

31 July 1977

Dear Harold and Lil:

This will be a hurried attempt to bring you up to date following my last of June 16. Jenifer's condition is not much changed. What has changed are circumstances. As you probably know, all hospitals whose services are covered by Medicare are required by law to maintain a utilization review committee to see that no unjustified cases are permitted./ Marin General of course has such a committee, and after Jenifer was there several weeks it decided nothing was being done for her in the way of acute care which is a hospital's specialty, so they notified us Medicare would no longer cover her hospitalization in an acute care facility after July 9. Actually this is not Medicare talking, but the commercial carrier, Blue Shield in this case, which administers Medicare coverage in this area.

Our doctor, the Hospice people and we held several councils of war to decide what to do. There were only two options: either bring her home and hire skilled nursing care pretty much around the clock, or put her in a convalescent home. Since I was not better equipped to handle the job here at the house than before she went to the hospital, and since all hands agreed I had better make sure I stayed on my feet whatever happens, we put her in the Hillhaven Convalescent Center here in Mill Valley on July 9, where she has been ever since.

Hillhaven is part of a national chain which has a good reputation, and occupies a fairly new facility housing around 100 patients which recently was busted under prior management for doing a lousy job. Consequently, the new crew is trying harder, the place is just around the corner from our doctor's office, and as such places go is probably better than most. Fortunately she has a private room and is pretty well insulated from all the senility; due to technicalities connected with Medicare coverage she has to be in a two-bed room, but since we're paying for a single room there is an extra bed. Here a strange thing happened: The very first night the head nurse, noticing how I took care of Jenifer, pointed out the empty bed and said she'd have it made up if I wanted to stay the night. Since Jenifer was not overjoyed at being in a strange place with unknown quality of care involved, I stayed. A day or so later I talked to ^{the} manager, seeking to put the thing on a regular basis of some kind, with some understanding of what extra charges might be involved. Again, a strange thing happened: the manager consulted the state (which is riding nursing homes hard here these days following several scandals) and the state said no dice. The manager apologized, said she'd be delighted to have me stay but that it couldn't be done. There followed a sort of nurses' revolt. They all got together and came to us with a proposition: I stay overnight whenever I feel like it and nobody knows anything about it. So that's the way it is. I tend to her needs throughout the night and relieve them of much detail which they can use other ways, and Jenifer has the satisfaction of knowing that I'm there when she needs me.

I come home most of the time for meals, but otherwise am with her as much as anyone could be. Under such circumstances it is difficult to assess her condition reliably, but in general I believe there is a slow deterioration, with gradually increasing loss of movement in her legs and arms. She has to lie mostly on her right side, with occasional brief spells on her back. She has a bladder catheter since losing the ability to sit up, and of course the colostomy continues to be more or less of a mechanical problem which I take care of entirely.

Thanks to the Hospice medication (morphine taken orally, which means it can be stopped at any time without withdrawal symptoms) she is just as alert and aware as ever, and in good spirits considering everything. She has known since early April that her case is considered terminal by all the experts concerned, but you'd never know it to look at her skin or by being with her. I'm able to exercise her and massage her enough that she's had no sign of bed sores, and except for the loss of the ability to move and the pain (still not well controlled) she appears in excellent health. Probably her greatest trials are the loss of vision (due to medication) and the difficulty of talking because of chest pains.

She does thank you both for your thoughtful letters and notes and appreciates them very much.

Since I am able to spend so little time here (coming home mostly to feed the cats, do what washing I need and feed myself, I am able to do no more than glance at papers, so I've given up doing any clipping. This brings up the question of what you want done with the file of stuff I have from you, mostly memos to yourself and other people, notes, letters to others, and so on which I've been holding for you since Verb dropped out of the picture several years ago. I have them carefully segregated, and while I know you sent them partly to assure yourself of copies if you needed them, it seems to me they might be valuable to someone as back-up material for other files you have. If you want them sent eventually to Lesar, Howard or to Wroner, please say which, or to whomever. Who ever it is, please provide the current address involved.

That's about it for now. I send you affectionate greetings from a brave and lovely woman whose superb body and spirit refuse to follow the predicted pattern, and who handles her problems with a calm and dignity that has to be seen to be believed.

I almost forgot: the Mattoses flew out during July to see her; Gil is crushed; he couldn't have been more shaken if his own mother had been involved. Lilly, an R.N., was wise and helpful. The kids were great. Jim is a handsome and very bright little boy of 7. His sister, Jenifer, is 6 and literally is a flower growing like a weed. I've never seen such spectacular skin and eyes. Jenifer was much boyed at seeing once again her lovely little namesake. The little girl is very much what Jenifer always has been, a truly unique beauty, with a sweet and thoughtful mind to go with it.

I add my thanks to Jenifer's for all your good wishes and kind thoughts.

Best,



Jim