest bone scan, it was quite obvious that the radiation treatments had failed and that there would be no further medical treatment of the cancer in her spine. But you stood your distance as you talked. And, in fact, you rather shortly dismissed us from the consultation. You will be interested to know that as we left your office, Donna's comment to me was that it was harder for you to talk about the test results than it was for us to hear them.

Doctor, a lot of counseling would have been in order right then and there. She, as a terminally ill patient, and I, as the caregiver, needed to know how the disease would progress. We needed to know what the symptoms would be. We needed you to paint a picture for us, give us a sort of scenario about what we might expect to happen. If it had been your decision not to speak of these things in Donna's presence, you could have asked me to come back for the consultation.

I needed to know that as the pain continued to increase, there were things that could be done. I needed to know that there would be a gradual lessening of her ability to do things. When she began to have difficulty even standing up and sitting in bed, when she began dropping things, I should have been smart enough to know that things were getting much, much worse. Dumb me, I just figured it was part of the ongoing process and nothing to be unduly concerned about.

I needed to know that the effect on her mental abilities would begin to become apparent. Probably the most emotionally disturbing thing that happened was the gradual change in her personality. From a gentle, loving, caring woman, she began to change

to a hostile, accusatory, even embittered person. At first, I took all this very personally. It took some time before it finally dawned on me that the disease was causing all of these things. I remember somebody asking me how I was doing; I replied I was doing okay, except for all the holes in my tongue from biting it so often and so hard.

Finally, Doctor, it would have been tremendously helpful to both Donna and me if you had told us about the hospice program on that March visit. Perhaps you did not think that the time left would be that short, but even so, you could have advised me that the program would be available when things got rough.

As it turned out, I finally gave up and phoned you one Friday. You immediately had a hospice nurse come by that afternoon to sign us up. She took charge at once, changing Donna's medication to morphine and adding some other medications. On Sunday, an aide came and did much to make Donna comfortable; another aide came to bathe her and trim her nails. The nurse herself came by later, even though it was her day off, just to see how things were going. And Sunday evening, Donna died without really waking up since the night before.

Had Donna been in the hospice program much earlier, I would have been able to secure a lot of assistance in taking care of her. It became increasingly difficult to help her shower and shampoo, and I had a devil of a time trimming her nails and keeping her hair fixed in the ponytail that she loved to wear even at 71 years of age.

I am ashamed to admit how unaware I was of the progress of the disease. I should have been smart enough to realize, as these things began to take place, that the end of Donna's life was coming sooner than I had expected. I don't know why I thought it would be months away. Perhaps after 7 years of being her caregiver, I just assumed it would go on that way indefinitely.

There were many things I could have done differently and better. And there were many things that never got done because I just didn't understand the time constraints under which we were living. Her children would have spent much more time with her had I been able to advise them about the seriousness of her condition. Because I did not realize it, I failed to alert them, and I know they feel guilty about not having visited more often.

But enough of this discussion. The whole point,

Doctor, is to try to motivate you into handling your future terminally ill patients somewhat differently. If you yourself don't feel comfortable with doing the counseling, why not get the patient in the hospice program right away? Those people know how to do it, are experienced in doing it, and, as I could tell even from my short experience with them, do it beautifully.

I can't close this letter without once again thanking you for all of the care you have given us, both Donna and myself, over the years we have been coming to see you. I don't know how much longer I will be your patient because this house is entirely too big and expensive for a single person like me to hang onto and I am already looking around for a community to which to move. Until then, however, I'll be bothering you for prescription refills and, once in a while, for an office visit.

I hope your vacation was a great one. I know it was past time for you to get away from all of us sick people for awhile.

Thanks ever so much for listening.
Richard J. Arthur

Sometime later, I called Mr. Arthur to ask if he had ever received a response from his physician.

"Not a peep," he replied.

Suzanne Gordon, BA
Arlington, MA 02476-7121

Requests for Reprints: Suzanne Gordon, 11 Ely Road, Arlington, MA 02476-7121.

Ann Intern Med. 1998;129:333-334.

Coming to recognize you are wrong is like coming to recognize you are sick. You feel bad long before you admit you have any of the symptoms and certainly long before you are willing to take your medicine.

Norman Maclean
Young Men and Fire
Chicago: Univ of Chicago Pr; 1992

Submitted by:
Malcolm L. Brigden, MD
Kelowna, British Columbia, Canada

Submissions from readers are welcomed. If the quotation is published, the sender's name will be acknowledged. Please include a complete citation, as done for any reference.—*The Editor*