

JAN 31 1976
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Dear Jen and Jim,

the medical correspondence

1/31/76

I've been worried that the carbons of what may in some cases seem like hysterical letters may trouble you. It is just getting to daylight, Lil went to bed with a severe headache that had been hard on her all day, it was hours before she turned the light out (Lil didn't sleep too well, either), and the one thing I can do that doesn't run the risk of waking her is type in my office, the remote end of the house. As it is set up, there really is about nothing else I can now do in my office. It is small, crowded and has no place where I can sit as I'm supposed to except at my desk. So, I'll try to explain and clarify.

I have one purpose in sending you copies and two purposes in the letters. I'm sending Howard what I'm sending you. Jim has more and knows more. It is not that I expect to kick over any minute. It is the kind of illness in which this can happen. It also is one in which there can be further hospitalization required at some point. Except for the manifestations I feel, the discomfort and the uneasiness they trigger, I have the physical capability I had before and when the mind is not preoccupied with all of this I can function as before.

As I'm sure I've explained, one reason for the carboning is because of the obligations I've asked you and Howard to accept should something happen. After the pneumonia, if that is what it was, I came to realize that at 62+ and with other circumstances I should make some arrangements.

The consultation with my friend Dick's internist shook me up quite a bit. It made me realize that at best I've received perfunctory, inadequate care for a serious illness that had been allowed to develop through the grossest negligence. The reaction to it, as I feared, was negative. And it happened that after it there were changes that I cannot see as signs of remission. Coinciding with this was new to me knowledge that the care ~~is~~ I am getting, if that word can even be used, has from the first been less than minimal. I have no doubt that when the New York doctor's letter reached GHA all they saw was a malpractice suit. It took a week + for me to get any reaction, then it was stonewalling. What this told me is that nothing is going to make any changes there, that they'll behave essentially as the government does in the FOIA cases. My own and I think under the circumstances polite letter was not responded to for a week. The call, which was not in response to Dr. Segal's letter, was at best offensive and sometimes insulting. Here is the doctor who let all this come to where it is if not to pass ignoring a recent examination by another doctor a month after he last saw me and a week after I saw that doctor actually telling me the clots are dissolving whereas the New York doctor told him he could palpate them. Meanwhile, if I can believe that some of what I feel is psychosomatic, I'm confident all can't be. One of the most troubling aspects is that I entered the hospital with no trouble in the right leg at all and now, after all the medication and carefulness I'm having the same symptoms in the right leg and what I take to be manifestations of clotting higher up because the sensations and reactions are like those in the left.

It does worry me, and it worries me more because what I can do is limited. I took the steps friends recommended to me immediately. Dick urged other medical arrangements and rightly or wrongly I started that as soon as there was no reaction from GHA to the letter from New York. I have a local appointment with a GP for the 9th. I now believe that I should have made it by an internist but I don't know one from the other and the only internists of whom I've been able to learn locally are so overloaded it seems improbable I could get on their list of patients. So, I'll have this GP and his recommendation on an internist, for which I'll ask. I took Jim's strong urging on cigarettes and made a deep inroad immediately, the first day cutting myself back to a pack or less and without too much trouble. I presume this is the easiest part. However, with these new manifestations coinciding with the very troubling call from the doctor, I've zoomed again. As a minor example, when the New York doctor tells me weight is a factor, the DC doctor hasn't weighed me since December 9 and then passed my expressed concern about weight off. He never raised the questions, weight and smoking.

When I came home from the hospital for about a week I could barely move, first from pain in the heels and then I suppose from inactivity. When I realized the latter factor I started moving around and seeming to be coming along well. When my doctor okayed the trip to debate Belin I had one setback. Floyd went with me, I was careful, I didn't do that much moving and my left foot swelled so I couldn't get a shoe on. I saw the doctor right from the airport and he said it was nothing. I was not really aware of the difference in the size of the legs until there. There remains a difference, the right being as much as an inch more in diameter. Maybe it existed earlier, but I've no recollection of it. After this was over, not having been warned, I took Lil shopping once and by the time I returned, this time attributable to standing, the same swelling but not as severe. Of course I should have been prepared for these kinds of things and warned. However, from the time the second ankle swelling passed off until after I returned from the hard trip that didn't really tire me I felt better and was able to do more. Then, beginning with that bad day, it changed, as it now seems to me rather abruptly. This, of course, did concern me. More, when the doctor did phone, after this past Monday's blood test reached him, he made no reference to it or to medication. Trying to get through to him by phone would have me climbing the wall. The local lab stays at it intermittently for a day to report by phone and fails to get through. They always mail the results anyway, so when he phoned me he had them. And made no reference. I found out at the local lab that there was a shift in four points, whatever that mean, from 25 to 21. The most obvious if perhaps wrong meaning I can take from this is that with the factor going down, the anti-coagulant dosage should be increased. I write and there is no response or reaction. So, it adds another worry.

Then I find that I can't work as well, two different days. Yesterday when I became uncomfortable typing I switched to sitting and reading, being careful to break the sitting up. Jim wanted me to read the Bazug transcript. Only, I find that with my legs up, in a comfortable chair to which I've added pillows, I stay uncomfortable and am where ~~it's~~ I've not been before. And that aches and other sensations develop in the suspended parts of the extremities, too, the parts not on the chair or the pillows under my heels. I can correlate feeling better and being able to do more with the intervening day's added walking, but what am I to do when I can't go out for walks? This time of the year I can expect as much as two solid weeks of this, if I don't think it probable.

Rolling it all into a ball, it does make for increased worry and there is the problem what to do. The only things I can think of with the medical appointments set is to make a record that can either impel GHA to want to do more or if there is the need, be helpful to Jim. These are the other two purposes of the letters. Lil has read and approved them all. She finds them understated and for me quite restrained. They express less indignation than she says she would.

As an example of the realities, in the short time I've been writing this I've been up and walked around twice and just had to lower the left leg from the raised position because of the feeling of strain in the left calf. That persisted last night in both. I do not take it as a sign of remission after three and a half months.

Meanwhile, also troubling, how am I to work? I've asked for guidance on this and been told only that I'm to learn for myself. Whether I should have some support for the entire leg and pressure from it on the restricted blood-vessels I'm to learn for myself? I'm also wondering how I'll sit and edit what I write.

Because of the persistence of these uncomfortable sensations, none extreme, in locations in which I did not have them on leaving the hospital, I feel one possibility is the spreading of the clotting, in both legs and thighs. And I do not look forward to another vein scan. I tolerated the last one without tears but it was not easy. And what if they have spread while being "treated?" While on an anticoagulant, anyway.

= All the factors make for a sense of extreme uneasiness. If all add up to nothing, which, of course, is what I'd like, it still has meant a very uncomfortable period that

with the most rudimentary preparation need not have been as uncomfortable. I could have been more productive.

There is no real end to these I think natural causes of worry. One is the possibility of a vascular disorder. Before I saw the New York doctor I was aware of persistence in coldness in the hands, for the first time in my life, especially the left. Lil immediately thought of this. I'd reported it by phone and had it dismissed, as everything was. Then it is again ignored when there is the recommendation of a vascular consultation.

I fear all this is working on Lil, who carries a heavy enough load now. I have just gone in to awaken her because some college kids are supposed to come and prepare books for shipping. I find she was awake most of the night and was ill, even vomiting. That her hiatal hernia started troubling her. Past correlation is with tensions, emotions, worry.

My inability to do anything meaningful magnifies it all and I'm sure contributes to my sense of uneasiness. I've had no vascular consultation set up or referral made by the New York doctor in two weeks and I've written my friend there is he if he could do anything to speed it up. I don't know what else I can do and, of course, I'm concerned about how I'll pay for other medical attention. I see no alternative except through a mappractise action, which will only begin with the impossibility of Jim's doing more than he is now and will require an expert I can't pay.

This is not to worry you more. It is to explain what may seem like hysteria or over-reaction. I am aware of feeling sort of boxed in by the combination of situations and my inability to do anything immediately. I do expect to demand an outside consultation Wednesday, when I think the session with the doctor will not be an easy one. I expect this to be refused. Once that happens I'll be asking around to find an expert on Phlebitis, is there is one here or in Washington, at least to learn how to reduce the discomfort of simply doing what I do and of substituting for walking when I can't do that. If it required different chairs then I'll have to get them, as I'm getting different anti-embolism protection - leotars, no less & measured and made beginning Wednesday. But I think that the unlikelihood of anything constructive coming from the first visit to my doctor in six weeks - after the New York doctor recommended more frequent consultations fairly firmly - does not ease any of this.

I have no worry about my emotional ability to contend with whatever situation eventuates. I do about my physical ability and I do about whether emotional involvements will interfere with my judgement. I have some concern that the consultation Wednesday will last only ten minutes, which will not be enough for the doctor to address the questions I've told him I want answered. One of the reasons for writing him was to give him time to find the time - and the answers. And to understand that I am determined. As of now, without thinking it over, if that visit is unsatisfactory I'll go to the administrator's office and lay it out - do something now or I do. That time will come anyway and I now have the added pressure of the perpetuation of the wrong optical corrections. I'll try to remember to ask JL about this. I've already asked him to meet me at the doctor's office just prior to the 10:30 a.m. appointment. He'll have the added pressure of being a lawyer and his wife's expert opinion as a radiologist that while the X-rays they failed to get on their own and refused to get when recommended by another doctor do not have to show anything, they can.

Of course there is the added concern that subsequent treatment can be a great waste of time because of all this neglect, that it can be an unpleasant thing, that it can interfere with what I can and want to do and that I may have trouble paying for it.

I hope this hasn't added to your worry. Also that it may ease you about the letters if they have worried you. As I may send them there is no need to read them.

Now I'll see if Lil is well enough for me to go for a little walk because I've heard nothing from the college kids and it is 9. Best regards and please don't worry,

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