

Dear Clay,

3/5/99

I appreciate your letter dated February 29 that was atop the package that came today. I read the letter and responded before looking at the rest of it. And I assure you that I do not question your motives and can't begin to tell you how much I appreciate what you have done and are doing.

But I think that largely you read into what you have read that is not there. At the same time in what you imply, that I am from time to time angry, you are 100% ~~correct~~ ^{correct}. It is unhidden in my writing in part because honesty demands it.

I used a highlighter as I read it and I'll address it from the top.

I do not remember the letter you refer to and if there is in it what you see it comes at least mostly from what has no connection with the work. I can't begin to tell you the current stresses and what I am aware that they are doing. I may not be aware of all of it but what I am aware of is more than enough.

The only thing I can remember that you could have taken that way is the great frustration I had with the confusion caused by getting the color into the Lovelady pictures. I spent several hours trying to figure out how it should be and that, for my present state of mind, was much too much. I finally gave up on it. Yet it may have been simple and I just didn't catch it. I was aware of that and that is the reason I kept trying to figure it out.

I am aware that getting roused up is not healthy for me and I try to avoid it and when I cannot I take a valium. But thanks for the caution.

When I do not send you what I've corrected in red that is because I got mixed up. I tried other colors years ago and red seemed to me to catch the eye better. That means for the retyped and for me in going over what is retyped. When I do not send the red I was confused.

I do not have to be told there is no malicious intent. And I also do appreciate the candor. I'll be giving this more thought later, when my mind is not on other things or wanting to get onto them.

On the new Introduction for Inside, if you think it is OK please find some way of inserting it at the beginning. And for what I have to give you on the Mailer ms, there is an added note that I ask you because you have a clearer

recollection of the content by chapter than I do, it add it at the end of one you believe is appropriate for it. *only on the disk. Not necessary to send me.*

What I think is not easy for younger people to understand that even those of us who had photographic memories lose them and, as with me, can have trouble remembering a letter of such recent writing.

Lil appreciates you call and told me about it. She will also appreciate the

beautiful axalea that came when I was not here. I missed it by five minutes. The shape I am in required that first I open the door, then fix the storm door open, then, after unloading the little I had like mail, I went back, held on the rail with my cane just inside the door, and picked it up. Inside the house I held it against my body and held the cane in the other hand. I'm actually afraid to try and take it out to the car but I'll get someone to take it in to her. I'm also afraid of trying to carry it into the nursing home from where I can park.

It seems to be planted in soil so I can water it and when it is finished blooming we'll get Eddie who does the mowing to plant it where Wil says. Maybe where we have other azaleas, where the soil is suitable acid.

If Lil can get up and walk over to you when you are here that will be some form of magic. So she won't be able to go to Hana's with us.

That is one of the things that are getting to me. She has not been able to walk since mid-October and the longer she is off her feet the longer it will take her to get back on them. She has been in constant pain since the Thursday before, at her request, I moved her from the nursing home to which the hospital sent her. I phoned its "medical director" and he did not return the call over that weekend, the home phoned him each of those three days and he did not return the calls from the home, and I suspect that innocently the physical therapist, who could not have been informed about the more recent hip operation because the hospital did not report it, had her do more than she should have.

On the theme of opposing emotions and trust and mistrust and subsequent betrayal, I could not care less about Posner and the reason I wrote that case (Open was to set the record straight. He did con us both, as did his wife, but that was not a factor in my doing that book or what I said in it. What was published is about 20-25% of what I wrote not all of which has been retyped. I gave Jerry one of the two retyped copies I had, something happened to at least parts of it, and I've just loaned him my file copy. On the others you mention what you think you see is not likely because I never had any use for any of them. I told Livingstone not to come back three times. I ducked Lifton after his first phone call to me in 1966 - never had any use for that phony Brown although with his first phone call, when I knew nothing about him, I told him to whom to speak to get his awful book that turned out to be published. He was quite annoying when he was here to videotape for Hal very, did not know what he was doing, and wasted much time for me.

On that I am aware that I am inclined not to be tolerant at this stage of my life

I've told all the people I've asked to get a psychiatrist to examine Wil

that I should be included. Including just about an hour before the mail came.

But I think you are wrong about "perceptions of betrayal." I have too little to do with those others for that to be a factor. But I am sometimes aware of feeling that some I care for shall I say let me down from time to time? But I do know they have their own lives to lead.

Oh the frustration you are 100% correct and that extends to many areas but not really to the work I've lived with those realities too intimately and too long.

As a matter of fact when I had a chance this morning to talk to someone who might be able to be of some help although I hardly know him I did just what you say is a good thing. Problem is there is nobody around here to whom I can talk like that and who can do anything, nobody I know. And those are real and oppressive problems of which I am aware and the probability is that they will be getting harder when I am in dialysis. If I do not have to have the prostate rooter job done over before them. And I am as well aware as I want to be of what I was treated for at Hopkins three years ago. And of the ensuing feebleness.

If I told you about it, I was angry with Medicare for repossessing the hospital bed that had been prescribed. That could have happened later but meanwhile, if there had been the possibility of Lil's coming home, she'd have had no bed. The

same thing is true about the special chair that was prescribed. That was to have been paid for by Medicare, I had to put out the \$700 for it, and it is sitting unused and Medicare has not paid for it.

The unjustified medical bills are also a real problem. We have a second insurer and the hospital is sending us bill when the second insurer has not refused to pay them and ~~will~~ ^{pay} will. But can't until after hearing from Medicare. I fear that a friend who was handling the books before tax season paid about a half dozen bills for which the hospital, by this dirty trick, will be paid twice. I've hung up on the collection agency when I caught them lying and told them ~~that~~ ^{that} ~~to~~ ^{to} call me when the hospital has a refusal to pay from the second insurer.

From my experience with the nursing homes they are more like storage bins for human vegetables. Lil has been in pain for some time and no doctors has examined her or even questioned her about it and we wonder what can possibly keep her in pain for so long. I made an issue of that at the home ^{again} this morning.

There looms the financial problem. Lil's Medicare will run out soon and then the costs get heavy. For not getting indicated medical care!

What you refer to as my bonds with my family are not the problem you seem to see. I have two sisters who have between them four children, all of whom have their own lives and interests. But there is no alienation and I've kept in touch with

my sister and they inform their families. The older one is not able to drive the distance and the younger one currently has a husband with some serious health problems, as does one of their daughters. But there is nothing like anything like alienation. We have been and we remain fairly close but separated by distance. *160 miles*

On Lil's side they have not been close and the ones who are closer relations are not close by, a sister, a brother and a sister-in-law. I've kept them informed, some of them phone Lil and just today I saw she has cards from some.

Her older sister has a son who lives not far away but he has never been real close and he just had surgery, his wife has overcome a stroke and that sort of ties him down, and his children have their own lives and interests. Before all of this we rarely saw any of them except one by his first marriage. When Lil was in the hospital and first in a nursing home she was a regular visitor. She has an ailing husband and with the sons grown and gone they have just moved and she is now getting them settled in after work. She works full-time. She and we and her husband have good relations.

Where there were bonds they were not broken and need no renewing. With some of the great-nephews and nieces, they never wanted to be close and were not but there is no alienation. I doubt any but ~~one~~ ^{that} one has gone to see Lil.

I do not think I am embittered and I hope I am not! I have no trouble falling asleep but some medical problems wake me often and I then have no trouble getting back to sleep. Sure I have had disappointments with some of the people but who does not.

I appreciate the time you've taken to think about this and to communicate it and when I can I'll give it more thought but I think what is reflected that you interpret as you do is that I hate to waste any of the little time I have and am frustrated by what I can do little or nothing ^{about} ~~best~~ in our lives. When you are here, if you have the time. I'll show you a long letter I sent to Medicare when it asked

me about Lil's "accident." I am concerned that we can run out of money, I am concerned that I may not be able to help Lil when she needs help or that she may be a permanent nursing-home resident and that I may not be here to be of the little help that I can be. I am concerned about the state of her mind and my inability to get any of our doctors to do a thing about it. I am upset because there was negligence that ruined her and that at our ages there may be little we can do about it, probably nothing. But I am trying and if you have the time I'd like to discuss with you what I plan for the near future. I have raised with Medicare the possibility of fraud in their being bills for what the hospital and the nursing home did that I believe is negligence. Before then, and I held off on this,

I tried to see the head of the hospital through the mistitled patient representative. I've heard nothing from her, no acceptance or refusal from him, and it has been more than a month. I also wrote her and asked for copies of Lil's records and got no response. Then I tried someone else and was told that getting them will cost \$15 plus 50¢ a page. I've sent the \$15 and should hear soon but there seems to be a hangup over what I regard as the negligence. I do not know that the matter got to the head of the hospital and can believe that it was cut off before it got there. Meanwhile, there is only one hospital in the county for the doctors to use so they ~~are~~ are all careful not to antagonize anyone on its staff.

I am aware that, as you say, what I am doing may just sit on a shelf. I am also aware that what you are doing is important in giving it more shelves to sit on, so to speak. But I have believed and do believe that if I do not do it it will not be done and if it is not on some shelf to be found what is in it will never be found. I have no reason to believe that if I do not do what I am doing that it will ever be done. If it is done and not used, at least it is there to be used. But if it is not done, there is no possibility of its being used. That I do feel this way and have tells you how much what you are doing means to me!

Having this situation has not been a frustration to me for many years, not after my early experience. The reality is clear enough but as you know it has not stopped me and all the many new problems I have have not either.

It was good of you to take the time for all of this advice and I do appreciate that, too. Many thanks!

I told Lil today that you are coming and she looks forward to it, as I also do and I'm sure the McKnights also do.

If you have time question me about these things that are on your mind when you are here. And at this point Lil phoned. I'd been to the patient's rep. as the proper channel to the head of the hospital about five weeks ago. When she did not get in touch after two weeks I asked her for copies of all Lil's records. That was three weeks ago. When I heard nothing I took another channel and sent in a signed request by Lil, with a check. And Lil just told me that the patient's rep. was just in to see her and to get her to sign all over again. In Lil's state of mind she apparently did not tell her that she had already signed for them. So, I wonder if there can be some hanky-panky. I just phoned medical records and was told that they cannot release the records because the file is not complete. After a while I learned that the discharge summary is missing. I said I'd come in for the rest and would get the discharge summary when it was ready. I'm now stonewalled on that until the middle of next week. I ~~had~~ had not to read.

I said not to mail it, that I'd come in for it. She said it's not all that ~~was~~ unusual for there to be delays with a discharge summary. Now three weeks after discharge. Maybe this was unusual for them and maybe I just had the notion that there was something in the mind of the woman to whom I spoke but I did tell her that we want all of them. And I do hope there is no hanky-panky.

Of course I also wonder why the patient's rep was not back in touch with me and ignored my request for the records for three weeks. And then goes to see Lil and I can only wonder what she may have gotten Lil to sign and if it is only coincidence that she went to see Lil for the first time after so long a time because I'd made a request for the records of if something was in channels and she had just been told whatever she may have been told,

I guess that surgical patients are discharged without a discharge summary on file and with copies to the nursing home to which the patient is sent.

Many, many thanks,

Harold