# DEATH WITH DIGNITY

## An Inquiry Into Related Public Issues

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# HEARINGS

BEFORE THE

# SPECIAL COMMITTEE ON AGING

# UNITED STATES SENATE

NINETY-SECOND CONGRESS

SECOND SESSION

## PART 3—WASHINGTON, D.C.

AUGUST 9, 1972

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[1] Senator Winston Prouty, Vermont, served as ranking minority member of the committee from September 1969, until his death September 10, 1971. Senator Robert T. Stafford, Vermont, was appointed to fill the vacancy on September 17, 1971.

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# DEATH WITH DIGNITY

## An Inquiry Into Related Public Issues

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WEDNESDAY, AUGUST 9, 1972

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
*Washington, D.C.*

The committee met at 10 a.m., pursuant to call, in room 1224, New Senate Office Building, Senator Frank Church (chairman) presiding.

Present: Senator Church.

Staff members present: William E. Oriol, staff director; Patricia Callahan, professional staff member; Robert M. M. Seto, minority counsel; and Gerald D. Strickler, printing assistant.

Mr. ORIOL. The committee will now resume the hearings. My name is William Oriol, staff director of the Senate Special Committee on Aging.

We just received a report from Senator Church that he has been called to a meeting unexpectedly, but he will get here as quickly as possible. He did indicate that he would like the hearing to begin, and so in his absence, I will call the first panel of witnesses, and we will continue.

May we now hear from Mrs. William Heine, Baltimore, Md.; Mrs. Gertrude Clark of Silver Spring, Md.; and Mrs. Faulkner Baird, Baltimore, Md.

Miss Callahan of our staff, I know, has chatted with all of you, and I guess you are feeling friendly by now. Pat, why don't you sit with the group in case some questions come up.

## PANEL OF MRS. WILLIAM HEINE, BALTIMORE, MD.; MRS. GERTRUDE CLARK, SILVER SPRING, MD.; AND MRS. FAULKNER BAIRD, BALTIMORE, MD.

Mrs. HEINE. I am Mrs. William Heine, and I am a woman who is not quite 62, married to a man who is 76 years old, who has cancer of the prostate among other things, and is now really, I feel, entering into the real stages of this terminal illness that he has.

We live in a senior citizens house so we see other illnesses around us, and it is part of our life. We do not quite feel the way other people do about it. We accept the fact that people have illnesses, that you get older, and that you have to face these things.

So, we have discussed what life is now to him compared to what life was and what life is for me because the members of the family feel it very strongly, and it is not always as easy to cope with as it seems as it goes along. All I can do is express for Mr. Heine and myself how we feel about it.

We are scared, scared to death now that he is getting to the point where he is more comfortable lying down than he is being on his feet. What is going to happen in the time to come? Suppose he becomes completely bedridden? Suppose he gets to the point where there is nothing of him left except his heart and his lungs, that his mind is gone?

He has already had a little stroke. He has had another little episode. He has had both eyes operated on for cataracts, which took something out of him, and he could not have another operation now on his eyes, or any time, that I know of.

## A Right To A Choice

He has the feeling, and I agree with him, that everybody has a right, if you have lived with dignity and respect all your life, that you have the right to decide to die with dignity. Because there is nobody to keep you alive after your mind goes and after everything that really matters is gone.

Just to keep you alive on a heart-lung machine and with glucose is not life enough for anybody. Then, as I say, those of us who are under Medicare and under Medicaid, do not really have those problems because there is not enough money to keep all the old folks alive just because they want.

But, we have seen, where we live, those who have been kept alive where the families hurt for the old people, could not wait for them to die because of the tremendous pressures that they suffered under. Being afraid their parents were going to die and not being afraid that they will die soon enough. The money went, the love went, the children felt guilty because they could not do anymore. They could not stave off the grim reaper, and we do not want that.

We do not have any children. We have no one who would care, and we cannot see it for ourselves and others that I have talked to. It is the middle-aged who are more afraid than the old. With the old, there comes a time when they say we have had it, and we welcome it already.

So, I do not know much more than I can add except that the golden years are not so golden. They are a little tarnished when nature catches up with you.

Mr. Oriol. I would like to thank you for sharing your personal experiences with the committee, and the same should be said to the other members of this panel. We have heard from many experts, and we will hear from some more, but I think the real experts on this subject are the people who have to face the subject very directly.

You mentioned that you are afraid, and that one of the reasons for fear, I sense that there is also a financial reason that may affect you directly even with Medicare?

Mrs. Heine. That is right.

Mr. Oriol. How far does Medicare go to help?

Mrs. Heine. Well, Medicare does not go half far enough. Medicare—by the way, they have already started taking off from the Medicare, the premium, the increase in premium before the Social Security raise went into effect, so there is an erosion.

Mr. ORIOL. Was that the check you got on July 1?

Mrs. HEINE. Yes, so there was 30 cents less, and 30 cents is a lot of money, and Medicare does not take care of medications. This man gets a medication every 5 weeks known as Estradurin. I think that the cancer specialists know about it, and it is money that I do not have to pay. I do not know what the price of it is, but it is more than I have and everything else, and the fear is not of death as such, but the fear is of who is going to take care of it, who is going to cover it.

Medicaid takes up the difference. You cannot go into the hospital unless you have the first $50 deductible. Medicaid takes care of that. But I said that this man had his eyes operated on for cataracts of both eyes. Cataract glasses are tremendously heavy, and if you have got the money, you can have plastic lens which are very light, but when you are on Medicaid, they do not care.

The fact that you are struggling to keep active and to keep going in the community, they do not care. You have to take these heavy glass glasses and that is it. This is a man who tries to keep living, who draws, who is a very good artist, and we have something going between the two of us working toward life rather than death, and that is the story of who is going to help. Nobody is going to help outside of the State. It is just our hard luck that is all.

Mr. ORIOL. Do you mind telling us whether you are on Social Security?

Mrs. HEINE. No.

Mr. ORIOL. I take it your husband is?

Mrs. HEINE. That is right.

Mr. ORIOL. Do you mind telling us what your monthly income is?

Mrs. HEINE. Our monthly income is, right now, $147.40 minus the 30 cents from Social Security. We get some supplementary income from the department of social services, not enough to even cover for what we need. Here and there, we scronge a dollar, as every living person does, and that is the word, "scronge."

Mr. ORIOL. And your husband has been retired since before his illness, I take it?

Mrs. HEINE. Yes, he is 76 years old.

Mr. ORIOL. What was his work?

Mrs. HEINE. He was a house painter.

Mr. ORIOL. And he retired at 65 or after?

Mrs. HEINE. He retired officially at 65, but he worked until he was 72 here and there within the requirements, because physically he couldn't. You know a house painter is not a steady working man. It is off and on.

Mr. ORIOL. Do you mind telling us how much roughly you pay for prescription drugs in a month?

Mrs. HEINE. I do not pay for them. Medicaid takes care of that. Thank God for that much.

## HOME HEALTH CARE

Mr. ORIOL. We have heard a lot of testimony on the potential values of home health care, of having different types of services which would enable a person to stay in his own home. How would you feel about that if you were able to get good practical help from one or more people, one or more times a week, to keep your husband there and to keep him with you? How would you feel about that.

Mrs. HEINE. I would want that. One of the things that I got help from the department of social services was so that I could have at least a woman come and clean once a week because we live in housing for senior citizens, so we do not have a big place, and I had to stop it because they did not give me enough money, and with the inflation, it did not cover.

Incidentally, I have a coronary problem that creates other problems in itself, and to me as long as a person has any sort of something, even if he is bedridden, as long as he can be helped, home is the only place.

I do not believe in institutions because he needs that love and that care.

Mr. ORIOL. Is there any pressure upon you now to put your husband in an institution?

Mrs. HEINE. No. He is still somewhat ambulatory.

Mr. ORIOL. Have you spoken to your physician very frankly about the fears that you mentioned earlier, the fear of helplessness?

Mrs. HEINE. This is a very good question you ask. Four years ago, when they first discovered that he was malignant, the surgeon told me plain, he has cancer. The surgeon told him that he has bad tissue. Now, you figure it out, what the difference is, bad tissue and cancer.

It amounts to the same thing. Our family doctor—who I want to state publicly for the record we respect as a doctor, we love him as a man and a person and as a friend—has a harder time putting into words and facing the problem of cancer than we have.

We talk about it very openly, and to me, cancer is something that can happen to anyone, but I say to my husband when the time comes that you get a venereal disease, then I want to know about it. Then I want to talk about it. But, cancer is like a cold today. It is not such a thing that you have to be ashamed of as a social disease.

And when I ask my doctor: how is he right now; and I can see the erosion that is taking place. I can see the fact that when on Medicaid, when they take a bone scan, then they have more than a suspicion of what they are looking for. It has seeded itself somewhere else, and the doctor says to me, he is doing fine. For the shape he is in, he is doing fine.

Well, that to me is not the complete answer, and I am sorry for the doctor, but not for myself or my husband.

## CANCER—A DREADFUL WORD

Mr. ORIOL. Have you ever asked your doctor why he finds it difficult to call it cancer to your husband?

Mrs. HEINE. Yes, and the answer was complete silence.

Mr. ORIOL. What is your guess? Is he embarrassed by the word?

Mrs. HEINE. I have a feeling that to my doctor my husband and I are friends and very close. He feels very close with us and cannot face it for us.

Mr. ORIOL. Have you ever considered the living will which other witnesses have talked about or will talk about today?

Mrs. HEINE. Yes.

Mr. ORIOL. Have you read one?

Mrs. HEINE. I have not read one, but I am familiar with it.

Mr. ORIOL. Do you feel that would give you and your husband all the protection you would like to see to avoid that situation you described before in the final stages of the illness?

Mrs. HEINE. I feel—and I can say right now that my husband asked me to speak plainly for him because he physically could not make this trip—yes, yes, that would help. We would be only too glad for something like that because once he loses his mind, once he is comatose, he is just a drag on society, and if he is lucky and I am alive—because my chances of dropping dead are much quicker than his are as a coronary patient.

There is nobody to care and there is nobody to provide for. As I say, the State will not, Medicaid will not keep patients like that alive, but our minds would be much more at ease. It is one of the things that makes so much sense to us because we have seen, and we have heard, living where we do, of people who are being kept alive just on the heart-lung-glucose machines, with tubes, and the middle-aged, the ones who have children coming up and who are facing this problem themselves are the ones that get to hate their parents, and get so scared and feel guilty because they are in that position. They feel that way, that it is terrible.

Mr. ORIOL. You mentioned before, that you personally do not have relatives, if I understood correctly?

Mrs. HEINE. That is right.

Mr. ORIOL. If you did have relatives, would you want them to have the authority to say when the life continuing effort should be stopped?

Mrs. HEINE. I cannot answer that honestly because I do not know. All I know is I can speak for my husband, he can speak for me, and as this one little unit between ourselves, that is it. He would have the right, with my consent, to say that is it. I would have the right to say, let him have the rest that is coming to him.

Mr. ORIOL. Miss Callahan has spent a lot of time discussing things with you. Do you have any questions at this point?

Miss CALLAHAN. No; I do not.

Mr. ORIOL. Mrs. Heine, I would like to thank you. I think you have said it very well; if you have life with dignity and respect all your life you deserve a death with dignity. I think you have expressed that feeling very well and I hope you will extend our thanks to your husband, too.

Is Mrs. Clark here?

## STATEMENT BY MRS. GERTRUDE CLARK, SILVER SPRING, MD.

Mrs. CLARK. Yes. In June 1970, 2 weeks after I became a resident of Springvale Terrace, an apartment/hotel for persons over 62——

Mr. ORIOL. If I may get a plug in, Mrs. Clark, one of the reasons we are so interested in Springvale Terrace is because that is a fine example of what is called 202 direct loan housing, a program started more than 10 years ago which has produced some very fine housing and which unfortunately now is in a state of limbo that we are trying to do something about.

Mrs. CLARK (continuing). I signed a "living will" which is distributed by the Euthanasia Educational Fund in New York City.[1] A copy was sent to my doctor, my lawyer, my trust company, my executor, and one is on file at Springvale Terrace.

However, this action has not given me the peace of mind I wish it might because I realize a "living will" is not a legally binding instrument. It is simply the best device available as yet to someone like myself who believes that a responsible person should have the right, under law, to choose ahead of time the manner of his dying, at the very least under the conditions listed in the living will. If there is any value in my being here today as a member of this panel it is the telling of what happened at my new home as an unexpected result of my having signed this instrument before two witnesses who are also residents.

We number 173, ages ranging just now from 62 to 94. We are men and women and represent a great variety of religious affiliations from Catholic, Jewish, Protestant, Christian Science, Unitarians, and evidently a widespread economic status. Most have children nearby, but some have no near relatives.

What I had done was an individual, private matter but not long after, a resident mentioned it to me and asked where she could obtain one. I saw that she received a form. Since then at intervals the same thing has happened and each time the resident expressed strong support for what the "living will" attempts to insure.

## CONCEPTS OF "LIVING WILL" NOT UNKNOWN

Their expressions each time revealed that the idea was not new to the person. It had long been in his thinking but until now they did not know what to do about it. This was something they could do until there was something better available, something that would make it enforceable under law.

Until this last week, about 25 persons had approached me quietly with this in mind, and I had become persuaded of how widespread—among those growing older—the belief is in this and how general is the desire that a way be provided by which their wishes can be assured.

I said until last week. What happened then? Circumstances contrived to bring an interview with a writer from the Washington Star and the story appeared in the August 6 issue. As a consequence in the last few days there has been a veritable explosion of expressions of approval from the residents of Springvale Terrace.

The significance of this, it seems to me, lies in the fact that this residence is a microcosm of the world of older people in the United States and can be considered a kind of laboratory for testing attitudes of that age group about this idea.

The terrace is also the center for the activity of various senior citizens groups in Silver Spring, the AARP, the Association of Retired

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[1] See appendix A, p. 141, a Living Will, Euthanasia Educational Council, New York, N.Y.

Federal Employees; and others. It also serves as a reservoir of participants in group activities of senior citizens in the community's churches and other organizations.

Would it be desirable and possible for the purposes of this study to arrange a well-devised and directed research program from this center on the attitudes and desires of the older citizen in this matter? I would hope such a project could be carried on. It seems perfectly evident to me from my experience that it would be welcomed by a large proportion of those who would be approached.

It would be a voluntary cooperation and would not infringe on the privacy of the feeling of anyone not wishing to participate. As for my own belief about the "living will," I look upon it only as a beginning step in the right direction. Its value at present is in providing a focus of attention and expression of support in promoting a widespread attitude of acceptance for the idea it presents.

## UNIFORM LAW NEEDED

To have real value for the signatory, there will have to be law which sanctions it. Necessarily such law will have to be uniform throughout the States because an older person is often taken from one State to another to be cared for when necessity comes, and an instrument signed under one State's law may not be binding in another State.

Perhaps there could even be a Federal law under the provision for the "general welfare" clause of our Constitution. Even with the sanction of law upholding it, the "living will" can not meet the full need either for the individual or society. There will have to be further developments with the society growing ever more understanding and responsive.

There is one plea to be made to those who are not sympathetic. Do remember that quality of life is more important than quantity of life. Do remember that the human machine does wear out. To live on past the point where there can be satisfaction and enjoyment in some significant degree comparable to what a person has been used to is no boon.

Mr. ORIOL. Thank you very much, Mrs. Clark. I understand you are a retired schoolteacher. Would you care to tell everyone your age?

Mrs. CLARK. I am 78.

Mr. ORIOL. By the way, we agree with you about that article in the Star on Sunday and another excellent one yesterday. I was going to ask you what sort of response you received from that article and you have already given us an indication.

Mrs. CLARK. I haven't been there very much. I have another project that takes time so it has been a very limited time when people have been able to approach me but I have been telephoned and people have leaned over the table in the dining room and they have met me in the halls, sought me out.

It is unanimous from them. I hear that other people have said the same thing and I began to get fan mail yesterday.

Mr. ORIOL. Did you say you received phone calls?

Mrs. CLARK. Yes.

Mr. ORIOL. From a fairly wide area?

Mrs. CLARK. No. I meant from the Terrace, itself. We each have phones in our room.

Mr. ORIOL. It does seem therefore that there is much anxiety very close to the surface on this issue.

Mrs. CLARK. I feel so. I have become convinced that is true. I am not there very much so I do not sit around talking in the groups in the different lounges which are provided, but I am told by others that there is a great deal of talk about it even before this came up, you see, and one of the things that seems so sad to me is people have told me in different words, they say to each other, "What are we doing except just waiting?"

### NO BINDING AUTHORITY

Mr. ORIOL. You mentioned that the "living will" has no binding authority and that it really is more or less to express the wish and to extend the idea. Would you like to see it have statutory on a State level? You mentioned possibly even the Federal level.

Mrs. CLARK. Well, if it is on a State level, it has to be uniform because so many older people are taken from one State to another. They may have signed it in one State under its laws and that would not necessarily be binding under another State's laws.

For instance, my own mother, I took from Michigan to New Jersey where she died. Of course there weren't laws about that. But the person who is middle aged who has to care for the older person has to take that person to her or his own home.

Mr. ORIOL. Do you feel there is anything in the "living will" as it now stands that would perhaps give relatives an opportunity to do something unfortunate or even greedy?

Mrs. CLARK. Unfortunate, did you say?

Mr. ORIOL. Yes.

Mrs. CLARK. Well, I think the unfortunate thing would be if they didn't carry out the provisions, what is requested by the person who signed it.

Mr. ORIOL. You feel that they get no special power over the person who signed the will?

Mrs. Clark. I can't believe that laws can't be set up, devised, that give adequate protection.

Mr. ORIOL. Have you done much thinking about this Federal possibility, what form it would take?

Mrs. CLARK. Yes, I have. I have even thought it would be desirable to have an amendment if it can't be covered under the powers that are already enumerated in the Constitution. I feel it is so important. It is just as important to have the right to die as to have life, liberty, and pursuit of happiness.

Mr. ORIOL. That is very similar to what a witness said on Monday, too. I would like to talk again. We'll consult with you more on that. We would like to follow that up, but I would like to talk now about the effect of good housing upon the elderly and we are partial to Springvale Terrace, but to describe it briefly, each tenant or couple has his or her own apartment.

On every floor there are conversational areas, and in the building there is a very good dining room and garden areas and so forth, and I understand that relatively few residents, despite the advanced ages you mentioned, require institutionalization. Most of them live in Springvale Terrace to the end of their days which strikes me as a very positive effect of good housing.

We hear a lot of talk about alternatives to institutions and I am sure everybody in Springvale Terrace does not want to go to an institution. Is this an overstatement of the case, do you think?

Mrs. Clark. Well, I don't know if you mean that they live there to the end of their days because I have been there 2 years and 2 months now and there is a great changeover. People are constantly leaving and constantly coming in, and so far as I know, only two people have died in the Terrace. They do go to nursing homes and hospitals and to the homes of relatives.

Mr. Oriol. Miss Callahan, do you have any points or questions?

Miss Callahan. No. I think it has been covered.

Mrs. Clark. As long as you are interested in housing, not only are there all these gathering places of different kinds, the television room, the auditorium where all kinds of activities go on, brought in by Silver Spring and other groups in the Washington area, but all the opportunity in the world is given for residents themselves to carry on activities such as several of the men are now painting the railings of the terraces.

Some of the men take care of the lawns, do the mowing. A great many of us have gardens, we can do what we want with our gardens. There is a person around there who plans it with us so there is a kind of unity in what is done, but all kinds of things are encouraged so that people participate and feel that it is their home. They really are contributing to the home as well as in other ways and, of course, you are as free as can be to carry on outside activities.

Mr. Oriol. Do you feel segregated from the community?

Mrs. Clark. No. I feel very much a part of the community.

Mr. Oriol. Yes. You are just a few blocks from the shopping areas.

Mrs. Clark. Not only that, there are all these groups who do things with us.

Mr. Oriol. Thank you very much, Mrs. Clark. We appreciate your sharing your personal experiences and observations.

Now we would like to hear from Mrs. Baird of Baltimore, a retired social worker, I believe.

## STATEMENT BY MRS. FAULKNER BAIRD, BALTIMORE, MD.

Mr. Baird. I am a retired social worker for a hospital and I was discussing with Miss Callahan one thing that so vividly came to my mind, that for a long time in the hospital we ran two groups of older people, a group of men and a group of women for counseling.

A doctor and a social worker were with the men and a doctor and social worker were with the women. One of the things we found was very difficult, and this is contrary to Mrs. Clark's experience, that was to get them to start to talk about termination of life.

However, when we did, when we finally were able to get them to the point where this was significant they would talk about it in relation to themselves, to their families. They all said we do not want to linger on.

"We do not want to have life prolonged." On the whole they fought the doctors with whom they have had experience because they had a mother who had been terminally ill, a father , a husband, anybody in the family, the doctors had been unwilling to discuss with them the problem from the point of view of medicine and in turn using that from the point of view of the person.

They found this upsetting and I found this also working with patients who have come in who would have a problem that they were having to face—this was on an individual basis—that they were very reluctant to face their doctor about this whole problem because they did not get in return from the doctor what they were asking for. They found it very frustrating. For that reason many people would come into my office and talk.

Mrs. Heine and I had discussed this. My office was in the out-patient department. I was available to anybody who wanted to talk, and I found there was a great need on the part of people facing their problem to be able to talk to somebody who was not a child or another member of the family. Even though you may have discussed this with the person who is ill, if the ill person has been able to do this as Mr. Heine has, and many people don't have the ability to discuss this as this particular couple did.

They are an exception, I have found, rather than the rule, when they are at this stage of an illness. I found that there is a tremendous need to talk about this and to do something to get the person to be able to talk about it.

## Restrictions on Medicare Payments

There is one other thing that I think we have not done for people that should be done, and that is extend the possibilities of home care. I was talking to Mrs. Heine about this. There is a home care program in Baltimore. However, HEW has put restrictions on Medicare in payments for home care and that was done a couple of years ago. I question whether or not this was done by the medical profession. My inclination is to believe that this was done by many of the people that wrote the bill in the first place, insurance people.

Mr. Oriol. Would you describe those restrictions to us?

Mrs. Baird. There has to be two things needed—skilled nursing care or physical therapy. It used to be that you could put a home health aide in with supervision going in on a weekly basis. A couple of years ago they put in the restriction.

Now, the rules operating with which I was familiar, there were three methods of payment: There was Medicare, Medicaid for those people who were under 65, and there was a fee for service. The people who are paying fee for service can still get care for terminal illness, and this has been a very gratifying experience for many people. There are also a few free slots for care under the same programs.

Mr. Oriol. Would you say that some people are in institutions now who wouldn't have been in there if those restrictions hadn't been put in?

Mrs. Baird. Yes.

Mr. Oriol. Nursing homes primarily?

Mrs. Baird. Yes.

Mr. ORIOL. And I take it if the objective was cost cutting, those restrictions were self-defeating.

Mrs. BAIRD. Cost cutting and the right of a person to die as they want to. They want to die in dignity. That is the reason the program was started in the beginning, long before it came under Medicare. It started in 1961.

Mr. ORIOL. The reason I asked for details, in a report which this committee issued in April, we pointed out that the number of home health care agencies is actually declining at just the time when HEW is sponsoring an effort to provide alternatives to institutions, so there is something very ironic and wrong, and the committee is trying to develop a positive program to reverse this trend.

Mrs. BAIRD. There was a seminar put on by our particular home care group several years ago at the request of Regional Medical Planning, hoping to get more hospitals and nursing groups involved in home care. I think there have been two since then.

As you say, there has been a decline in the numbers of this service.

One other thing I would like to say: That is, I had a very personal experience in relation to death. My father became ill with cardiac involvement and was in the hospital 30 days with all kinds of treatment. My mother wanted very desperately to bring him home. The hospital said, "If you take him, you take him against medical advice." My mother couldn't do that.

Had there been home care, this would have alleviated the situation. Finally, my sister and I persuaded the doctors involved that this could not go on. This was not a matter of anything but the withdrawing of a particular kind of medicine. Let's be very frank about that.

Mr. ORIOL. Have you finished your prepared statement?

Mrs. BAIRD. Yes.

Mr. ORIOL. Mrs. Baird, I mentioned before that you were retired, but you are newly retired. Would you care to mention your age?

Mrs. BAIRD. I am 66.

## ADULT HEALTH CENTER

Mr. ORIOL. Could you tell us a little more about the Adult Health Center? What is the status of this project now?

Mrs. BAIRD. It was started as the Aging Center on a grant from U.S. Public Health for a 3-year demonstration. Because it was successful, it continued as the Aging Center, which consisted of a comprehensive care clinic, the home care program, and information and referral service.

We ran the group counseling for men and for women, and my job was to supervise the comprehensive care clinic and run the information referral service, which was, in the beginning, a case-finding and an information service.

Medical assistance for the aged had just gone into effect. There were many people who did not know the benefits that were involved, and what we did was put out flyers, we put notices on radio, television, in the various papers, and we gave information in relation to services that were available for the aging population.

This continued until about 2 years ago, when we became the Adult Health Center. We changed from the Aging Center because we were also taking care of those people who were under 62 who were chronically ill. However, the whole thing has now been abandoned and put into the outpatient department, because our staff, our medical staff, was paid. We had one doctor who was paid half-time, and we had nine who were paid quarter-time. There was just not the money to continue to pay.

Mr. ORIOL. Are the services that you provided now being provided in some other way?

Mrs. BAIRD. Some of the services are being provided by social service. The advantage, we thought, in relation to this for the patients was, I was in the outpatient department, not in a separate area. I was there when people came in. I was available and they did not have to make an appointment to see me unless it was somebody from whom I had gotten a telephone call that they wanted to come in and discuss something about a problem they had in the family.

I spent a lot of time on the telephone. I had many people who called to know what to do about an aging parent; was it more advisable to take him home or put them in some kind of a home. The difficulty was, what do you have?

### SCARCITY OF FOSTER HOMES

Foster homes are almost impossible to find, good foster homes, and what I tried to do with these people was to work out some kind of plan for the particular problem that they had in relation to this older relative.

Mr. ORIOL. As a result of your work, many people who might have gone to institutions didn't have to go?

Mrs. BAIRD. We did everything we could to keep them from going to an institution.

Mr. ORIOL. Sometimes just good advice and information can keep a person——

Mrs. BAIRD. Yes. Sometimes all you need is a person to whom you can talk and sort it out so that you could mentally put it in front of you and look at it, and this was a tremendous help.

Mr. ORIOL. At the time this program was suspended, how was it funded?

Mrs. BAIRD. We were funded through fees.

Mr. ORIOL. Fees solely?

Mrs. BAIRD. Yes, and the hospital appropriation. There was no outside money.

Mr. ORIOL. So there was no HEW; no public Health grant?

Mrs. BAIRD. Right.

Mr. ORIOL. As a result of the suspension of this program, do you believe people are in institutions now that perhaps could——

Mrs. BAIRD. I can't tell.

Mr. ORIOL. What is your suspicion?

Mrs. BAIRD. I only hope that there is someone who is going to put out sufficiently to carry on what I did in some way or another, the agencies, our own social service department.

Mr. ORIOL. Did you in that work see any pressures that Medicare or Medicaid might be exerting that intensifies the problem we are discussing today, death with dignity? In other words, are there deficiencies or policies——

Mrs. BAIRD. Well, the trouble with the Medicaid program is always that fear hanging over everybody that it is not going to be funded. This is particularly true in the State of Maryland, and this is one of the things Mrs. Heine mentioned.

Medicaid pays for drugs; Medicare does not. If you are limited and you are not eligible for Medicaid, you are just overscale, and who knows when that scale is going to change? If you are just over, you have tremendous bills and you are not eligible for care; say a fee from the Cancer Society, you are in a real, tough spot.

Mr. ORIOL. Yes, but State legislatures are having so many budgetary problems you never know from one year to another what may happen.

Mrs. BAIRD. Not only from one year to another. It can be within a year that something can happen.

Mr. ORIOL. To go back to Mrs. Heine, what would you estimate you have to pay out for prescription drugs in a month if you don't have Medicaid?

Mrs. HEINE. If I didn't have Medicaid, frankly, I would be dead now. Mr. Heine would be dead, because we couldn't do it. I think the Estradurin is $5 a shot. That is every 5 weeks. He gets Darvon, as much as he needs. He gets Donatol, he gets Malanthal. I get nitroglycerin. I get peratrate. We both get diuretics. These are members of our family. We take them as regularly as we brush our teeth.

We don't know. I figure that it is a good $20 a month, roughly, for the two of us, on drugs alone. We don't have it. We don't have it and I would like to say one thing: That I know that when I could come into Mrs. Baird and talk to her, she helped clarify my thinking, so that I could go back and help clarify Mr. Heine's thinking on something.

I was never under any pressure. I never felt that I was talking to a social worker about a social problem, because to me, cancer is not a social problem; it is a health problem. But just her very attitude in acceptance of it made it easier for us to accept the fact that death is with us whether we want to face it or not. Death to us is as natural as birth. That is why you have the four seasons. Nature takes care of it. You have spring, the renewal, and you have winter, the death, and the human body is no different.

Mr. ORIOL. Mrs. Clark, that is the general attitude you were describing, too, wasn't it?

Mrs. Baird, were you visited more times by spouses of the ill person than by the ill person himself or herself?

Mrs. BAIRD. Spouse or a relative.

Mr. ORIOL. Did you find that the strain on the spouse was very severe?

### WHAT WILL HAPPEN WHEN THE TIME COMES?

Mrs. BAIRD. There have been many patients who really are not able to cope, as my neighbor on the left has been able to cope. "What am I going to do when the actual time comes? I can't stand this. What am I going to do?"

I must say a number of my patients have been in their late 70's, their 80's. I have one couple 88 and 86, and she is living in fear of what is going to happen. No matter which way it goes, if something happens to her husband, how is she physically going to be able to cope with the problem? If something happens to her, who is going to take care of her husband?

Mr. ORIOL. That is the greatest fear. How can you cope?

Do you have any suggestions on how home health care can be provided in a good, practical way?

Mrs. BAIRD. In the first place, I don't think there should be the restrictions on it that there are now under HEW. How you can get more agencies started, I don't know, because I know many of the calls I got in Baltimore were from people, who would call in hospital service, Blue Cross and Blue Shield in Maryland. They would tell them that there are two home care programs under Medicare in the city.

There is one in Baltimore County which gives nursing service only. There is one hospital-based program in Baltimore, the IVNA program, and if those patients were out of our area, and you would try to tell them that they had to go to IVNA, and they wanted a service that was not part of the IVNA program, they were very upset.

Our program was restricted geographically. I think there should be more home care programs. How you get them to do this, I don't know, but I do think there definitely should be some provision for the person who is terminally ill who wants to die at home and there is somebody there who wants that person at home.

## NEED FOR EDUCATION

Mr. ORIOL. One of our first witnesses, Elizabeth Kubler-Ross, the author of "On Death and Dying," spoke about the need for more education in this area. Do you have any suggestion on good, practical ways to do this?

Mrs. BAIRD. There should be education that starts in the nursing school and in the medical school. Our young medical men are afraid; they are afraid of old people, and I think there is something lacking somewhere.

Mr. ORIOL. You said our medical men are afraid of old people?

Mrs. BAIRD. Young doctors. Many of the young doctors don't want to take care of the older patient. Now, when they have gotten to the point where they, by necessity, had to take care of some of the older patients, they changed; but there is resistance when they come into the hospital clinic. They don't want them. They are afraid of it.

Senator CHURCH. Why do you suppose that is?

Mrs. BAIRD. I don't know. Young people just don't think about dying. This is something that is just not ever a part of their thinking.

I think, however, when you get to the point where you are of an age to be in medical school, this has to be looked at. I think it is true in medical school, nursing school, dental school, and I add the last, because we had dental students from the University of Maryland who were looking at some of our home care patients who had dental problems and they never before thought of the possibility of dental care for the homebound person.

Senator CHURCH. I would like to apologize to you ladies for not being here at the commencement of the hearing. We had a special event this morning that came up, a caucus with Senator McGovern and Sargent Shriver, that I had to attend, and on that account I couldn't be here for the commencement of the hearing, but Bill Oriol tells me that he will sum up for me what you have said and, of course, I will have an opportunity to read the record. But I do apologize for missing out on your testimony.

Mr. ORIOL. I asked Senator Church whether I might sum up, because I think that each of you, in a different way, has shown how, because of deficiencies in our existing health care system, institutionalization quite often results, even though alternatives are not only feasible; they have been tried and they work.

Mrs. Clark resides in a very appropriate and homelike apartment area and finds that the atmosphere is conducive to enjoyment of life, and she finds that people are ready to face death and want to talk about it.

Mrs. Heine mentioned that her own physician would not mention to her husband, who has a terminal illness, at least the onset of one, and that she and her husband can talk about it, but she finds resistance.

Mrs. Baird has shown how social workers, by giving practical advice and information, and sometimes just listening, can help people and spouses of dying persons to face it and to find what we are all talking about—death with dignity.

Incidentally, I thought that comment about physicians was very interesting in view of that survey.

Senator CHURCH. Yes; Mr. Oriol has called to my attention a survey that appeared in Life magazine just recently.[1] This is the current issue. For purposes of the record, I think it is of some interest to note that of 41,000 readers who responded to this survey, 55 percent of the families who have experienced a terminal illness say the patient was not told of his condition; 70 percent say the patient should be told; and 91 percent believe a terminal patient should be permitted to refuse further treatment that will artificially prolong life, if that is the choice.

That certainly does tie in with the subject of our inquiry and it does bear out much of the testimony that we have heard in the past few days.

Ladies, I want to thank you very much for your contribution.

Our next witness is Melvin J. Krant, Boston, Mass., executive director of the Equinox Institutes. He is also the author of a very informative article on organized care of the dying.

You are professor of medicine at Tufts University Medical School?

Dr. KRANT. That is correct.

Senator CHURCH. You have a prepared statement, Doctor. We would like to hear it at this time. Then there will be questions.

## STATEMENT OF MELVIN J. KRANT, M.D., EXECUTIVE DIRECTOR EQUINOX INSTITUTE, BOSTON, MASS.

Dr. KRANT. Well, after listening to the ladies who preceded me, I am not sure I have anything that my statement would add, but if you would like, I will read it.

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[1] See appendix, B, p. 142.

While it seems blatantly obvious that death is the consequence of life for all human mortals, the manner of dying, and simultaneously living while moving toward death, is of serious concern to everyone, and especially to those with a physiologic and biologic disturbance that can be called a terminal illness.

While a considerable number of Americans may die suddenly through trauma, violence, or an acute heart attack or stroke, the vast majority of Americans today die of a terminal illness which occupies a considerable period of time in their lives. Such diseases as cancer, chronic arterial diseases of the heart or of the brain, respiratory diseases, kidney diseases, and the like, are responsible for the deaths of approximately 1.5 million Americans per year.

### "NATURAL DEATH"

In this very technical age, the term "a natural death" is used rarely. Even the very elderly must have a pathologic diagnosis at the time of death, although they may well go through a period of deterioration of health appropriate to the particular age of the individual, which may be called a terminal period. During this time of dying, people continue to live in one manner or another.

A small number lose all sentiment existence, either from irreparable brain damage, or passage into coma, which takes away from them and from those who must attend to them the status of being a conscious and interacting human being. But most people are alive and alert and aware in this period.

Because of the significant advances in biology and medicine today, disease processes now take longer to effect the death of a particular patient, resulting in a longer period of time associated with the dying process, and a longer time of living through the process than in the past.

When we speak of death with dignity, we are speaking fundamentally of the right to dignity in all of its definitions and consequences during the period of time which constitutes the dying-living time. In effect, when death does occur, it is not simply the moment of termination which we must consider, but how that particular death comes about at the end of a period of time in which the person and his dignity have either been encouraged to coexist or have been so separated by the nature of the health-care system that the death can never be considered the end of a dignified life.

To speak of dignity is to speak of those characteristics of a human being, and the environment or the world in which he exists, which allow him to feel an identity, or a sense of order, which promotes an inward feeling of goodness. We are talking of a man's concept of himself as being worthy, esteemed, and capable of being loved or liked for himself.

Such a concept implies, in our culture, that an individual has a sense of stature and a sense of control of his destiny. To feel helpless, hopeless, damaged, deformed, or alien is synonymous with feeling powerless, out of control, and distanced from those people and those objects in life which provided a sense of stability, safety, security, and ultimately a sense of being a dignified human being.

By its very nature, a serious illness such as cancer, heart disease, renal disease, or multiple strokes causes individuals to feel damaged, dependent, disgraced in a way, and unworthy. This is especially true of diseases such as cancer. As one becomes sicker, and moves from one treatment to another, and from one facility to another, as is frequent in large cities, those characteristics which make us feel that our lives are under our control, that stability is within our grasp, and that we are worthy and dignified people, are gradually eroded, so that the terminally sick individual feels more and more that he is less and less of a person, and that he moves toward death in dissolution, disaffection, and in resignation, terms that are hardly to be associated with dignity.

Simplified analyses of the complicated problems of the dying individual rarely succeed. Riskily, therefore, let me offer some analysis of the problems. I have done so, and I beg forgiveness if they seem to be very much simply topping the surface.

## MODERN MEDICINE—ORIENTED AGAINST DEATH

First, modern medicine is clearly oriented against death. Continued evolution of new types of treatments, ongoing research into biology and disease, and the establishment of large and specialized treatment institutions are phenomena oriented against disease and death. Death has come to be viewed an accident and not a necessity, and the patient with a terminal illness is constantly being implored in one fashion or another to get better. The medical care establishment in general has little positive strategy toward death in the dying time. People, therefore, often go through that dying time and approach death alone, unsupported, or, in fact, antagonistic to the aims of treatment.

Second, there is a considerable lack of preparation, rehearsal, and understanding of the meaning of death in modern society. Death is not "educated for" in our population, either for children or for adults, and death and dying, awesome as these events are in the life of an individual and his family, become even more so by the absence of a policy of education.

Third, the growth of professionalizations, secularizations, and institutions in general, have removed the dying experience from the interstices of family life, religion, community, and other natural settings where people live. Dying and death are left to the care of the professional, and the vast majority of people, especially in urban areas, live out the last days of their lives in institutions such as hospitals, extended care facilities, nursing homes, and so forth, as opposed to homes. Institutions tend to be much more concerned with efficient operation than with human need. Where death is unwelcome, the enemy, and evil, the dying individual has little opportunity to be assisted in working out meaningful details of the dying experience. He is often treated as a leper, rather than as a man or woman reaching the end of a personal life.

Fourth, the very nature of such institutions and professionalization removes the control over the manner and style of one's death from the individual himself, and places it in the hands of others. This loss of control over the meaningful events inherent in the dying experience, and removal of the individual from the environment where he could maintain some of that control, such as at home, fosters feelings of hopelessness, helplessness, and deceit in the interaction between the health care system and the dying person.

## DISGUISING THE INEVITABLE

Physicians, nurses, clergymen, and others who have worked closely with the dying individual have commented upon the ability of such individuals to face and confront the issues surrounding their dying and the dying process itself. It would appear, however, that most health care institutions and most physicians still prefer to articulate one form of deceit or another in the belief that this offers hope. Hope, in these terms, is construed as protection against confrontation with the limitations of the "curing" ability of medicine, and protection against the psychologic reactions, including depression and, indeed, despair, which are often intrinsic to the realization that one is indeed mortal and that death may be close.

Part of the problem also rests with the fact that official policy in the United States as concerns the health care system in relation to the dying experience is that death is an evil to be overcome. The implication in the investment of large quantities of Federal funds for biologic research investigation is that disease processes no longer need to exist as they do now.

While, in effect, this position seems generous toward relieving human suffering, the inherent implication that all disease, including even the aging process, can be eradicated, places a burden on all dying people, or individuals with serious terminal illnesses, in the sense that in some fashion they are out of keeping with national expectancy.

The large investment in eradication of disease, prolongation of life, and even elimination of aging, has not been balanced by a policy of helping individuals confront and work through those tragedies and suffering of the life conditions which are basically natural to man. Whether or not we succeed as a Nation to extend life expectancy beyond where it now exists, the question of a terminal illness and eventual mortality will always face men. The absence of a public policy to help the individual and his family and community to face human tragedy, especially that of the loss of his own life. results in dignity becoming a curious and ill-defined term when applied to the dying experience.

## THE MEANING OF DEATH

What is needed, I believe, is a threefold program to assist in conceptualization of the meaning of death and dying:

First, an emphasis must be placed on childhood and adult education in which confrontation with major human problems of loss, dying grieving, and other such affectual material, can be explored. Our schools are much better equipped to deal with skills and facts, such as solving arithmetic problems. than they are in dealing with the emotional world of a youngster in relationship to problems he must confront virtually on a day-by-day basis in the areas of psychic pain, hurt, loss, and abandonment.

Such an educational thrust would require considerable training of teachers who, themselves, have been victimized by a "quietism" in the public school systems regarding such intense human feelings. An education program of this type should be aimed at helping the individual to face the naturalness and consequences of mortality in his life and in the lives of those who surround him.

A second part of the program must be aimed at concepts which indoctrinate health care workers with the psychology, sociology and economy of dying and of death. Such education must be devoted toward those problems and processes which are associated with the support of self-esteem and dignity in illness and in dying. It must deal with the development of strategies for improving institutional care, encouraging functionaries who can deal with the complicated emotions which develop during the dying process for a patient and also for his family, and reexamining the issue of the services, necessary to help a patient in dying at home.

I refer to economic, psychologic, and other types of support, as opposed to the pressure for institutionalization which now exists, as was mentioned by several of the ladies who preceded me.

If one simply looks at health care insurance, what health insurance will pay, one realizes that economically the pressure is severe upon a family to keep a sick and dying individual in the hospital rather than at home. Blue Cross, for example, will not even pay for a bandage in the care of the patient at home. It is not only the patient, but the family as well, who needs support in helping a loved one at home through a terminal illness.

## DEFINITION OF "CONTROL"

Third, it will be necessary to review and explore the meaning of control on one's dying and death in terms which include various forms of behavior which have been labeled "euthanasia." I refer to the ability of the individual to have some control over the ultimate ending of his life, and most physicians are very cautious when it comes to looking at this carefully. I think, in fact, there are only two choices in this regard: Either some self-control as to the manner and style of dying is supported for the individual by those in the environment, or this control is taken completely away by the professionals and the institutions.

By "control," I do not necessarily imply that people should end their own lives by a suicide, or by an assistance from a physician or other health care worker who would administer some form of lethal medication. Since most people move slowly unto death, and will die by "nature" rather than by their own hand, control here really means control over those few remaining choices and options and desires which may be left during whatever time is involved in the dying process.

Such control includes being at home and feeling "safe" there. But as important is a feeling of control over what happens to one in an institution. When elements of control are taken away from an individual, he must then die under someone else's control over his own life. Efforts, therefore, should be made to improve understanding of fundamental human properties and the meaning of control.

Part of that understanding includes the nature of decisionmaking. Being in control of one's destiny implies being responsible, in suffering, disease and death, for intelligent decisionmaking, and not having this process removed by another, as well meaning as that other may be.

Next, we must examine whether the very growth of professionalization, specialization and institutionalization are necessarily in the best interests of health care. Certainly, in terms of chronic illness, terminal illness, dying and berevement, institutions and specializations squander and diminish the ultimate meaning of life. There needs to be developed a much larger helping system for dealing with illness in the home setting, and for dealing with family and community around issues of support of each other and of the terminally ill patient.

This may prove to be costly, as compared to institutional economy. Services for the family's needs, as well as for the patient at home, are conspicuously absent in most communities and have become foreign in the world of specialization against disease. But before this services can be truly elaborated, it will take an emphasis on education to promote the notion that each and every citizen is basically entitled to a dignified death as part of a dignified life, and that dignity resides with the individual, but must be supported by systems interplaying in his life.

Senator CHURCH. Thank you very much, Doctor, for a fine statement. I am going to have to leave in a minute to respond to a rollcall vote that is now in progress, but you refer in your statement at one point to the way that the system emphasizes institutionalization of the dying patient, and for an example, you refer to the insurance that pays only hospitalization costs. The Blue Cross, for example, doesn't pay anything if you are getting your treatment at home; you have got to be hospitalized before the insurance will pay.

## HOUSE CALLS—A THING OF THE PAST

Isn't it also true that doctors themselves tend to make this so? In other words, this very survey that I referred to earlier in Life magazine shows that out of the 41,000 readers who responded, 58 percent, nearly 60 percent, say their doctors will not make house calls.

Well, if someone in the family is stricken with a fatal illness and it is made plain to the family one way or the other that if the doctor is going to treat the patient, the patient has to be at the hospital, aren't doctors themselves contributing directly to compounding this problem?

Dr. KRANT. Oh, yes; I think you are quite right. A further extension of that question is, "Why should this be? Why have we so evolved in our present medical system that doctors have attitudes like this?"

These aren't accidental derivatives. They come about by certain social pressures, and I would suggest that there may be two or three reasons. If there are any more, I can't put my finger on them. One certainly has been an enormous elaboration of technology so that a doctor now feels in his training inadequate to go in with a small bag. He now needs enormous amounts of equipment about him to feel that he is doing a good job.

Second, there has been such a change in the feeling of being secure in cities that there is a feeling of being unsafe going into private homes. I know some men feel strongly that they have to bring people into hospitals rather than going out into homes.

Senator CHURCH. There is an interaction of many forces, all of which are pushing us in the wrong direction.

Dr. KRANT. Third, of course, it is that whole sense of education of what life is. I think we do not teach people the basic inherent human qualities. Therefore, I think every effort is always made to extend life, put life into quantity rather than quality, as expressed before. That kind of thinking then makes illness the devil itself, something to be exorcised by technologic means rather than interfacing and trying to develop attitudes of going beyond this. These are only several of the reasons why, but I think they can be overcome.

Senator CHURCH. I hope so, and I hope that in some way these hearings can start a process or help to stimulate a process of reconsideration.

I have to go make this vote. I will be back. In the meantime, I am going to ask Mr. Oriol if he will continue with the questions.

Mr. ORIOL. Thank you, Senator.

## ORGANIZED-CARE SYSTEM

Dr. Krant, I wonder if you could tell us about your work in Boston at Tufts University to develop an organized-care system for the dying.

Dr. KRANT. To bring about, I think, a change in atmosphere, we began a service in the hospital where I work among the patients in which we would attempt to undo some of the processes which I mentioned before, and in that regard we very quickly come to recognize that patients and families were awfully complicated.

Simply saying to somebody, "We wish not to control you, not to have control of your life," was not very gratifying. There is much too much of a complicated thing going on in one's head at a time of crisis, and people aren't prepared to take back responsibilities for themselves.

Physicians are often looked on rather oddly by the general public, and I suppose it is true that most people harbor great fantasies of rescue or parental relationships in which dealing openly with their feelings is just taboo. They cannot do it.

So we developed a concept in which the deriving of information of what is going on psychologically and sociologically with patients and their families was stressed.

What we did fundamentally was create an atmosphere among all people working on the unit, that they were responsible, in one fashion or another, for the basic human consideration of the care of an individual, and that they had a right to inquire and to take information from patients and their families, and they also had an atmosphere of equalitarianism where they could share this coming together for decisionmaking. These conferences include the patient and his family.

Mr. ORIOL. How far along are you now in this project?

Dr. KRANT. Well, we are quite far along with it, with a lot of ups and downs. The project is unsupported by the hospital. It is supported by Federal grant funds, but some look upon it as an official function. It is sort of welded on top of the ongoing service which the hospital makes available for the patients. We have brought in a large number of nursing, theologic, and other students to learn from each other the roles of various professionals in the area of human tragedy and human suffering. It has become a triad of a complicated group—call it "a team" if you will—a triad consisting of a group of people concerned with care-giving, the patient himself as the subject of the care, and the family, all brought together.

A lot of that has had to go outside hospital walls. We have had to go into homes.

Mr. ORIOL. How have you gone into homes?

Dr. KRANT. There is one existing service that has always been there, and that is the Visiting Nurse Association of Boston. Even now, though, they are threatened again with insecurity, but they are still on the scene.

We simply began visiting with them, going out with the nurses to see what home life was like, and what we could do, and tried to develop the concept that a hospital should be a wall-less place, a place where in-service, out-service, and home care is the same thing, and that the best place for a patient is where he and his family choose to be, and that we then become responsible for him being there.

That doesn't sit too well. There is a kind of lazy comfort in being ensconced within the walls, a tremendous security that this is a safe place to be as far as the physician is concerned. Physicians in training almost detest having to make home call visits. They don't like the idea of being taken away from the institution. But the struggle goes on. We are trying to get people more and more to be out into the home environment.

Mr. ORIOL. About how many patients are being served by your program?

Dr. KRANT. Our ward unit is a 30-bed unit. The total number of patients seen in a year—new cancer patients a year—is about 600. Ongoing, it is several thousand a year.

Mr. ORIOL. Now, you mentioned that it was funded by a Federal grant, and I take it you are the only one of this kind in the United States. Do you know?

Dr. KRANT. I don't know. I am sure there are home care services——

Mr. ORIOL. Well, no. But the fundamental concern is the organized care of the dying, isn't it?

Dr. KRANT. Yes; but I am sure that there are others who are concerned with that. We traveled a good deal to give local talks, and there is a lot of emerging feeling among institutions throughout the country that there is need for some of this to happen. I cannot say that we are the only one. The interest in the Nation at large is very, very high.

Mr. ORIOL. You apparently had little difficulty organizing your team, the many disciplines you mentioned. Apparently they were ready for you when you came.

Dr. KRANT. No, I wouldn't say we had little difficulty. We had lots of difficulty, but we were able to work out the essentials, principally because we are in the right institution. It is a chronic disease hospital. There is not a great pressure to exchange people in beds every five days.

Second, our resources from Federal grants and of other kinds were rather legion, and we could use some of that money to begin certain things with.

Third, I think the interest was just right.

Mr. ORIOL. I didn't mean to minimize your difficulties. What I really meant, the interest was there.

Dr. KRANT. Yes, that is quite true.

Mr. ORIOL. Do you think that an organized program could be evolved from yours possibly in other cities, to develop this to the next stage?

Dr. KRANT. The answer would be yes, in a way. One can build models which then can be looked at as models by other places. That certainly has been done, but I think that each place will have to work out its own methodologies. There won't be just one model. Different communities need different things. A large urban community needs one kind of thing; a suburban community needs something different; a small community hospital needs a whole other structure.

Mr. ORIOL. To go back to your difficulties again, are public programs, health care programs such as Medicare or Medicaid, helping you or causing you problems on certain policies or regulations? How is that working?

Dr. KRANT. I am not sure I can answer that. I do not know much about how these programs work because, in effect, on our unit we don't charge patients any medical fees, so we don't get involved with that. I am not the best to answer that question.

## QUESTIONS ABOUT UNCONSCIOUS PATIENTS

Mr. ORIOL. You assert that one element of dignity is controlled by the patient over the course of his treatment, and yet in your statement you mentioned that most health care institutions and most physicians prefer to deceive the patient in the belief that this offers hope. If the right of the mentally competent patient to make an informed consent regarding his method of treatment is so obviously violated by such a situation, then what can be said on behalf of the dignity of the comatose or unconscious patient?

Where should control lie; with the doctor, the relatives, or the patient's prior wishes?

Dr. KRANT. First off, I would like to clarify. I do not think physicians purposely go out of their way to cause deceit. If the goal of medicine is cure or rehabilitation, as it is today, then the narcissistic needs of the physician are to deal with situations which are rewardable, namely, people get better.

The need to protect people then, from looking despairingly at what is the truth bring the physician to expect a form of protection, rather than willfully wishing to lie to hurt. I think there is an important difference between wishing to protect somebody from having to be human—in the way many physicians will deal with the patient—or going out of one's way to purposely do evil.

The former implies a lack of understanding of what the human condition is about. It goes simply to the false philosophic assumption that all humans can do is look for joy. As far as the comatose patient, et cetera, this is obviously a very difficult ethical area. I can only answer as follows:

If the patient's wishes were known, I think they should be adhered to. But a family's pressure on the health care system is enormous. The family who says "Do everything that you can," while the patient has said, "Leave me alone," presents the physician with a terrible problem.

The burden is sometimes seen in legal terms, the physician being insecure that he will end up being sued or that he will end up being disgraced, one or the other. Where there is harmony between the three—patient, family and physician—then I think one acts in a very simple and dignified way. Where there is disharmony between the three, and they are out of step with each other, that is a tough problem, and people simply do what they think is best to be done.

Again, I don't think there is evil implicit in this. I think physicians sometimes keep tubes going, don't turn off switches, in a sense that they are pressured by families not to let go and there are just no mechanisms available to explore with the family why a family makes that decision. I think this is a very frequent occurrence.

We have guilt, pain, and concern in intrafamily life. Sometimes one just cannot let go of a dying individual and the physician is oftentimes caught right in the middle.

## EDUCATING THE YOUNG

Mr. ORIOL. Dr. Krant, you and other witnesses have talked about the need for education on this issue, beginning even in public school for youngsters, and frankly, I had a little problem trying to visualize what form this would take.

Dr. KRANT. If we accept the concept that youngsters, as they begin to mature, starting in the school system, are confronted continually with certain problems, certain sociological problems, one of the things I think that emerges out of that acceptance is the fact that we only have several choices of what we allow that youngster to do with that problem: Either he is allowed to confront it, to deal with it, to look at it in some way and not be terrified about it, even though it is an awesome and difficult problem, or, in fact, he must bury it. He can't share it with anybody.

At the very root of most psychologic disturbance in personality, or, indeed, in psychopathology, the very root of the system we believe in, is the concept that as the individual was developing his personality, intense emotional experiences were not allowed to be worked out, but had to be buried, which then, in some way, poisons the normal maturation of that personality.

In the concept of education, we are not concerned with making teachers psychotherapists, nor with making the young child growing up burdened by too much material he can't handle. But since children have to face the death of grandparents, parents, brothers and sisters, animals and pets and also divorce, all kinds of break-ups in their normal kind of world, then the ability to look at some of these issues, the ability to deal abstractly with some of these materials, can be a very important assistance in helping that child to grow, to be a more normal or more mature individual.

Did I answer your question?

Mr. ORIOL. Yes.

Senator CHURCH. What changes, Doctor, do you think should be made in medical school training? Is anything being done now to educate doctors to the issue of terminal illness?

Dr. KRANT. I think when you try to educate in concepts of death, you must begin educating in concepts of the whole human sense of what it is to be a dignified person. That is a very difficult issue.

The medical schools have been overwhelmed with technological material. Students have a terrible time surviving the simple retention of information. The idea of interacting with humanistic issues, or with this concept of dignity, requires a maturation of a student, even a freedom to confront, which he often doesn't have time or space for in the overcrowded curriculum which exists.

Senator CHURCH. Well, then, the answer to my question is no.

Dr. KRANT. The answer is, there is very little being done.

Senator CHURCH. Isn't the problem exacerbated by the fact that not only do the people regard medicine as a kind of uninterrupted procession of miraculous cures, successful operations of extraordinary complexity—and we love our machines in this country like nothing else—and now medicine is adorned with such lovely machinery. So this sort of triumphant appeal that modern medicine has, not only to the people but to the doctors themselves, all operates, doesn't it, to make death the enemy. There is this kind of implantation of the notion that medicine will conquer all.

One day medicine will conquer death itself, or the process of aging, and no one seems to consider that to be the ultimate tragedy, that when it happens it will be the greatest blow that could befall the survival of the race, because, as I said the other day, if you end death you must also end birth or see the race perish.

I am wondering, is there any difference at all in your experience between the treatment of dying patients in nonreligious hospitals and religious hospitals? Say Catholic hospitals? There are many of them in this country. You mentioned in your statement that the educational system should have a role in changing attitudes toward death in this country, but shouldn't ministers play the central role here? What are the churches failing to do in preparing patients for death, and isn't this essentially a ministerial duty, that the comfort and understanding and acceptance of death seems to me to be distinctly appropriate to the ministerial function in our society?

## RELIGIONS SAID TO BE DEATH ORIENTED

Dr. KRANT. I think that one of the previous roles of organized religion, whatever it was, was to proclaim doctrine ritual and dogma, which, indeed, became then the external circumstances of life itself. All religion is basically death oriented. That is the reason for it.

With the death of the feeling that organized religion and its dogmas really played a common part in the everyday life of man, individualization—individual responsibility—became larger than what simple externalized dogma handed down. We have come to rely on the notion that "every boy can be President" kind of thing, that clearly the idea of identity rests on an individual, and every individual must make it on his own. Religion no longer holds the channels for an effective life. In that regard then, I think most young people going into theology do not know what their role is.

They are no longer entitled, they believe, simply to speak of the dogma of the church. They now must speak of the logic of psychology.

In the Boston area, the greatest problem for the person going into the ministry is total loss of identity. He doesn't speak God's language any more. He only speaks Freud's.

Second, clearly the church had much more to say when people lived in the natural communities, their homes and environments, church yards filled with cemeteries, et cetera.

People don't live there much any more, and they don't get ill and stay there much, and they don't die there very much any more. In larger cities upward of 70 percent of all people die in institutions. This is a very uncomfortable thought and is not welcomed. In some of our seminars we have had medical students call theology students a third-rate psychologist.

They don't know what their roles are and the ministers in turn feel diminished and terrified going into hospitals. They are not wanted. If there is a crisis in the patient's condition, the minister is pushed out of the room and the EKG machine is rolled in.

Senator CHURCH. But that is awful.

Dr. KRANT. But that is what it is.

Senator CHURCH. Awful. That is why everyone feels awful going to a hospital. Any time I have a member of my family in a hospital, I feel awful going into the horrible place and everybody is immensely relieved to get out of the horrible place. That is the truth. Something has got to give unless we are going to create a society of horrors for the inhabitants of this country.

Dr. KRANT. I agree, and I am not quite sure what role the Federal Government can play in helping. My own feelings are that to simply legislate a Euthanasia bill is unlikely to succeed at all simply because the authority will still be in the physician.

Two things are very sure. One is that medicine does not like to deal with death, and therefore, everything about it will be organized against it, and second, they will not be able to force the physician to accept the patient's wishes so long as he doesn't understand what it consists of. He is so organized against that principle of death being part of life.

### INDIVIDUAL'S WISHES IGNORED

In some of the testimony you have had, mention was made several times of people signing their own will directing the doctor not to do anything courageous. If I am that sick, let me die. But the fact is that most physicians will disregard it. If I get sick in a nursing home or some place, I may be shoved into a hospital.

The moment that happens a young intern or resident or some practitioner takes over my life. Whatever I have got to say about it is no longer important. It is what he judges to be correct which then becomes important. In that sense I am violated, and I must simply resign myself to the fact that he will control me. No matter what I sign, it is not going to make any difference.

Senator CHURCH. Well, then, the educational process in your view though, must begin with the medical profession itself. I mean that is the first and most important place to start.

Dr. **Krant**. Well, I would think that absence is a general U.S. policy, and that is this enormous investment of health has been conquering diseases. There has been very little money in developing ways of dealing with human suffering.

The purpose of the cancer battle is that it is to be conquered. Well, let's hope that it is, but in that process what will happen to all those patients who get cancer? We've spent millions of dollars out there as if sick people were simply articulations, experimental things to be conquered, rather than to help the sick live through that process of suffering with illness.

I think in some way challenge can be inspired. I am not quite sure how, but education is critical.

Senator **Church**. Thank you, Doctor.

Our last witness in this series of hearings will be the Rev. Edward F. Dobihal, Jr. of New Haven, Conn., professor, Yale Divinity School and chairman, Hospice Planning Group.

We are very pleased to have you. We have not relegated you to the last place in these hearings because we think your testimony is less important. I think that perhaps you should regard your testimony as the finale in these hearings or the summation, because it all sort of leads in your direction.

## STATEMENT OF REV. EDWARD F. DOBIHAL, JR., NEW HAVEN, CONN., PROFESSOR, YALE DIVINITY SCHOOL; CHAIRMAN, HOSPICE PLANNING GROUP

Reverend **Dobihal**. That causes me some anxiety. I was fortunate to be able to be here yesterday as well as today and I want to thank you, Senator Church, and your committee for giving all of us this opportunity to speak to this issue.

I think we have all noted that as you opened the topic, "Death With Dignity," for dialog and for various presentations that it allowed people to speak to the many facets of this problem about which they are particularly concerned. I am not going to read my entire statement since I have written a rather lengthy paper.[1]

I don't know whether that is because of being a long-winded preacher or what, but I am not going to read it all. Particularly since the first sections have been very adequately covered in prior testimony.

One of the things that I emphasized in the first portion of my statement was the fact that most people today are dying in general hospitals and that I think they have received inadequate and inappropriate care.

That has been said before in the hearing, amplified, and certainly Dr. Krant has remarked on it today. It needs to be emphasized. I have also, in those first sections, commented on how unfortunate it is that terminally ill patients are now being classified as a somewhat unwanted population in many institutions at the same time that our policies which favor institutionalization relegate them to those institutions.

I can think of nothing worse than to be in an institution where you must sometimes be, solely because of financial reasons due to insurance regulations. Patients often feel unwanted, feel that they are

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[1] See prepared statement, p. 129.

not doing the job of getting better, which people seem to expect of them, and grow to feel more and more isolated.

That issue hasn't been mentioned as much in this hearing. Although I am not reading from my paper, I would stress that in addition to some patients being subjected to the extraordinary means of treatment that we have emphasized here, treatment which is often painful and prolongs existence, not life, many, many patients that I have seen in our hospital and in others feel a great isolation.

This was certainly pointed out by studies by Dr. Lashan years ago where, as treatment is withdrawn from patients, they simply are left in their rooms with very, very little support. I think enough has been said about the inappropriate and inadequate care but I think that we really need to begin to do something about it.

## COMMUNITY INTEREST

I am encouraged by the amount of community interest and community support and community requests for aid with this issue of "Death With Dignity." I was particularly pleased that there was the panel of the three ladies who appeared today who spoke so eloquently from their own experiences.

We in New Haven are working on a project since we do feel that we must begin to experiment with new systems of delivering health care to the terminally ill. Since our project has become known—and we have not gone out of our way to say much about that project—some newspaper articles have been written.

One of them hit an AP wire and was sent throughout the country. We have received mail from all over this country. In fact, we didn't solicit for funds but in that mail were $1 and $5 bills and some major contributions. It added up to about $3,000, plus simply or elaborately worded letters saying, "Please get on with your work."

I was on the radio about 2 months ago. It was one of these evening talk programs and there were so many calls that night the station had to ask me to come back because we couldn't answer all of the calls that were coming in. It was obvious there were going to be many, many more, demonstrating the interest of community people.

There is an atmosphere of openness and, in fact, I think there is more of a community atmosphere of openness than there is an institutional or medical atmosphere of openness. As we have tried to work on developing a system that would provide terminal care, we have had the same experience that they had in England; that is, that the community, those who were very involved in the topic because of experiences in their families, nursing staff, clergy, social workers and others are very, very interested.

The last group to become interested have been the physicians. We now have some of them, including pediatricians. I remark on that because of the educational comments that Dr. Krant has made. These pediatricians feel it is extremely important to help children to cope with the dying that occurs, for example, in their household when a parent dies.

One of our concerns is that when you talk about terminal illness you are talking about many, many people who are in the older age group but you are also talking about many people who are in the 40- and

50-year-old categories. The kinds of problems they experience are phenomenal.

## Is Hospice the Solution?

I will turn to my paper now and read the statement that we as an organization have proposed. "After 3 years of work with patients in existing health facilities, we conclude that there is a need for a health delivery system to help patients round out their lives and live with meaning although they are dying of a degenerative irreversible disease, a system of care which will offer a less expensive alternative to care that is now primarily based in acute hospital. We have decided to establish such a system and call it Hospice. It will include care at home and in an inpatient setting designed to meet family needs as well as patients."

We have decided to do this as a different system at the encouragement of a university medical center which says that it cannot adapt its system at this period in time with the attitudes and values that they hold to provide this kind of care.

We have heard it from a general community hospital which happens to be a Roman Catholic hospital. They also encouraged us to do this on our own. The VNA encouraged us to do this on our own because they said that some of their nurses had many fears and apprehensions in providing this kind of treatment.

They needed us to develop a staff which would hold these goals very, very high and which would be willing not only to provide treatment but to help educate others. That was the same request that we got from the hospitals. The personnel there are afraid of many of these issues and we have some people in our project who are not afraid of them.

We feel that we cannot only provide the kind of supportive care that is needed but we must be a demonstration model to people so that they can see what can effectively be accomplished. When they see that you can do something, then perhaps we will begin to change the system and the attitudes.

Some of the reasons for this being stressed as a new system of coordinated terminal care is that it is very important for patients and families to have a group of caring people meeting their needs and to know that they aren't going to be shuttled about any more. Most of these patients have been shuttled about a great deal. They need consistency and they need someone to help them maintain the integration that they want in their lives, and that they feel they are losing.

## Cure Versus Death—A Conflict of Goals

We want to be away from the conflict of goals between cure versus death. Certainly cure is a reasonable goal for many people who are ill and for most people in the acute hospital. It is simply an unrealistic goal for others. There is nothing wrong with the fact that everyone in this room is going to die, that all people are going to die at some time. What is wrong about it is that we, unfortunately, don't provide much help to persons when they are in that process.

One of the things that we would want to do is change the patient category to the patient and the family. Both are ill at this moment, one might say, or both are involved in this need for care. That raises a very important research area. We know from preliminary research studies, for example, that psychological trauma and physical trauma may be much higher in a recently bereaved family than a family without this crisis. We need to know much more about this since one of the areas of preventive health care that may be involved in terminal care is helping the bereaved. The other thing is that we want to help the family to stay together and go through this experience together. They are not allowed to do this in the kind of facilities that now exist.

Senator CHURCH. I know the last hospital I was in refused to have any dealings with children under 16 years of age.

Reverend DOBIHAL. Right. If you will note in——

Senator CHURCH. As a visitor.

Reverend DOBIHAL. As a visitor, yes. If you will notice in my prepared statement, we plan to train family members to participate in the treatment. When I was in England there was a lady and man that I met in their home who were very, very concerned about any kind of further institutionalization.

The wife talked to me about this and expressed her concern by saying:

> If he has to go back into the hospital I will no longer have any real way of relating to him and this is very important to both of us.

We were able to describe the facilities that he could go into if he needed to, either to give her a break at home or to help her when he became absolutely bedridden. She went and visited the facilities as did her husband. When her husband became bedridden the wife accompanied him while he was admitted, had unlimited visiting hours and began to learn how to help nurses provide care.

She was able to bring him special food that she had prepared at home. The grandchildren came to visit. They could even bring pets in.

This kind of maintenance and support is quite possible but it is not possible in present systems.

It has to be designed. For example, you have to have differently designed space to provide for families. One of the things that we haven't learned enough about is that when you do have families and patients like this together they are a great help to each other. It is not only the professionals that can help. That is a big part of our concern, how to allow these patients and these families to be of assistance to each other.

### A SYSTEM WHICH HONORS THE "LIVING WILL"

It seems to me that in light of what has been said of the living will, a very important document, we must begin to change the system of care. Unless you have a system that appreciates, honors, and aids people in carrying out the intentions of the living will it will not be significant. Presently, I think Dr. Krant is right. It would be set aside. In our medical center, which is the University Teaching Hospital, in fact, probably, it wouldn't even be discovered until the patient was in the midst of all kinds of treatment.

Another reason for the need of a hospice-type program is the many, many medical problems that are not being dealt with adequately and that need to be dealt with for terminal care patients. My prepared statement referred to the problem of pain, as one example. We do not handle the pain that terminally ill people have very well in an acute facility.

There are doctors who are concerned about addiction. There are other doctors who feel the best way to handle pain is to knock the person out. True, the patient won't feel any pain but he will not be able to communicate, either. There are others who feel everyone should be able to handle pain. This attitude is often phrased like this, "If he lets us know when he feels pain we will ease it and probably take most of the pain away. Really, you know, you have to have guts and everybody has to suffer a bit when you're this sick. He will handle that on his own." In fact, the attitude often grows that anybody who asks for pain medication too much is a crank. Yet, we know that if we entered into an administration of drugs for pain control rather than dealing with pain as a symptom we could do it much better.

Finally, the last point in my presentation is that really providing good terminal care makes a tremendous demand and is very draining on the staff who are providing the care. Here is where I think we have developed a philosophy that is pertinent to the Catholic, pertinent to the Protestant, to the Unitarian, and to the agnostic humanist. We have agreed among ourselves that one of the things that draws us together is a reverence for life.

It is a concern for our own living and also to support each other as we try to provide this kind of care. In an acute general hospital that kind of support does not exist. It is going to be very important to develop the kind of community that will allow staff people to take strength from themselves and the patients and families they are working with and also to be able to welcome into that community the terminally ill who are in need of its love and care.

For me this is something of a mission. I feel very similar to Dr. Cecily Saunders who in England felt called to this task. I feel that same call. Read the last paragraph where the patient in England said, "Go back to America and provide places like this, where I have found a place to belong, if you don't have them there." I feel that is a task for us to do. I am going to end there.

Senator CHURCH. That is a good place to end your testimony and the prepared statement will appear in the record.

(The prepared statement follows:)

## PREPARED STATEMENT OF REV. EDWARD F. DOBIHAL, HOSPICE, INC.

### INTRODUCTION

Hospice, Inc. is a non-profit corporation in the State of Connecticut with a volunteer membership of health professionals and community persons who have organized to plan, design, and implement a coordinated program of health care for the terminally ill. The program is planned to be a demonstration model for service, a training center to develop manpower, and a research center primarily in the fields of dying and bereavement but also which will provide data on other types of health care problems. This is a unique endeavor in the United States and considering the tremendous need of terminally ill patients and their families is long overdue.

In many individual situations terminally ill patients and families have received excellent medical, nursing, social, psychological, and spiritual assistance. However, approximately 70% of the individuals who die in our country die in our health care institutions, predominantly in acute general hospitals. The majority receive care that is inappropriate and inadequate to help them come to the end of their living in a meaningful and gratifying way. Death and dying have been taboo topics for too many years. They have finally surfaced and we have discovered the overwhelming concerns of both the lay public and health care workers to consider what is being called "Death with Dignity." Hospice, Inc. is concerned to demonstrate that life can be lived with dignity right up to the time an individual dies and that we can include this final act of death, required of us all, as part of our living.

### PROBLEMS FOR THE DYING PATIENTS AND THEIR FAMILIES

*An unwanted population*

For the new, possibly critically, injured accident victim or the individual who has a sudden, acute life threatening illness the acute general hospital is the most appropriate facility. For the chronically ill person with a disease or several diseases that have been treated fully by acute medical procedures and who is now being gradually debilitated the acute general hospital is not the most appropriate facility. For such a patient rehabilitation efforts have to be assessed and then specialized home care or treatment in an extended care might be needed. For that patient when he or she becomes terminally ill, with a limited expected life span, there probably is no appropriate program or facility available.

For the latter patient located in the acute hospital the medical team will often say to the social worker, "Mr. A should be discharged. Will you take care of that right away." A simple sounding request that often introduces a horrendously complex task. The most appropriate discharge plan might be to send Mr. A home, but he would need well coordinated support services from nursing, home health aides, perhaps physio-therapy, occupational therapy, et cetera. At this moment we are in the realm of unrealistic abstraction since these services have not been developed in many places, are severely limited in other locales, and present public policy makes payment for such services almost impossible.[1]

Aften such a patient will be discharged to his home with a few support systems provided but with the expectancy that the ambulatory services of the hospital will meet his needs. The clinics, even if they are numerous and elaborate, the emergency room, even if it is well equipped and served by excellently qualified persons in all specialties and sub-specialties 24 hours a day, are not the kind of ambulatory services that our Mr. A needs to support him in his discharge home. They are not anxious to have this kind of patient and the direction of the ambulating is wrong. Services need to be taken to him in most instances rather than expecting that he will take himself to the services. This the acute facility is seldom prepared to do and fewer and fewer physicians even make home visits. Then we must stop depending on the acute facility to be the comprehensive facility and develop and fund the other necessary programs. This means changing the institutional bias of insurance plans, including Medicare and Medicaid. Currently the type and quality of care needed by individuals must be ignored all too often because of the practical issue that the individual must be cared for where he can receive reimbursement from Medicare, Medicaid, or other insurance plans.

The second possible discharge plan the social worker can consider is to an extended care facility. On this particular day she may know that there are twenty-five beds vacant of the 350 available in these facilities (an average for our area). But her inquiries are greeted with comments like these, "I'm sorry we don't take anybody who has had neck or head surgery." "We couldn't possibly take Mr. A, he needs too much nursing care." "Is Mr. A terminally ill? Our staff can't take any more of those kind." "Would you say Mr. A's state of health can be improved? If it can't we won't be reimbursed and we can't take him. You did say he didn't have much money didn't you." In the latter case Mr. A may be elderly and eligible for Medicare. However, the regulations are being interpreted in such a restrictive way that the terminally ill are being discriminated against. It is very difficult to be terminally ill and at the same time meet regulations demanding rehabilitation or potential for altering the state of health in a positive direction.

Finally, the social worker finds two extended care facilities that can take Mr. A. One is within five blocks of his home and his elderly wife will be able to walk

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[1] "Home Health Services in the United States, A Report to the Special Committee on Aging, United States Senate," U.S. Government Printing Office, Washington, D.C., April 1972.

over and see him frequently. The bed will be available in three days. The other facility is fifteen miles from his home, public transportation is unavailable, and Mrs. A doesn't drive. If the social worker keeps Mrs. A in the acute facility Medicare may not pay for his last three days since Mr. A could have been moved to the distant facility. As a social worker said to me, "This is cruel. They really don't care about Mr. and Mrs. A. When I die I hope its sudden. I don't want to have to go through all of this."

Being ill, particularly terminally ill, is a lonely, difficult task. We don't help such patients and families when we convey the fact that they are unwanted. All too often we convey exactly that fact. Just listen to some comments of patients, "I don't belong here. I'm not getting any better. But I don't know where I belong." "I must be a disappointment to my doctors and everybody. I'm not getting well like you're supposed to. Why don't they just take me out and shoot me." "They say I can go home. How can my husband take care of-me. He has to work and I can't even go to the bathroom by myself. Oh God, I'm useless and no good to anybody any more." You can't in all honesty, though you may out of anxiety, answer these feelings with "Now, now, you shouldn't feel that way." If we really do care about the terminally ill we haven't given much evidence of it in the way we've constructed our systems of care and left such a gaping void.

### *A feared population*

Much has been written about the fact that the dying person maks.us face our own death and that is threatening. Philosophers, psychiatrists, and theologians disagree on their theoretical formulations in this area but the clinician who works with the terminally ill knows that these fears are expressed consciously and unconsciously by many people.

For example, since our research projects[2] and our planning have focused attention on our interest in the field we have had innumerable requests for information, speaking engagements, and seminars for hospital staffs, nursing schools, clergy groups, community groups, et cetera. Three topics always are identified within these groups: 1) The staff's identification with the patient and personal concerns about their own death, 2) Apprehension about how to talk to the patient because of anticipating the patient's fear and possible loss of hope, 3) The patient care team has great difficulty with open discussion and joint decision making regarding treatment of the terminally ill patient.

Our own work, that of Dr. Cicely Saunders, Dr. Elizabeth Kubler Ross, the late Chaplain Carl Nighswonger, Dr. John Hinton, and many others have demonstrated that the fact of death is not the primary fear of many patients, but often is the projection of the health care team and frequently the projection of the physician. The secretiveness, seldom a secret from the patient, does create a lack of communication and a sense of isolation which is a primary fear of the patient. With sufficient data to demonstrate these facts, to continue the too general practice of withholding reality from the patient would suggest more fear within the helping person than the patient.

In the care that is given terminally ill patients in many acute facilities two dramas are often acted out. The first might be entitled "Quietly Isolated." The terminally ill patient is gradually receiving less and less treatment and is, therefore, needing less and less treatment time of the kind usually given in hospitals. Almost imperceptibly the patient becomes isolated as time is spent giving active treatment to other patients. Fewer people are in contact with the patient and they spend less time with the patient, since though hospital personnel are very skilled "doers" they may be very anxious at simply relating to people who desire their presence and to talk. This will be particularly so if the

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[2] Wald, Florence S. "A Nurses Study of Care of the Dying Patient." U.S.P.H.S. No. NU 00 352–01. 02. 1969–71.

Wald, Florence; Dobihal, Edward; Goldenberg, Ira; Wessel, Morris. "An Interdisciplinary Study of Care of Dying Patients and Their Families," American Nurses Foundation No. 2–70–023. 1970.

Dobihal, Edward, "Bereavement and the Church's Ministry." Unpublished doctoral dissertation, Drew University, 1965.

Lipman, Arthur; McCart, Gary; Beste, Donald, "Care of the Dying Patient, An Interdisciplinary Approach." Unpublished paper presented at the 6th annual midyear clinical meeting, American Society Hospital Pharmacists, Dec. 14, 1971, Washington, D.C.

Wessell, Morris, "To Comfort Always," Yale alumni magazine, June 1972.

Eisenberg, M. and Goldenberg, Ira S., "A Measurement of Quality of Survival of Breast Cancer Patients" in Clinical Evaluation in Breast Cancer. Academic Press, London and New York, 1966.

physician has said, "This patient is not to be told she is dying," or if he hasn't told the nursing staff what he has told the patient. Nurses know that they can't relate long to the patient without getting into topics that are forbidden or that they have not been told how to deal with. It is more comfortable to stay away.

The second drama might be entitled, "Never Give Up." In this instance acute treatment, uncomfortable and demanding procedures, are imposed upon the patient to the very end. This may be an effort to avoid "failure." Death is seldom because of a failure of the physician, nurse, hospital, or extended care facility though it often seems to be perceived that way. The larger failure is when the existence has been too long prolonged by procedures and technology because we've confused that existence with life.

This is a very difficult area and I would not belittle the physician's sense of responsibility around complex decisions. In a recent article in Medical Dimensions, March 1972,[8] Dr. Eric Cassell calls for small group discussion among housestaff and attending physicians, rooted in specific case to develop the values and climate which will improve decision making. He adds, "There are others to help, the clergy and philosophers (he could have included other health care workers)—it won't hurt them either to see the pain of individual decisions in the real world." This writer agrees, but with the recognition that many professions beside the medical have known this pain for years, want to be included in such discussions and will appreciate it when physicians feel sufficiently comfortable to invite their participation.

Extended care facilities suffer from the same fear of the terminally ill. Many are currently stressing rehabilitation, and appropriately so, but these are often the facilities with sufficient personnel to provide terminal care except that their treatment goals are quite different. Most accept a very limited number of the terminally ill and give the best care they can in an environment with mixed goals and a patient population with varying degrees of need. However, it is difficult when the director and workers from a facility stress that they don't want to get a bad name from too many people dying in their facility or as one said in a recent meeting, "We don't have those kind of people in our facility. We have very few deaths." The writer was in the emergency room the next week to help receive one of their residents. He was dead on arrival, but it was true he died in the ambulance and not in that facility.

I have critiqued some of the current practices known to me and others who care for the terminally ill and their families. I also critique the attitude that these are persons we can't do anything more for. We haven't started to do much for them yet in this country and that is why Hospice, Inc. is at work.

## THE HOSPICE—A SOLUTION

In several grant proposals Hospice, Inc. has stated, "After three years of work with patients in existing health facilities, we conclude that there is a need for a health delivery system to help patients round out their lives and live with meaning although they are dying of a degenerative irreversible disease, a system of care which will offer a less expensive alternative to care that is now primarily based in acute hospital. We have decided to establish such a system and call it Hospice. It will include care at home and in an inpatient setting designed to meet family needs as well as patients."

The word Hospice means a community of people with a common goal—to care for travelers on the way. We chose the name because it is most appropriate for the person resting and finding refreshment and renewal in concluding the journey of life. We also chose the name because of its international usage since several of our group have visited and studied at St. Christopher's Hospice, a terminal care facility in London, learning much that has helped us in our philosophy and planning.

The planning group has stated their philosophy in part as follows:

"The professional and scientific knowledge of nursing and medicine combined with this reverence for life and its spirit, serve to help the staff understand the experiences of the patient and his family and to relieve their distress. We find that this type care increases the capacity of the patient and his family to live through this period with meaning and dignity. It is important to dis-

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[8] Cassell, Eric, J., M.D. "Treating the Dying—The Doctor vs. the Man Within the Doctor," Medical Dimensions, March 1972.

cover the patient's and family's life style so that we can adapt to them and help them include this experience of dying and bereavement in their life, in their own way. The patient and his family, therefore, assume active roles in the decision making processes. They also become teachers for other patients and families and for staff members seeking to be more understanding and helpful during this moment of crisis in life experience. Thus, the work of the Hospice is shared among patients, families and staff; all cooperating in the caring task.

Persons helping terminally ill patients round out their lives expend tremendous energy; this needs replenishment. Patients and families help with this replenishment, but since they come and go, there is need to recognize the importance of the ongoing relations of the Hospice workers to one another. This is the Hospice "family" which welcomes those in need, serves them and helps them on their way. This "family," in its openness and concern for all members, is what sustains. It is necessary for all in the Hospice to be both strong and weak, giver and receiver, and to be strengthened by bonds between people and not only one's internal resources."

This philosophy is now being put into practice by a group of people in Connecticut who are active in the planning stage of the Hospice which is supported primarily by unsolicited funds from many individuals and a planning grant of the Connecticut Regional Medical Program. A Board of Directors is responsible for policy decisions for the project. Task forces composed of many of the 200 volunteer friends of Hospice are working on patient-care, community relations, professional relations, building and site, finance, and research. A part-time staff is working with the task forces, developing and conducting educational programs in the community, and developing the collaborative relationships with other health care groups in the Greater New Haven area so that Hospice will be well integrated into the existing medical delivery system.

The latter task of the staff is extremely important since Hospice is not to be an isolated facility but plans to work in close collaboration with a major university center, an excellent community hospital and a V.A. hospital, extended care facilities, two health maintenance organizations, the V.N.A.; homemaker associations, et cetera. But in our preliminary planning all of these organizations agreed that terminal care was not now adequately being provided and that it could best be provided through an independent program, affiliated with others for specific service, teaching and research.

There were several reasons for the encouragement to establish a new program and facility which I will briefly describe:

*Coordinated terminal care.*— With the advances in medical science there has been a necessary increase in specialization. The terminal patient-family often falls between the specialists and experiences extreme anxiety because of the lack of integration between medical specialties, physician-nurse, social planning, psychological and spiritual support. At a time when a patient-family are attempting to bring life strands together, to conclude a whole life, they are often experiencing a destructive inconsistency and divisiveness. Consultants strongly encouraged a new program with common values, a small staff where much role blurring could occur because of mutual trust, and where consistent support could be offered by a coordinated, collaborating staff.

*Conflicts of goals—"cure" versus death as the end point.*—Acute hospitals and extended care facilities give their highest priorities to "cure" or control of disease so that the individual with the disease can continue to cope with life as productively as possible. Medical insurance basically supports this disease treatment process. However, as Lerner points out:

"One of the most significant changes in the mortality experience of this country since 1900 has been the decline in the major communicable diseases as leading causes of death and the consequent increase in relative importance of the so-called chronic degenerative diseases, that is, diseases occurring mainly in later life and generally thought to be associated in some way with the aging process."

At some point in this degenerative process "cure" and even rehabilitation become impossible goals. To continue to apply those goals is to mistreat the patient-family. The goal of sustaining the patient-family demands a new type of care, accepting that the end of such care will be death, but that that will not be defeat.

*Defining patient-family as the unit for care.*—This concept has applications for much of health care but nowhere is it more important than in terminal care.

For example, in the processes of dying and bereavement it is extremely important that relationships are lived out and concluded as productively as possible. Neither the physically ill person nor the family should be so separated by the treatment milieu that they are forced to abortively terminate their relationships.

Hospice will continue to include family members as important members of the team when the patient is at home or in the inpatient facility:

1. To train them to participate in treatment.
2. To encourage them to do such things as continue to cook special meals for the patient (very important for ethnic groups and to stimulate appetite).
3. To have unlimited visiting so that the total family unit including children can participate.
4. To provide special space for families to meet each other and space for family members to live-in when death is imminent.
5. To provide special social and educational programs for the family-patient, including continuing those plus visitation for the family after death has occurred. The latter is a prime area for research in a preventive health field since studies show greatly increased mental and physical trauma, including death, when the bereaved are compared to a control population.

This emphasis on Patient-Family also means that they will be very involved in teaching the staff of their needs and in the decision making regarding their treatment. To assist the Patient-Family to utilize their own life style and to maintain a sense of their own responsibility while receiving supportive service will develop interdependence that is much more dignified and elevating to the ego than the type of dependence and regressive behavior we now often force upon patients. This also will be important research data, available because of this concentrated population, to be applied to other treatment modalities.

*Inability of staff within existing facilities to modify more primary roles and methods.*—Our consultants from other treatment facilities were excited by the concepts of care described in the preceeding section and pointed to them as essential reasons for an independent program such as Hospice. Staffs serving in acute hospitals, extended care facilities, and in home care programs have so few Patient-Family terminally ill at any time that they cannot modify their primary rolls or procedures or regulations to fit the special needs of the terminally ill. Also, since the terminally ill are so scattered among the existing programs they cannot provide the mutual support to each other that is so important (an excellent 120 bed extended care facility in our area will only serve one to three persons in this category at any time). Our consultants rightly pointed out that this was a program demanding very individualized care within a carefully developed community environment that would require considerable application of group works skills. Since the program was so innovative they cautioned against its being a portion of an existing program where it could be sabotaged by being made a second-class citizen, a new competitor to be limited, or a cause of friction and jealousy because of its special mode of operation.

*Need for a strong community of staff.*—The team which collaborates with the Patient-Family in providing care will include many disciplines—medicine, pharmacology, clergy, nursing, social work and psychiatry as well as non-professionals. We believe patients and their families together with staff and volunteers can do this best in a community which shares the work and provides a system for support and mutual understanding. Having seen how team work is an actuality, not simply a concept, in the Hospice community in England we believe we can develop exciting interdisciplinary relationships, health care worker-lay person realtionships, shared roles, and relationships across age lines. The latter is very important for the elderly persons who will be involved since they will be important receivers but also givers, a role they have too often been denied.

The base for developing such a sound community is the dedication to the values and goals of the program and to the tremendous need for support that the workers experience. We recognize that those who help the terminally ill, whether family, friend or worker expend tremendous energy which needs replenishment. Therefore the quality of the ongoing relations of one worker to another, especially in the openness and concern for one another, is essential to sustain the Hospice community. Dedication and need will not be restricted to the doctors, nurses, and other professionals, but will include the housekeepers, clerical workers, volunteers, day care center workers (for children of staff and patients), full and part-time staff. Groups will be established cutting across all the usual role boundaries so that questions of values and belief, concepts of life and death, issues of organizational and personal tension an be open shared matters of concern.

Such community development can only come from a program limited in size and purpose. The purpose has already been stressed. The program will provide for up to 100 Family-Patient outpatients and in inpatient facility of 50 beds. Our research indicates that this will be needed to serve a geographic area of approximately 500,000. It is also needed so that the staff is small enough to become a "family" and the facility a place with a homelike atmosphere.

Several issues of national significance will be discovered by research included in this process: (1) Concepts and programs to develop a sense of community and meaningful team work. (2) Discoveries of how to utilize less technically skilled persons in effective patient care thus providing manpower possibilities for persons now unemployed. (3) Collaboration between professionals and lay persons that identifies appropriate specialized functions but also responsibilities that can be shared rather than claimed by particular disciplines. (4) Effective ways of caring for a special population of the sick in coordination with existing facilities thus keeping cost at a minimal level.

*Focus on special medical problems and needs.*—The method of care given by Hospice will depend on the scientific management of symptoms. The patient's course will be determined by his or her life style. By relieving the physical, mental, spiritual, and/or social distress; by managing pain, nausea, anxiety, depression, fear of the unknown and their concern for their families, the Patients-Families will be helped to garner strength for living and for doing what is important to them as life comes to a close.

Physical pain will be used as one example of a special problem for the terminally ill. First, it is necessary to correct the assumption that unbearable physical pain is a factor in all terminal illness. It is not. However, it is present for many patients and severe intractable pain is present for 12 to 13% of these patients. It can be controlled as has been shown by Dr. Cicely Saunders, medical director of St. Christopher's Hospice, with whom we will continue to collaborate on research into this area. With the expertise of such persons as herself, and close collaboration between nurse, pharmacist, doctor(s), patient, family, and often psychiatrist, differential diagnosis can reveal whether the pain comes from muscle tension, nerve involvement, poor body posture, anxiety, pathologic invasion of sensitive body tissue, or inappropriate medication. Daily assessment of professionals at the patient's bedside can do much to find the appropriate medication blend and dosage to alleviate pain. Keeping close watch on the effect of drugs will control the titre level so that patients receive as much as they need to avoid the pain but not so much that they cannot be alert and available to do the visiting and/or work they have in mind.

The research in this field, and the demonstrations of treatment measures, hopefully will assist the terminally ill in many facilities. Currently in acute hospitals there is a great deal of suffering by the terminally ill because not enough attention has been paid to pain control as a primary treatment need. There is still too much fear of addiction when we really know too little about addiction, its physical and psychological factors, and when addiction is not a great problem for the terminally ill. Another attitude in acute hospitals is that when paid isn't a symptom of something that might be interesting and diagnostically important, then it soon becomes a nuisance. I have heard too many terminally ill patients in severe pain called "old crocks" when the physician has been too casual, even careless, to pay sufficient attention to preventing pain. I have also seen too many patients knocked out by medication when that too is an inappropriate way to prevent pain since it robs the patient of the little time available for concluding life.

Hospice physicians and nurses will be trained to provide appropriate care in this and other regards. They will make home visits, see family-patients in a medical-social clinic, and care for inpatients. Where there is a family physician they will work with him to support his ongoing relationship with the Family-Patient. But those receiving care in the Hospice program will not have to worry about who their doctor is or which specialist should be called for which symptom.

Space does not permit attention to the special spiritual, social, and psychological needs of the terminally ill patient. I simply refer to these areas as also involving pain and demanding special attention. The end of a lifetime is not always undesired, particularly among the elderly and others who have been chronically ill. But it is always a unique, once in a lifetime experience, and is seldom desired to be lived through alone whether the individual is regretful and afraid, or celebrating the fact that he will soon enter the mystery that faith has directed him to.

### SUMMARY

Terminal care has been too long ignored. The current health care delivery system does not provide adequate care to the terminally ill and too often provides inappropriate, damaging care to the Family-Patient. We know enough to begin demonstration models where we can serve, where we can learn by very valuable research projects, where we can be flexible and adapt our new discoveries, and where we can train professional health workers and lay people so that they can be more helpful to their patients and neighbors wherever they are. The interest, the pleas of community people and professionals are to begin these projects. Hospice is planning to do so and has received encouragement from individuals throughout the country and from overseas, including requests for job information and for volunteer positions before we have even reached that stage. But a project of such national importance should not be planned and implemented only by local community or national philanthropic support. It needs the encouragement of the federal government through financial support and technical aid with planning and development, capital funds, and operating costs.

In England I met and talked with patients whose physicians had predicted a life expectancy of five to six weeks. I was talking to these patients two years later. Their life included work, continuing to maintain the home, gardening, enjoying a holiday, a satisfying personal and social life. The Hospice caring for them had not treated their disease but it had loved and cared for them as important persons. We wonder and would like to find out through research whether good terminal care might not add to the longevity to life even more than the continuation of the treatment of disease sometimes does. But even if the length of life is not increased we can help the terminally ill to find importance in the last days and moments of their life. They may in fact help us to be more aware and appreciative of the present and look less to the past or the future for our satisfactions.

One of my dying friends in the Hospice in England said, "You know its good to be in this place where I belong. Where I felt welcomed. Where people care—even love me. A place where people have time to share with me. They're never too busy for a smile, a word, or to sit down and hold my hand, even cry with me. So you've come all the way from America to learn from us. Well go back and if you don't have places like this, start one for people like me." I heard her request on behalf of others, pray to God daily to help us to meet it, and share it now with you.

Senator **CHURCH**. On the first day of hearings we heard from Elisabeth Kubler-Ross. She referred to this hospice in England and then she made the comment that sort of thing couldn't happen in this country. You are trying to make it happen.

Reverend **DOBIHAL**. Yes. And we disagree on that. I think it can.

Senator **CHURCH**. Do you agree with our previous witness, Dr. Krant, that the modern theological student is looked upon by young doctors as a sort of third-rate psychiatrist? Is that in fact what theological schools are turning out these days, third-rate psychiatrists who speak the language of Freud and not the language of God.

Reverend **DOBIHAL**. I don't think so. They ought to be intelligent enough to know what the language of Freud is; they ought to be experts in knowing what the word of God is and being able to testify to that.

### DUAL DEGREES

I feel that the identity crisis that Dr. Krant labeled the theological students with is an identity crisis that practically all students that I know are in, even the medical students. In fact, I would say that medical students are a little behind the times if they do not recognize the crisis that they are in. Many of these students are coming in to talk with us in our department with many, many social and ethical concerns about medicine and its practice.

Some of them are coming in asking for dual degrees, in fact, in theology and medicine. Unfortunately the value system, the reward system of research and academic medicine, puts them into traps if they want to advance. The system doesn't allow many of them to advance in some of the areas that were the reasons they came to medical school to learn. Serving becomes very secondary to science.

That is a great dilemma for me. Now, I think that Dr. Krant is right when he says there is an anxiety among many clergy about going to the hospital. But you were very apt, Senator Church, when you said you feel that anxiety. Whenever you go into a closed system, and a system that is kept closed, naturally there is going to be an anxiety.

We take students, however. I direct the department for religious ministries at the Yale New Haven Hospital and we always have theological students with us. We are beginning to needle the system. We are beginning to speak what we feel in a secular institution is the kind of humane word that needs to be heard but what we, from a theological perspective, see is the word of love, of God.

We also have placed a chaplain in the medical school and that chaplain is beginning to teach medical students and others. We are teaching them in interdisciplinary groups because we don't want the physicians or the budding theologian or the nurses or the social workers any longer to maintain their own kind of tracts with the usual difficulty of communication, particularly around terminal care.

Senator CHURCH. That is a very interesting combination of disciplines: theology and medicine.

Reverend DOBIHAL. It gets us back historically to where it started.

Senator CHURCH. Yes; it does, I think. I have a friend who just came out of prison who is pursuing an even more interesting combination. He was pursuing theology to start with which got him into prison, and now he is taking up the study of law, I suppose to understand the discipline that put him there.

But in any case, these combinations do reflect, don't they, the dilemmas of our present society and the way that old specializations no longer seem adequate within their own limitations to meet the needs of people.

Reverend DOBIHAL. Yes. In fact, that to me is a very current theological statement, you see. Today we are not simply identifying God as being in the churches and synagogues. We are identifying that God is in the world and our ministry must be in the world, whether it is here in these halls or the halls of the hospital or the halls of justice. The word of God can be spoken there and can be heard there.

Senator CHURCH. Do you suppose if we ever came to feel that heaven is the world that the world would become more heavenly?

Reverend DOBIHAL. It is a good combination of both at the moment, isn't it? Heaven and hell is the world.

Senator CHURCH. Yes; but some question as to which is winning out.

Reverend DOBIHAL. Yes.

Senator CHURCH. We had one witness who liked the present system very much. Dr. Foye said on Monday that pain in most terminally ill patients is almost nonexistent. It is controllable and almost nonexistent and that the hospitals, as they are presently administered, deal with this problem most effectively, more effectively than any alternative method. But what is your feeling about that?

## CONTROLLING PAIN

Reverend DOBIHAL. I don't know Dr. Foye's hospital but this is not so in the hospital that I serve nor is it true in the hospitals that I have seen. It is true that many, many dying patients fear pain and the statistics in England at least showed that only 12 to 13 percent of these patients would probably experience what is called intractable pain. But that intractable pain could be controlled and the physicians there were able to say to the patients, "We will help you with this pain." I think that statement can be made but I haven't seen in this country enough examples of the use of pharmacological agents in the correct manner to control this pain.

It is what I meant by—for example, if we are ministering to a family in our hospital and someone is in pain and we say to the physicians, "This person is in pain. He needs more pain medication." It is not very helpful to come in the next day and find that the way that pain is being controlled is that the patient is knocked out completely. That is controlling pain but it is not allowing the patient to be awake and alert and interacting with his family.

Senator CHURCH. Have you set up this hospice at Yale?

Reverend DOBIHAL. Now, we are in the very preliminary stages.

Senator CHURCH. So there is no such institution at the present time anywhere in this country?

Reverend DOBIHAL. Not that we know of and we have had meetings with many, many people across the country. It would be unique and we consider it very important. It is true it would not be the kind of thing that could be duplicated everywhere.

It would have to be adapted and changed, but we consider it a very important demonstration model providing the kind of care for learning more and for training.

Senator CHURCH. It is a very difficult concept, as much as it would seem to be needed, it would be a very different concept, I should think, to convey to people because it is so easily mislabeled and would be so easily misconstrued.

You would start out calling it a hospice and it would soon be referred to by the manipulators of public opinion as a death house.

Reverend DOBIHAL. That is true. We need to be extremely careful about that. I was very, very concerned about that when I studied the one in England. My wife and I worked at the one in England for 7 months a year and a half ago and I had thought that everyone who came to the hospice knew that they were terminally ill. That was not true.

What they had discovered was—and I think it is very reasonable and you heard it here as these ladies talked—when folks have the need for a particular kind of care and support, it is important for somebody to say and be able to say honestly, that this is the kind of thing we do well and that is the way people were introduced to the hospice in England.

Senator CHURCH. Is there just one of these institutions in England?

Reverend DOBIHAL. Well, it is going so well now that its influence is being felt. Another that was earlier in it's existence is a part of the Roman Catholic tradition in both chronic diseases hospital and a terminal hospital. It is where Dr. Saunders first worked. They are adapting many of the things learned in the new hospice.

Senator CHURCH. But even in England it is just beginning.

Reverend DOBIHAL. Yes, a new one has opened now in Sheffield. One of our nurses who is working with us has just come back after working there this summer and she has exciting things to say about their adaptations of the original principle.

Yet, this concept is old in history, of course. In the 1500's there were hospices in France and Germany and in other places, but it is new in this scientific age.

Senator CHURCH. If you were to set up this hospice, do you think you might have liability problems under the laws of Connecticut, that State of general liberal enlightenment, to withhold certain supports even with the consent of the patient?

Do you run any risks under the present law?

Reverend DOBIHAL. We might. We have an attorney and several people who are working with the State group looking into those kinds of things. It is their feeling that we would not because it is their feeling that we would be very, very careful in working with other health facilities. The kind of person we would be receiving, other than say, if they would have a broken arm or something that would need acute treatment, would have had the kind of treatment for the disease that they need prior to being considered for admission to hospice.

We would be providing the kind of care for them to maintain them with that disease, not to further treat that disease. I think a lot of intervention that now goes on and on with people seems to be saying that we can still do something about the disease. I think that is a denial, sometimes an unconscious kind of denial, more often a conscious pretense.

Senator CHURCH. Well, I thank you for your testimony. The time has come to conclude these opening hearings on this subject. I want to insert two excellent Washington Star articles that were written by Betty James.[1] They are helpful for purposes of the record in a summation of the testimony we have heard.

I also think that the committee needs the benefit now of a written record. The record of these public hearings will be published and distributed. Hopefully that in itself will assist the educational process and members of the committee need to mull over what has been said.

We shall be in touch with national organizations and other experts in various disciplines for further guidance and we will consider on

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[1] See appendix C, pp. 145–148.

the basis of that whether we should proceed further into this very delicate and novel subject for a legislative committee, but I don't know how the Committee on Aging can ignore this very poignant matter of death with dignity considering how little of it occurs in this country under the present practices and attitudes and I can't help but feel that many elderly people must sense this and it must disturb them greatly.

Thank you for your testimony and with that we conclude these initial hearings.

(Whereupon, at 12:15 p.m., the hearing was adjourned, subject to call of the Chair.)

# APPENDIX A

## A LIVING WILL*

TO MY FAMILY, MY PHYSICIAN, MY CLERGYMAN, MY LAWYER—

If the time comes when I can no longer take part in decisions for my own future, let this statement stand as the testament of my wishes:

If there is no reasonable expectation of my recovery from physical or mental disability, I, ______________________________ request that I be allowed to die and not be kept alive by artificial means or heroic measures. Death is as much a reality as birth, growth, maturity and old age—it is the one certainty. I do not fear death as much as I fear the indignity of deterioration, dependence and hopeless pain. I ask that drugs be mercifully administered to me for terminal suffering even if they hasten the moment of death.

This request is made after careful consideration. Although this document is not legally binding, you who care for me will, I hope, feel morally bound to follow its mandate. I recognize that it places a heavy burden of responsibility upon you, and it is with the intention of sharing that responsibility and of mitigating any feelings of guilt that this statement is made.

Signed ______________________

Date ______________________________________________

Witnessed by:

______________________________________________

______________________________________________

______________________________________________

______________________________________________

*To secure extra copies for your own use and to give to friends, tear off and mail this portion to:*

EUTHANASIA EDUCATIONAL COUNCIL

250 West 57 St., New York 10019

Please send me ____ copies of A Living Will

Enclosed is my contribution of $__________ (tax deductible)

NAME ______________________________________________

ADDRESS ___________________________________________

______________________________________________

___________ zip

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*See pp. 103–107 for discussion.

# APPENDIX B

## WHAT DO YOU THINK ABOUT YOUR MEDICAL CARE*

[From Life magazine, Aug. 11, 1972]

(Life Reader Response)

In the April 7 issue LIFE published a story titled "More than Compassion" about a harassed but dedicated hospital nurse. We invited readers to fill out a questionnaire expressing their own opinions on the medical care they and their families receive. Forty-one thousand readers responded. Several hundred also wrote letters describing their personal experiences. Here are the results of this informal survey. Although the responses were well distributed among city dwellers, suburbanites, small-town and country people, the survey is by no means a scientifically calculated cross section of the nation. The readers who responded are generally well insured against medical costs and are well above average in education: 77% have attended college, 50% have college degrees (compared to 6% nationally). The responses indicate the sharp concern with which Americans view their medical care and—with some angry exceptions—a surprising degree of satisfaction with the treatment received.

"We were a young couple, new to a strange town, when my wife became ill," writes a LIFE reader in Wilmington, Del. "I located the only doctor in the area who had Wednesday office hours. He saw us early that evening, diagnosed the problem, called in a specialist and arranged to admit my wife to a hospital. At midnight the specialist, who we later learned was the best in the area, and the general practitioner, whom we had never met before, operated on my wife. Without the operation, she would not have lived until morning."

The young husband's letter reflects a sense of gratitude and trust that many people still have for doctors. One-third of the readers who answered LIFE's questionnaire say the medical treatment they received in the past year was "excellent." Another one-third call their care "good." Approximately the same percentages say their doctors appear to "care some" or "care a lot" for them personally as patients. Only one reader in 15 considers his medical care "poor," and just one in 20 thinks his doctor is "indifferent."

Naturally enough, it was mainly the dissatisfied who felt strongly enough to write letters describing their experiences. Some complained of callous, inaccurate treatment that ranged from paying $10 for a bloody nose that stopped bleeding before the doctor saw it to death in the emergency room while the patient waited in vain for medication. Many spoke of the difficulty of finding a doctor. "As newcomers we found it nearly impossible to find a doctor who would see our children," writes a mother in Bangor, Maine. A Pennsylvania man adds, "It's frightening. The good doctors in our area are refusing to take new patients and no new doctors are coming in." A frustrated reader in rural Nebraska says, "We have three doctors in our whole county. One is leaving, another is a heavy drinker and the third is just swamped with patients all the time."

Long waits in the doctor's office and short shrift when you finally see him also irritated the dissatisfied readers. "It's almost impossible to get one of them to look me in the eye, realize that I am a human being and spend even a few moments explaining my problems to me," says a Schriever, La. woman. A reader relates another familiar complaint: "When my mother was in the hospital my sister and I waited three days trying to see the doctor. Only when she went into a coma did he appear and talk to us. Yes, he billed us for visits every day."

The sin that the readers most often attributed to doctors is greed. "Pernicious money-grabbers," writes a Utah man. One woman tells of the family doctor of 20 years' standing who came to the house to certify the death of her mother. "The first thing he did was ask for his fee."

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*See p. 113 for discussion by Senator Church.

Most readers (58%) say their doctors won't come to the house at all. Only 23% say their doctors will regularly make house calls. The rest say he will come "sometimes." The responses vary little by the size of town the reader lives in. Evidently the country doctor of today is no more willing to make house calls than his city colleague. But apparently Americans are adjusting to the situation. Of the readers whose doctors will not make house calls, 40% said they didn't mind.

Some readers blame the inaccessibility of doctors and their high fees on what they consider a "controlled shortage" in the profession. A man in Williamsport, Mass., blames the medical schools: "Every year many bright, dedicated students are turned away because of racism, sexism, and the typical doctor's feeling that he should be one of a very select group, entitled to very high pay for his work." Another reader asks, "Why should girls be all but excluded from our medical colleges? Only 7% of our doctors are women, while in Europe 50% are women." Still others blame the American Medical Association for "perpetuating the exclusive position doctors have in this society by deliberately withholding funds for the construction of more medical schools."

(In response to this charge, the AMA states that for ten years it has supported every health manpower bill and has particularly supported programs designed to produce more family-practice physicians. According to the AMA, the number of medical schools has increased from 88 to 108 since 1965, with five more scheduled to open this fall. The number of new medical students—11,348 last year—is increasing each year, and since 1960 the number of doctors has increased more than twice as fast as the population as a whole. The percentage of incoming medical students who are women—11%—and minorities—10%—while still not impressive, are at record highs and rising.)

The importance, and the wide coverage, of health insurance was underlined by the readers. One-third of them report that their entire hospital bills were paid by insurance. Four out of five say at least 75% of their bills were covered. Those who lack insurance coverage appear to hold a more negative view of medical care as a whole. Of respondents who had to pay 50% or more of their bills themselves, half rated their medical treatment as fair to poor and say their doctors were indifferent or "just doing a job."

Overall, 17% of the readers had to borrow money to pay their hospital bills. Twice as many of those who had to pay more than one-half of their own bill had to borrow to do it. Whether presently insured or not, a majority of the readers said they favor a plan for national health insurance, paid for by payroll deductions and administered by the federal government. The questionnaire did not ask which of the several different plans currently under consideration they would prefer, and many readers said they wish they had been offered that choice. Their demand for *some* kind of national health program is tempered by a severe reluctance to have big government do it all. "Cases that require long-term hospitalization or nursing home care frequently bring financial disaster," writes a retired civil engineer in Seattle. "Many families, especially those with senior citizens, dread that more than anything else. But based on our experience with Medicare, it seems safe to predict that with government administration and full dependence on payroll deductions, we would end up with another mountainous financial burden and a molehill of benefits."

Several readers recommend the Kaiser plan as a national model. Essentially, Kaiser is a prepaid group-practice system in which patients visit salaried doctors at clinics and hospitals run by the plan. "It isn't poshy," writes a reader in El Cerrito, Calif. "They don't do unnecessary handholding, but the care is good, in many cases extraordinarily good, and a real effort is made to maintain a relationship with one doctor."

On the sensitive question of whether to tell a terminal patient that he or she is going to die, the survey reveals a major gap between what the readers want and what actually happens. Seventy percent of those who responded believed a dying patient should be told. But in more than half the families that have experienced terminal illness, the patient was not told.

"The medical profession has no right to withhold such information," argues a reader in Euclid, Ohio who is a registered nurse. "Anyone who has ever worked with a terminally ill patient is kidding himself if he thinks the patient isn't aware he is dying. Patients aren't told because the medical staff doesn't want to face up to it." A mother whose teen-age daughter died in surgery wrote: "If I were terminal, I would want to know. There are many things to get in order, people I would like to see for the last time, passages of books I would like to reread, and thoughts, dreams and ideas to be straightened out."

Sometimes thoughtlessness makes the question academic. We wanted to keep my mother's spirits up during the time she had left," writes a Seattle reader "But the nurses constantly made remarks in her presence, such as, 'Well all we can do now is to keep her comfortable until the end.' One day even her doctor said, within earshot, 'Worst case of brain malignancy I've ever seen.' There seemed no way we could spare her the almost hourly reminders that the end was near."

Almost unanimously, the readers endorse the right of a dying person to refuse further treatment. "To torture a terminal patient with tests, X rays, injections and various other treatments, when it is certain that they cannot help, should be forbidden by law," contends one angry reader. A Virginia woman whose own daughter died of cancer at age 4 expresses the common feeling best: "I hope if I get a terminal illness, my doctor will be the friend I have always thought him to be and will tell me. Then, God giving me the strength and the will to do so, I will ask that nothing more than pain-killers be used. I hope to go with the dignity befitting a human being."

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*Of the 41,000 readers who responded to* LIFE'*s survey:*

68% rate their medical treatment good to excellent;
70% say their doctor cares about them personally;
58% say their doctors will not make house calls;
55% of the families that have experienced a terminal illness say the patient was not told of his condition;
70% say the patient should be told;
91% believe a terminal patient should be permitted to refuse further treatment that will artificially prolong life;
81% had at least three-quarters of their hospital bills paid by insurance;
17% had to go into debt to pay the bill; and
55% would favor national health insurance paid for by payroll deduction and administered by the government.

# APPENDIX C

## ITEM 1. CLAIMING THE RIGHT TO DIE*

[From the Sunday Star and Daily News, Aug. 6, 1972]

(By Betty James)

When Brock Clark was a little girl her mother took her to visit her grandfather, who was on his death bed many weeks in a long-ago Michigan summer.

On those visits, her mother explained that the only thing they could do for her grandfather was to keep him comfortable.

He was suffering from dropsy and the doctor had told the family not to give him water.

But Mrs. Clark remembers her mother going to the well that was her grandfather's pride and bringing him a drink of water—"marvelous, cool, cold water."

It might make a few weeks' difference in how long her grandfather lived but it was the right thing to do, her mother said.

Mrs. Clark remembered her mother's "rational" approach to her grandfather's last days when her mother had a stroke from which she could not recover.

Although barely able to speak, she won from her daughter a promise not to make her do anything she didn't want to do, and then refused to eat. The doctor told Mrs. Clark the decision on whether her mother should be forced to eat was hers.

Think about it overnight, he said.

Mrs. Clark thought about it. Her decision was not to force her mother to eat.

"I have never regretted it," she said. Her mother died and was buried in Michigan with her ancestors.

Now age has come to Mrs. Clark, who is a widow.

The years have only strengthened her conviction that Thomas Jefferson should have included the right to die at the right time along with the more familiar rights to liberty and the pursuit of happiness in the Declaration of Independence.

So Mrs. Clark has signed what is called a living will. It says that if the time comes when she no longer can take part in decisions affecting her own future, and there is no reasonable expectation of recovery from physical or mental disability, she wants to be "allowed to die and not be kept alive by artificial means or heroic measures."

The testament declares, "I do not fear death as much as I fear the indignity of deterioration, dependence and hopeless pain. I ask that drugs be mercifully administered to me for terminal suffering even if they hasten the moment of death."

The living will concludes, "Although this document is not legally binding, you who care for me will, I hope, feel morally bound to follow its mandate. I recognize that it places a heavy burden of responsibility upon you, and it is with the intention of sharing that responsibility and of mitigating any feelings of guilt that this statement is made."

The number of Washington area residents who have signed a living will or a similar document is unknown, but support for the concept is growing. The elderly are not the only ones interested.

Younger persons who have seen their parents suffer or linger through last illnesses that modern technology ironically could prolong but couldn't cure are making out testaments that will spare them and their survivors similar anguish.

Mrs. Clark, who is retired from the Potomac School, where she taught ancient Greek civilization, has no children, who would certainly have been given a copy of the living will.

She has given copies to her doctor, her lawyer, the executor of her estate, her trust company and the management of Springvale Terrace, the apartment hotel for older persons in Silver Spring where she lives.

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*See p. 139 for discussion by Senator Church.

Her living will was witnessed by two people at Springvale Terrace. Other residents soon heard of the will and asked how they could obtain copies. Of 170 residents, Mrs. Clark estimates that 20 people already have talked to her about the living will, people of many religious persuasions.

"The interesting thing is that this is something that doesn't come as a new idea to them," she said.

Mrs. Clark "had a little bit of a hard time" with her doctor. He will only say that he knows what she thinks, but she feels her wishes are protected by having the living will in the hands of other people, too.

The medical profession probably is more receptive to the idea than laymen would assume.

Dr. Darrell Crain, president of the D.C. Medical Society, said the society has no position on the matter, but he gladly would include a living will in a patient's medical records. The medical profession doesn't feel obligated to keep someone technically alive indefinitely by artificial means, but the patient's family must be involved in the decision, he said.

A spokesman for the Washington Hospital Center said the issue of the living will has not arisen as a hospital issue, probably because it essentially is a message to the family physician.

Dr. Neville K. Connolly, an attending surgeon at the Hospital Center, said he would do what the patient requested and explain to the relatives what he was doing.

"I'm not prepared to execute someone and I want that made abundantly clear," Connolly said. 'But, if they are dying, I'm not going to keep them alive unnecessarily because technology could keep them alive. If the family didn't agree I would ask them to get another doctor.' It is against medical ethics to prolong suffering, he said. He hasn't had trouble with any family.

Should a malpractice suit occur later even though the family had agreed, which Connolly conceded is a "lurking fear in the back of my mind," as it would be in any doctor's mind, he would look to a good judge or jury for exoneration, he said..

Both doctors favor some form of legislation that would crystalize the doctor's position.

Bernard I. Nordlinger, president of the District Bar Association, said the bar has no position on the living will, but "as a person, of course, I would accept a letter of intention and point it out to the family and physician at the appropriate time." The decision is a medical not a legal one, he said.

Nordlinger said he knew something of the anguish in the situation because his mother's body functions were sustained for 30 days before she drew her last breath. "This is a terrible thing," he said.

Mrs. Clark regards the living will as an interim measure worth using but believes legislation—perhaps something as major as a constitutional amendment—should be enacted to protect a person's wishes.

The living will she signed was developed by the Euthanasia Educational Fund in New York City, which has distributed 90,000 copies, although society spokesmen are quick to point out that the living will is not a request for euthanasia which generally is regarded as an active mercy killing.

Mrs. Elizabeth T. Halsey, executive director of the Euthanasia Educational Fund said, "We're very much opposed to so-called mercy killing. We do say a patient should have enough drugs to make him comfortable even if it would shorten his life. What we're talking about is almost a civil right—do you have a right to die with dignity."

Dr. O. Ruth Russell of Washington, professor emeritus in psychology of Western Maryland College, who is writing a book on euthanasia, is unenthusiastic about the living will.

She believes it diverts attention from the basic issue, which she feels is the need to enact laws that would make euthanasia legally permissible in certain circumstances and in accordance with legal safeguards.

At the other end of the scale, it has been argued by at least one physician that a hopeless case isn't easily defined and the existence of a living will can tie a physician's hands when the heroic measures the will deplores might be effective.

The Senate Special Committee on Aging tomorrow opens three days of exploratory hearings on "Death with Dignity: An Inquiry into Related Public Issues." Mrs. Clark will take part in a panel of older citizens.

Sen. Frank Church, D-Idaho, chairman of the committee, said in announcing the hearings that their purpose is to determine whether federal policies and programs are contributing to problems that arise when elaborate efforts are made to preserve life even when it appears that the patient may be beyond help or even the desire for help.

Obviously, the committee does not endorse euthanasia or any means of reducing or eliminating treatment for any patient, no matter what his age, Church said in announcing the hearings. "But I personally am concerned with reports that costly and often impersonal maintenance of life takes place quite often in our institutions simply because clear-cut policies on such pratices do not exist, or are not widely understood or accepted."

In the House, Rep. Tim Lee Carter, R-Ky., one of four doctors there, has introduced a bill that would create a 12-member commission appointed by the President to study under what circumstances modern technology is being used to deny an individual the right to die with dignity and to what extent federal funds are contributing to this.

One objective of the commission would be to find a way to relieve a doctor of complete responsibility for the decision, on his patient, Carter said. Committees might be formed at a hospital or through a medical society whose members would make the decision jointly, he said.

Carter said the commission should consider the role that federally funded programs like medicare and medicaid play in making it possible to provide such efforts as tube feeding and x-ray therapy in cases where life is being maintained after life isn't worth living. The commission would not confine itself to the aged but would explore maintenance of life under hopeless circumstances in various age groups.

Carter, who has been in Congress eight years, had no experience with the living will where he was in active medical practice but would have included it in a patient's medical jacket, he said.

Living wills can take various forms. One version begins "this letter is not a request, it is an order." It instructs that no attempt should be made to prolong life by extraordinary measures if the person becomes old and ill and unable to make a rational decision. It also asks that if the person is stricken with an irreversible illness and is unable to speak for himself those to whom he has entrusted the will speak for him.

"I want no surgery, no cobalt, no blood transfusions and no intravenous feedings," the signed and witnessed letter asserts.

"Instead, please see to it that the physician gives me plenty of medication and sedatives. This letter of instruction will relieve you of the burden of making the decision. It is made. I have made it. My thanks and my love."

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## ITEM 2. DOCTOR TELLS SENATORS OF LETTING PATIENTS DIE*

[From the Evening Star and Daily News, Washington, D.C., Aug. 8, 1972]

(By Betty James, Star-News Staff Writer)

A Florida doctor has told a Senate panel that he and other physicians had let patients with incurable illnesses die and urged that a more merciful legal approach to the question of the hopelessly ill be developed.

Sen. Frank Church, D-Idaho, chairman of the Special Committee on Aging, heard conflicting advice on death with dignity as the committee opened three days of hearings on the subject yesterday.

Dr. Walter W. Sackett Jr., a physician who is a member of the Florida house of representatives, told the committee the right to die when a person is irreversibly ill should be legalized, and he is pressing a bill in the Florida legislature to bring this about.

Modern drugs and techniques can so perpetuate life that "if we can get you to the hospital alive, it's going to be a hard job to die." he said.

### 'A FORTHRIGHT MAN'

Sackett said he had let hundreds of patients die. If the patient is unable to speak for himself Sackett asks the family what they would want if they were the dying patient, to be kept alive or to be made comfortable, he said. They in-

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*See p. 139 for discussion by Senator Church.

variably answer that they would want to be made comfortable, he said. Sackett insisted there are incurable cases where damage is permanent, indicating that even should a cure for such disease be developed the ravages of its progress would be irreversible.

"You're a forthright man," Church declared. "You've said that in your practice you have let patients die. Do other doctors do the same?"

Sackett replied that 75 percent of the doctors he has known did.

Dr. Laurance V. Foye, Jr., who was associated with the National Cancer Institute for many years, taking the opposite view, said a doctor must fight to the end to keep his patient alive, that incurability must not be equated with hopelessness.

### JUDGED BY EXPERIENCE

Still another, Dr. Elisabeth Kubler-Ross, the country's best-known spokesman for understanding the needs of the dying through her book "On Death and Dying," didn't agree with Foye but also is opposed to legalizing the right to die because she believes such laws would contain loopholes that could lead to active euthanasia and mercy killings which she opposes.

A fourth witness, Dr. Arthur E. Morgan, 94, an educator who was the first chairman of the Tennessee Valley Authority and a former president of Antioch College, told of his distress at a nursing home's efforts to force-feed his late wife who had lost speech, hearing, and much capacity for motion.

The probabilities that a person can recover must be judged by experience, Morgan said. His wife, Lucy Griscom Morgan, had once written an article on the right to die called "On Drinking the Hemlock."

Church stressed at the outset that the committee has no preconceived ideas on the question under study which revolved around "the right to prolong life by extraordinary means when all hope for recovery—or in some cases, even for consciousness or lucidity—has vanished." He also stressed that this is not a hearing on euthanasia.

The differing opinions summed up "the sensitiveness and the importance" of the hearings, Church said.

The fundamental question is when is an illness truly so hopeless that no fight should be made against it, he said.

### 'LIVING WILL' OPPOSED

Church said he had reason to appreciate Foye's observation that it was hard to be certain about the imminence of death. He himself is one of those "legendary cases" who once was told he had six months to live and later was told the diagnosis of his illness was wrong, the senator said.

Yes, he asked, could it not be argued that it might be better to allow 100 people on the verge of death to choose death without treatment than to save one who might prove savable?

Foye opposed the "living will," a document which interest is growing. It is not legally binding, but asks that if a patient can no longer speak for himself and has no reasonable expectation of recovery from physical or mental disability he be allowed to die and not be kept alive by artificial means or heroic measures.

### 'PANDORA'S BOX'

The living will "really solves nothing but does create problems of its own," he said. It will merely convert a possibly fatal outcome into a certainly fatal one, he said. The physician's hands may be tied in just those cases where his skill and modern technology can make the greatest contribution to saving lives, he added.

Once the right to die concept becomes operative, whether the patient was going to die or not, stopping treatment ensures his death "and the physician's confidence in his ability to predict death is dangerously enhanced," he said.

Sen. Charles Percy, R.-Ill., asked Sackett whether his bill before the Florida legislature wouldn't open a Pandora's box, giving relatives the chance to get their hands on the money of the wealthy relative who couldn't protect himself. Sackett replied that relatives with "evil intent" will find some way to kill.

The law is going to have to face up to the question of the technical perpetuation of life by modern medical techniques, he said. Medicine ought to stop stressing prolongation of life and concentrate on its quality, he added.

# APPENDIX D

## STATEMENT BY SISTER VIRGINIA SCHWAGER, DIRECTOR, DIVISION OF HEALTH AFFAIRS, UNITED STATES CATHOLIC CONFERENCE, WASHINGTON, D.C.

We have a deep concern that so delicate and personal a matter as the right to life and the right to accept death with dignity could be the subject of legislative efforts to rid society of those who no longer benefit society. We note from your letter of August 2, 1972 that "the Committee does not endorse euthanasia or any means of reducing or eliminating treatment for any patient, no matter what his age." Governments of other countries have adopted such policies within our lifetimes. Just as we must view the dying with compassion and not fear to allow death to come when it is inevitable, we cannot countenance any means to take life directly under legal auspices. The prospect is grotesque.

His Eminence Terence Cardinal Cooke, Archbishop of New York, addressed the American Health Congress in Chicago on August 8, 1972.

The following is a quotation from his address:

"If there is to be a real quality to life, there first must be full recognition of the dignity inherent in every human life. Whatever might arise to modify or re-define values which are changeable, we must never lose sight of those values which are changeless. And paramount among these changeless values is the essential God-given dignity present in every human life at every stage and in every condition. Whatever winds of change may alter one philosophy or another, human life *is* an all important value as it comes from the Hands of God.

"Human life is a God-given gift. It is an innate right bestowed by the Creator. If there is to be any real *death* with dignity, every person's innate right to *life* must be respected. But in our technological society, there is a tendency to adopt a limited view of man, to see man only for what he does or produces and to overlook the source of man's dignity—the fact that he is made in the image of God and that, from the moment of conception to the moment of death, he is worthy of the full support of the human family of which he is a member.

"The American Declaration of Independence testifies to values that are changeless and it speaks of life as an inalienable right. Basically, the Declaration of Independence states that the human rights to life is beyond recall by anyone—individuals, physicians, or legal statutes.

"There are some who equate "death with dignity" with allowing a person to die comfortably when death is inevitable. But, there are others who mean by "death with dignity" the direct termination of a person's life.

"I believe that directly to take one's own life or to permit another person to do so is contrary to nature and against the law of God. I also believe that to deprive the deformed, the mentally ill and those who suffer from incurable disease, of their lives, as though these people and their lives are somehow inferior in value and in dignity, is a crime which offends all humanity."

Pope Pius XII took very special interest in the question of medical care of dying patients. We are guided by his wisdom: ". . . does one have the right, or is one even under the obligation, to use modern artificial-respiration equipment in all cases, even those which, in the doctor's judgment, are completely hopeless?" This is the way he put part of the question dealt with at your hearings, in 1957. Pope Pius answered his questions in terms of these basic principles:

"Natural reason and Christian morals say that man (and whoever is entrusted with the task of taking care of his fellowman) has the right and the duty in case of serious illness to take the necessary treatment for the preservation of life and health. This duty that one has toward himself, toward God, toward the human community, and in most cases toward certain determined persons, derives from well-ordered charity, from submission to the Creator, from social justice and even from strict justice, as well as from devotion toward one's family.

"But normally one is held to use only ordinary means—according to circumstances of persons, places, times and culture—that is to say, means that do not involve any grave burden for oneself or another. A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important good too difficult. Life, health, all temporal activities are in fact subordinated to spiritual ends. On the other hand, one is not forbidden to take more than the strictly necessary steps to preserve life and health, as long as he does not fail in some more serious duty."

Pope Pius also made it clear that the physician acts only with the permission of the patient, either express or implied, and cannot render care beyond that desired by the patient or his representative. In this connection, Pope Pius said that the family and physician were bound by the presumed will of a patient unable to speak for himself, and were usually bound only to the use of ordinary means of preserving life. He said:

"Consequently, if it appears that the attempt at resuscitation constitutes in reality such a burden for the family that one cannot in all conscience impose it upon them, they can lawfully insist that the doctor should discontinue these attempts, and the doctor can lawfully comply. There is not involved here a case of direct disposal of life of the patient, nor of euthanasia in any way: this would never be licit. Even when it causes the arrest of circulation, the interruption of attempts at resuscitation is never more than an indirect cause of the cessation of life . . ."

One learns from these few comments that the teaching of the Church has long recognized the following principles:

1. consent of the patient
2. implicitly, the right to be informed
3. the lack of necessity of employing extraordinary means to preserve life
4. consideration of what constitutes necessary efforts to preserve life in the context of the total condition of the patient and his circumstances

Cardinal Jean Villot, Vatican Secretary of State, put the basic principle in perspective in a letter to the International Federation of Catholic Medical Associations in 1970. He would base judgments in this area on the sanctity of life and the dignity of the human person and on the need of physicians to respect this dignity.

"We must also stress the fact that it is the sacred character of life that forbids the doctor to kill, and at the same time imposes upon him the duty to make use of all the resources of his profession to fight against death. But for all that, a medical man does not have to use all the techniques of survival offered him by a constantly creative science. In many cases would it not be useless torture to impose vegetative resuscitation in the final stages of an incurable sickness? The doctor's duty here is rather to ease the suffering instead of prolonging as long as possible, by any means whatsoever and in any condition whatsoever, a life no longer fully human and which is closing to its natural end: the sacred and inevitable moment when the soul meets its Creator, after a painful journey in which it participated in the passion of Christ. In this way, too, a doctor must respect life.

"Furthermore, what should we think of human experimentations in medicine? May the physician experiment on a man for the sake of scientific progress? Everyone certainly and rightly condemns as monstrous the criminal experimentations practiced on a large scale by totalitarian governments. But everyone also recognizes that we cannot condemn unconditionally every experimentation made on a man when it is respectful of man, and particularly in the case of new therapies. It is true that medicine has often progressed in the course of the centuries only by laborious and cautious procedures."

Cardinal Villot summed it up at the close of his letter this way: "In short, the medicine is at the service of man; man is not an instrument in the service of science."

A prominent theologian and professor, Father Kiernan Nolan, O.S.B., St. John's College, Minnesota, put it:

"The Christian concern must be to provide for human survival, and not mere biological preservation. One does not give much help to the living sick by threatening him as though he were about to die. Neither does one honestly provide the dying with the assistance he requires by treating him as though he were going to get well."

The topic "Death With Dignity" raises a number of issues related to the medical care of the dying. We have, in this statement, communicated guidance from Pope Pius XII, John Cardinal Villot, Terence Cardinal Cooke, and Father Kiernan Nolan.

These basic pronouncements are incorporated in the moral and ethical principles subscribed to by Catholic facilities across the nation. They are not new but have drawn increased attention in recent years among Catholic scholars, medical-moral writers, and many other theologians and scientists not of our faith.

The Church will continue to study, discuss, and explore this issue of death with dignity.

We stand ready to respond to any invitation you may make for assistance from us at future hearings or informal discussions.

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