

I will move to as of 1-11-89 → C/O GREEN TREE HOSPICE
6925 N. PORT WASHINGTON RD.
MILWAUKEE, WIS. 53217

414 / [REDACTED]
EXT 625

Saturday, January 13th, 1989

Dear friend(s),

I will use this for a ~~several~~^{period of} ~~years~~^{beginning/end} news-
letter & holiday greeting. I am writing this
on my lap as I sit on the toilet with my
catheter bag hung at my side in St. Joseph's
Hospital. I have A.I.D.S. plus many other problems
which I seem not to be able to get over. To tell
about it all will be too depressing for you and
me but that is the news.

I am doing very well and should not be
here but my home was burglarized 3 nights in
a row right after I drove back from my sisters in
Wheaton, Ill., where we hold our Thanksgiving family
celebration.

Breakfast has arrived at 8:37 A.M. so if I
want it warm I should eat it now. But I am not
really hungry now, and it can be microwaved
later. So I'll sit in this chair and keep on writing
until as the nurse takes my normal temperature,
pulses, and blood pressure. I have been taking
AZT capsules since last summer's ~~flu~~ on set of
pneumonia. I was over it in one week and back to

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work at the Library. My boss and ~~colleague~~ ~~colleague~~ noticed I was ^{not} my normal self, making odd mistakes. So I had a C.A.T. scan done on ~~my~~ ^{my} brains. It showed 2 growths, one the size of a tennis ball deep in the left side, the other the size of a golf ball near the right ear.

Doctor ^{Rita} Hanson was told by Dr. Taff that he believed the growths were Toxoplasmosis and to treat them with sulfadiazine pills. She was reluctant to use a sulfa drug because I had had a ^{bad} reaction to too much sulfa back in Belmont College 1957 or 9. She feared another anaphylaxis reaction.

Since a C.A.T. scan ~~only~~ ^{is a} photograph, not a diagnosis, it was decided to do a biopsy on the growth in the right brain.

My nurse says I will feel better and brain do better if I eat now. So I will stop and eat at 9:30 AM.

I ate very fast and will start again at 9:45.

The biopsy had excessive bleeding and paralyzed my whole left side but I am not paralyzed

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any longer. I just now have a poor left leg. However it was a very close call requiring me to stay in Hospital til Sept 2nd.

I got over the ~~toxoplasmosis~~ and had no reaction to the sulfa drugs and wanted to take it ~~for~~ ^{for} control of the toxoplasmosis.

Since back sitting on the toilet, I left the rehabilitation unit with the catheter still still in me and in a wheel chair. I could not get walk and only left because ~~because~~ the maximum insurance would no longer cover hospitalization. They would pay home care. Luckily my long time friend Miriam Ben-Shalom and her ^{new} friend Hope Gentle had bought a home and they were willing to take care of me with home health aides coming in several times a week. Under their loving care I made a remarkable recovery and learning to walk again. I was planning to return ^{to my} home Dec. 4th.

Then those 3 breakins were called to me in the middle of 3 successive nights and that started me into a serious depression and I ^{secretly} stopped taking

all my medications which led to even more serious and suicidal depression. The pain got worse and I cut off the catheter I am told for I was out of my head by then. The home hospice people talked me into readmitting myself to St. Joe's.

on Monday Dec. 5th. Most there after for several days is a jumble in my memory. I was put in a restraint and forced to take my medications. On Thursday ^{even} my friend Michael Lisowski came and visited me as did my Mom & Dad and several other friends. Suddenly it stopped and I was feeling my old normal self again late that day.

I got better rapidly and was targeted to return to Hope & Miriam's home the next Wednesday. However I still had not ~~had~~ any psychiatric help and did not feel sure of my self, nor had Miriam been given the training she knew she needed to better monitor my medications and mental condition.

As he had not been called because the pharmacist and doctor some how had been trying to call ^{her} the 6 month old number. I had not ~~seen~~ been counseled by

by a psychiatrist because Maxicare would not pay for it. But it seemed I was having episodes of not being my self ^{or my handwriting changed} and being very anxious & ~~W~~ ^{they} ~~that~~ from the HIV infection, the toxoplasmosis, the scarring from the biopsy, the depression, or the medication side effects? I could not sort it out nor do I have the knowledge to do so. Therefore I demanded to ~~talk~~ to a psychiatrist ^{because} Dr. Taft could not sort it out either.

So I eventually was accepted as a patient by the psychiatrist Marta Muller and have now seen her several times. She has been a great ~~x~~ help, as has Dr. Taft before.

In the mean time, the situation with Hope & Miriam's house changed. Who would feel comfortable or safe ^{in their home} with a man who was having episodes of potential suicide. It was clearly seen then that I needed more competent ^{care} than the Milwaukee Hospice Home Health Care could provide. So we attempted to put together friends of mine to ~~the~~ come in and be with me much of the time

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the Hospice nor Miriam & Hope could ^{not} take care of me. But to get that many people lined up and trained could not be done. ~~With~~ ^{the door} out such care ~~was~~ was no longer open for me to return to their home. ~~Even~~ Even fewer volunteers could be lined up to come to the potentially dangerous situation at my own ~~home~~ house.

So it was now realized I would have to go to some sort of nursing home. I agreed that would be best for me. I chose the ^{Hospice} ~~Hospice~~ at the Woods, Veterans Hospital. But it was full up, so I was put on a waiting list.

It seemed a poor choice to go to either Fond du Lac or Racine where I could not see nor talk friends easily nor they ^{do the same} ~~do the same~~. There were the only nursing homes ^{in W.I.S.} ~~willing~~ willing to take an A.I.D.S. patient such as ~~me~~.

As the above all ^{was} occurring the week prior the Christmas, problems began to again develop with Medicare. They cut off their insurance payments as of ~~the~~ Christmas eve. The hospital did not want a non-paying person ⁱⁿ there seemed no place for

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for me at the time just like Joseph & Mary on Xmas eve. Yet this is St Joseph's Hospital, how odd. So they are keeping me on here as a "charity" case, until arrangements can be made to take me at a Milwaukee County area nursing home. I'm not the first person with A.I.D.S. to have trouble getting into a home but Milwaukee A.I.D.S. Project, whose people have been working on my behalf through much of this, and I will bring a law suite against those homes which categorically refuse to serve a P.W.A. (person with A.I.D.S.)

I have left out one factor in the prior description of the episodes of depression & anxiety which happened after the 1st visit. I was readmitted. I was put in a room directly under the demolished ^{for} remodeling of the floor about. So I was subjected to loud, random, jack-hammering and construction noise which made that room like a torture chamber. Only after nearly a month ^{and more suicidal} did I finally get moved out that room and get issued earplugs.

I also have not told that my weight is down from 185 ^{lb} a year ago to about 140 ^{lb}.

Parker

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the fall, to 130[#] now. So there is just too much skin and not the ability to build up the muscles and ~~flex~~ clothes that fit any more. Plus my boxes have no padding to sit on, so I sit on a pillow now as I write. No one in Milwaukee has seen me with a 32" waist. If I recall, the last time I had that size was in 1966 or 7 while at the U. of Ill. studying Landscape Architecture.

I've begun to get a few new smaller clothes and I've received my 1st social security disability check on the 3rd. I should be getting the City's disability check starting at the end of January. Also I should be getting my private disability insurance I got thru the Landscape Architects Society National group plan. I should be getting some money to live on and pay my own way again.

1989 would be ~~up~~ a very good year for me. I hope it will be at least that good for all of you too.

Love us always
Alvin W. Hess