

REMARKS OF SENATOR BOB DOLE
NATIONAL HOSPICE ASSOCIATION

WASHINGTON, D.C.

OCTOBER 5, 1978

I AM VERY PLEASED TO BE HERE WITH YOU TODAY FOR THE FIRST ANNUAL MEETING OF THE NATIONAL HOSPICE ASSOCIATION AND TO BE A PART OF A GROUP THAT HAS AS ITS GOAL PRESERVING THE QUALITY OF LIFE FOR PATIENTS WHO ARE TERMINALLY ILL.

THE TERM HOSPICE HAS COME TO MEAN PHYSICAL AND EMOTIONAL SUPPORT AND DIGNITY TO THOUSANDS UPON THOUSANDS OF INDIVIDUALS AROUND THE WORLD.

-2-

THE CONCEPT OF HOSPICE CARE CARRIES WITH IT THE THOUGHT OF LIVING, NOT OF DEATH AND DYING. THIS MODEL OF CARE AND TREATMENT IS LONG OVERDUE IN THE UNITED STATES.

QUALITY OF HEALTH CARE

THE QUALITY OF HEALTH CARE IN THE TWENTIETH CENTURY IS GOING TO BE JUDGED NOT ONLY BY OUR EFFORTS TOWARD PREVENTING ILLNESS BUT ALSO OUR EFFORTS TOWARD MAXIMIZING THE QUALITY OF LIFE FOR ALL, INCLUDING THE TERMINALLY ILL.

-3-

FOR MANY YEARS, THE THRUST OF HEALTH CARE IN THE UNITED STATES HAS BEEN TOWARDS THE GOAL OF EXTENDING LIFE. OUR EFFORTS IN THESE AREAS HAVE BEEN REWARDING. HOWEVER, WE HAVE LOST SIGHT OF A CONSIDERATION THAT IS CRITICAL--HOW TO CARE ADEQUATELY AND SENSITIVELY FOR THOSE IN OUR SOCIETY WHO ARE DYING. HEALTH PROFESSIONALS AND LAYMEN HAVE ASSUMED IN THE PAST THAT THE HOSPITAL IS THE MOST APPROPRIATE PLACE FOR TERMINAL CARE, AS WELL AS FOR DEATH ITSELF. WITHOUT QUESTION, THE AMERICAN TABOO AGAINST DEATH HAS BEEN SO INGRAINED THAT THE LIVING HAVE DIFFICULTY PERCEIVING THAT THE DYING ARE PEOPLE, TOO.

-4-

IT IS THROUGH THE EFFORTS OF INDIVIDUALS SUCH AS YOURSELVES THAT THE SUBJECT IS MOVING OUT OF THE SHADOW OF TABOO AND INTO THE LIGHT. WE ARE ALLOWING THE DYING TO BECOME TUTORS TO US ALL AND TO TURN THE MYSTERY OF DEATH INTO A SUBJECT WITH WHICH WE CAN DEAL.

NEEDS OF TERMINALLY ILL

WITHOUT QUESTION, WE MUST BEGIN TO EXAMINE HOW WE CARE FOR THE TERMINALLY ILL--WE MUST BEGIN TO FOCUS OUR ATTENTION TOWARD WHAT THEY NEED AND WANT.

WHILE DEATH LOOMS CLOSE AT HAND, WE CONSISTENTLY REMOVE THEIR ABILITY TO CONTROL THEIR OWN LIVES LONG BEFORE THEY ARE READY TO GIVE AWAY THIS RIGHT. MORE OFTEN THAN NOT, THEY ARE NOT GIVEN A CHOICE OF WHERE THEY WANT TO DIE, A CHOICE OF TREATMENT AND, IN MANY INSTANCES, THEY ARE NOT EVEN TOLD THE TRUTH ABOUT THEIR ILLNESS OR PROGNOSIS.

-5-

TRADITIONALLY, WE HAVE NOT SUPPORTED THE BASIC HUMAN RIGHTS OF THESE PATIENTS WHOSE NEEDS OBVIOUSLY RANGE FROM PHYSICAL TO EMOTIONAL. ALTERNATIVE FORM SO CARE WHICH CAN ADDRESS THESE PROBLEMS MUST BE FOUND.

THE U.S. HOSPICE MOVEMENT

THE SENSITIVE AND DEEPLY MOVING ARTICLE WRITTEN BY VICTOR AND ROSEMARY ZORZA ABOUT THE DEATH OF THEIR BELOVED DAUGHTER, JANE, MOVED MANY OF US FOR THE FIRST TIME TO TAKE A REAL INTEREST IN THE HOSPICE FORM OF CARE. MORE RECENTLY THE DEATH OF MY VERY GOOD FRIEND, SENATOR HUBERT HUMPHREY, AT HIS HOME IN MINNESOTA, BROUGHT HOPE TO MILLIONS WHO FEARED THE DEATHBED INDIGNITIES AND INCONSISTENCIES OF AGGRESSIVE TREATMENT THAT DYING PATIENTS OFTEN FACE.

-6-

CURRENT ACTIVITIES

THERE IS NO QUESTION IN MY MIND THAT WE SHOULD BEGIN DISCUSSIONS ON HOW THE FEDERAL GOVERNMENT CAN APPROPRIATELY HELP IN THE DEVELOPMENT OF PROGRAMS WHICH PROVIDE OPTIONS TO THE TERMINALLY ILL. HOWEVER, OUR EXPERIENCE HAS SHOWN US THAT THE OFTEN HEAVY-HANDED INVOLVEMENT OF THE FEDERAL GOVERNMENT STIFLES CREATIVE AND SENSITIVE EFFORTS THAT HAVE LED TO THE DEVELOPMENT OF MANY OF THE PROGRAMS THAT ALL OF YOU HERE TODAY REPRESENT. CERTAINLY, WE MUST MOVE FORWARD, BUT CAUTIOUSLY. INCREASING DEMONSTRATION PROJECTS, SIMILAR TO THOSE PRESENTLY FUNDED BY NCI, SHOULD BE ONE AVENUE TO CONSIDER. DEMONSTRATIONS FREQUENTLY SERVE TWO PURPOSES, IN THAT THEY GIVE DATA UPON WHICH TO BASE LONG-TERM SOLUTIONS AND AT THE SAME TIME, HELP TO FINANCE CARE.

-7-

BUT DEMONSTRATIONS ARE BY NO MEANS THE ONLY OPTION WE SHOULD CONSIDER. OTHER METHODS ARE ALSO AVAILABLE. PERHAPS AN ALLIANCE BETWEEN THE GOVERNMENT AND THE PRIVATE SECTOR, TO EXAMINE THESE PROGRAMS AND THE SURROUNDING ISSUES, SHOULD BE ENCOURAGED.

THERE WILL BE BUDGET CONSTRAINTS THAT WE MUST CONSIDER. HOWEVER, WITHIN THOSE LIMITS, WE MUST SET NEW PRIORITIES, WHICH PLACE AN EMPHASIS ON THE GROWTH OF THE HOSPICE MOVEMENT.

BIPARTISAN ISSUE

THE CARE OF THE TERMINALLY ILL MUST BE CONSIDERED TO BE A SERIOUS NATIONAL ISSUE, ONE THAT DESERVES CONGRESSIONAL BIPARTISAN SUPPORT. IT WAS IN THIS SPIRIT THAT THE SENATOR FROM KANSAS, THE DISTINGUISHED SENATOR FROM MASSACHUSETTS, MR. KENNEDY, AND MY DISTINGUISHED COLLEAGUE FROM CONNECTICUT, SENATOR RIBICOFF JOINED TOGETHER IN AN EFFORT TO BRING THIS MATTER TO THE ATTENTION OF THE CONGRESS.

-8-

IT IS MY HOPE THAT THROUGH OUR COMBINED EFFORTS, ALONG WITH THE FINDINGS OF THE TASK FORCE SET UP BY SECRETARY CALIFANO, AND OUR EXPERIENCES WITH SOME OF THE DEMONSTRATION PROJECTS, WE WILL OBTAIN ADEQUATE DATA UPON WHICH TO MAKE OUR DECISIONS. THE ANECDOTAL EXPERIENCES WHICH I HAVE HEARD ABOUT HOSPICES ARE HEARTENING AND IMPRESSIVE. YET I BELIEVE THAT A CHANGE IN OUR HEALTH CARE SYSTEM AS DRASTIC AS THIS MAY BE MUST BE BASED ON MORE THAN ANECDOTES. I DO, HOWEVER, HOPE THAT AS WE EXAMINE THE RESULTS OF THESE STUDIES WE WILL NOT FORGET THE PEOPLE BEHIND THE STUDIES. AND I HOPE THAT YOU, THE PEOPLE WHO WORK DIRECTLY WITH HOSPICES, WILL CONTINUE TO HELP US TO MAKE OUR DECISION.

-9-

CONCLUSION

WE MUST ALL WORK TOGETHER TO PROVIDE FOR THOSE IN OUR SOCIETY WHO ARE NEAR DEATH AN ENVIRONMENT THAT RECOGNIZES THEM AS INDIVIDUALS; INDIVIDUALS WITH DIGNITY, SEEKING ONLY TO SPEND THEIR LAST DAYS AND HOURS PEACEFULLY, IN A MANNER OF THEIR CHOOSING. SENATOR HUMPHREY SHOWED US THAT DEATH NEED NOT BE SOMETHING THAT IS INFLICTED UPON US, DONE TO US. DEATH IS NOT A UTOPIAN SITUATION, AND THERE IS NO ONE PERFECT WAY OF DYING. DEATH IS TRAUMATIC, NO MATTER HOW IT OCCURS OR WHERE IT TAKES PLACE. BUT, PERHAPS THE LAST AND MOST IMPORTANT GIFT THAT HUBERT HUMPHREY GAVE US WAS THE SENSE DEATH COULD BE GENTLE AND THAT THE DYING ARE PEOPLE WHOSE LIVES CAN BE MADE BETTER, IF ONLY FOR A SHORT TIME.

-10-

AS THE RANKING REPUBLICAN MEMBER OF THE FINANCE COMMITTEE,
I MAKE A PLEDGE TO YOU THAT I AM COMMITTED TO THE HOSPICE
MOVEMENT--TO DEATH WITH DIGNITY. I ASSURE YOU THAT THE
FINANCE COMMITTEE, WHICH HAS WITHIN ITS JURISDICTION THE
MEDICARE AND MEDICAID PROGRAMS, WILL STUDY AND CONSIDER
LEGISLATION NEXT YEAR IN THE 96TH CONGRESS THAT DEALS WITH
THE REIMBURSEMENT FOR HOSPICE SERVICES.

-11-

HOSPITALS AND NURSING HOMES CONSUME OVER 75% OF THE MEDICARE AND MEDICAID BUDGET. FOR TOO LONG, WE HAVE STRUCTURED OUR REIMBURSEMENT SYSTEM SO THAT PEOPLE DIE IN INSTITUTIONS WITH COLD, UGLY GREEN WALLS AND LITTLE COMFORT.

THIS MUST STOP. AND I HOPE YOU HERE TODAY WILL JOIN WITH ME IN WORKING TO FOSTER THE NECESSARY REFORMS SO THAT PATIENTS CAN DIE WITH DIGNITY. I PLEDGE TO YOU MY COMMITMENT. I ASK FOR YOURS.

FOR IMMEDIATE RELEASE
THURSDAY, OCTOBER 5, 1978

CONTACT: BILL KATS
202-224-8947

ISSUE OF CARE FOR THE TERMINALLY ILL ONE DESERVING CONGRESSIONAL SUPPORT, DOLE SAYS

WASHINGTON -- Sen. Bob Dole (R-Kan.) today called on Congress and the private sector to renew efforts to provide treatment for the terminally ill, placing an emphasis on the growth of the hospice movement as a positive solution to the problem.

Dole, speaking to the National Hospice Association, said, "The concept of hospice care carries with it the thought of living, not of death and dying. This model of care and treatment is long overdue in the United States.

"The quality of health care in the 20th century is going to be judged not only by our efforts toward preventing illness, but also our efforts toward maximizing the quality of life for all, including the terminally ill.

"There is no question in my mind that we should begin discussions on how the federal government can appropriately help in the development of programs that provide options to the terminally ill. Certainly, we must move forward, but cautiously. Increasing demonstration projects, similar to those presently funded by NCI, should be one avenue to consider."

Dole stated he was committed to the hospice concept -- that of death with dignity. As ranking Republican on the Senate Finance Committee, Dole said that that committee, which has within its jurisdiction the Medicare and Medicaid programs, will study and consider legislation next year that deals with the reimbursement of hospice services.

"Hospitals and nursing homes consume over 75 percent of the Medicare and Medicaid budget," he said. "For too long, we have structured our reimbursement system so that people die in institutions with cold, ugly green walls and little comfort. This must stop.

"We must all work together to provide for those in our society who are near death an environment that recognizes them as individuals; individuals with dignity, seeking only to spend their last days and hours peacefully, in a manner of their choosing."

Last May, Sen. Dole and Sens. Kennedy (D-Mass.) and Ribicoff (D-Conn.) gave a colloquy on the Senate floor, informing other senators of the hospice movement's potential for treatment of the terminally ill.

REMARKS OF SENATOR BOB DOLE
NATIONAL HOSPICE ASSOCIATION

WASHINGTON, D.C.

OCTOBER 5, 1978

I am very pleased to be here with you today for the first annual meeting of the National Hospice Association and to be a part of a group that has as its goal preserving the quality of life for patients who are terminally ill.

The term hospice has come to mean physical and emotional support and dignity to thousands upon thousands of individuals around the world.

The concept of hospice care carries with it the thought of living, not of death and dying. This model of care and treatment is long overdue in the United States.

QUALITY OF HEALTH CARE

The quality of health care in the twentieth century is going to be judged not only by our efforts toward preventing illness but also our efforts toward maximizing the quality of life for all, including the terminally ill.

For many years, the thrust of health care in the United States has been towards the goal of extending life. Our efforts in these areas have been rewarding. However, we have lost sight of a consideration that is critical--how to care adequately and sensitively for those in our society who are dying. Health professionals and laymen have assumed in the past that the hospital is the most appropriate place for terminal care, as well as for death itself. Without question, the American taboo against death has been so ingrained that the living have difficulty perceiving that the dying are people, too.

It is through the efforts of individuals such as yourselves that the subject is moving out of the shadow of taboo and into the light. We are allowing the dying to become tutors to us all and to turn the mystery of death into a subject with which we can deal.

NEEDS OF TERMINALLY ILL

Without question, we must begin to examine how we care for the terminally ill--we must begin to focus our attention toward what they need and want.

While death looms close at hand, we consistently remove their ability to control their own lives long before they are ready to give away this right. More often than not, they are not given a choice of where they want to die, a choice of treatment and, in many instances, they are not even told the truth about their illness or prognosis.

Traditionally, we have not supported the basic human rights of these patients whose needs obviously range from physical to emotional. Alternative forms of care which can address these problems must be found.

THE U.S. HOSPICE MOVEMENT

The sensitive and deeply moving article written by Victor Zorza about the death of their beloved daughter, Jane, moved many of us for the first time, to take a real interest in the hospice form of care. More recently the death of my very good friend, Senator Hubert Humphrey, at his home in Minnesota, brought hope to millions who feared the deathbed indignities and inconsistencies of aggressive treatment that dying patients often face.

CURRENT ACTIVITIES

There is no question in my mind that we should begin discussions on how the federal government can appropriately help in the development of programs which provide options to the terminally ill. However, our experience has shown us that the often heavy-handed involvement of the federal government stifles creative and sensitive efforts that have led to the development of many of the programs that all of you here today represent. Certainly, we must move forward, but cautiously. Increasing demonstration projects, similar to those presently funded by NCI, should be one avenue to consider. Demonstrations frequently serve two purposes, in that they give data upon which to base long-term solutions and at the same time, help to finance care.

But demonstrations are by no means the only option we should consider. Other methods are also available. Perhaps an alliance between the government and the private sector, to examine these programs and the surrounding issues, should be encouraged.

There will be budget constraints that we must consider. However, within those limits, we must set new priorities, which place an emphasis on the growth of the hospice movement.

BIPARTISAN ISSUE

The care of the terminally ill must be considered to be a serious national issue, one that deserves Congressional bipartisan support. It was in this spirit that the Senator from Kansas, the distinguished Senator from Massachusetts, Mr. Kennedy, and my distinguished colleague from Connecticut, Senator Ribicoff joined together in an effort to bring this matter to the attention of the Congress.

It is my hope that through our combined efforts, along with the findings of the Task Force set up by Secretary Califano, and our experiences with some of the demonstration projects, we will obtain adequate data upon which to make our decisions. The anecdotal experiences which I have heard about hospices are heartening and impressive. Yet I believe that a change in our health care system as drastic as this may be, must be based on more than anecdotes. I do, however, hope that as we examine the results of these studies we will not forget the people behind the studies. And I hope that you, the people who work directly with hospices, will continue to help us to make our decision.

CONCLUSION

We must all work together to provide for those in our society who are near death, an environment that recognizes them as individuals; individuals with dignity, seeking only to spend their last days and hours peacefully, in a manner of their choosing. Senator Humphrey showed us that death need not be something that is inflicted upon us, done to us. Death is not a utopian situation, and there is no one perfect way of dying. Death is traumatic, no matter how it occurs or where it takes place. But, perhaps the last and most important gift that Hubert Humphrey gave us was the sense death could be gentle and that the dying are people whose lives can be made better, if only for a short time.

As the ranking Republican member of the Finance Committee, I make a pledge to you that I am committed to the hospice movement--to death with dignity. I assure you that the Finance Committee, which has within its jurisdiction the Medicare and Medicaid programs, will study and consider legislation next year in the 96th Congress that deals with the reimbursement of hospice services.

Hospitals and nursing homes consume over 75% of the Medicare and Medicaid budget. For too long, we have structured our reimbursement system so that people die in institutions with cold, ugly green walls and little comfort.

This must stop. And I hope you here today will join with me in working to foster the necessary reforms so that patients can die with dignity. I pledge to you my commitment. I ask for yours.