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Hospice Address

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Hospice Address  
For Dr. Lowell E. Davis  
*delivered*: 03/25/87  
at National Conference

It is a pleasure to speak to a group of professionals who are at the leading edge of a relatively new revolution in America's concept of health care.

I view those of you in the Hospice movement as pioneers who are pointing the way to a new philosophy in health care delivery, and guiding our nation to look beyond its trouble-plagued traditional medical systems and consider alternative methods of attending the critically ill that are ultimately more compassionate and humane.

Our host for this conference, Hospice Care of Pinellas County, had a dream some ten years ago. The dream was shared by a small group of people who saw, in 1977, a need for a special type of care for terminally ill patients. These people realized the extreme stresses that are faced by people who were dying and their families, and set about making their ideas transform into reality. They formed an organization that provides a comprehensive range of medical and counseling services for those individuals with terminal diagnoses and their loved ones. Once their organization was officially initiated as one of the first Hospices in this country, these Pinellas founders received widespread acceptance and gratitude for their concept of treating and training their patients' families as a unit, and encouraging, as much as possible, primary care in the patients' own homes. Today, Hospice Care has more than 70 paid staff and 400 volunteers who care for more than 140 dying patients and their families, on a daily basis. In addition, the Hospice's bereavement program is providing regular support and counseling to at least 700 family members who have experienced the loss of their loved ones.

The rapid growth of this Hospice is not surprising, for it is a sterling testament to the feeling of many Americans that our traditional health care systems are failing us in several crucial ways. In large facilities like many of our hospitals, economic and
efficiency considerations often overshadow the encouragement of individual, personalized care. The concept of integrating the patients' families into the treatment remains quite foreign to the procedures of many institutions. And as our government continues to make severe cutbacks in allocations for health care, the needs of the elderly, the poor and even middle-income Americans are going unmet in increasing numbers. To some people it is not the time or the climate to look for progressive changes within these financially-strapped institutions, and many Americans are being forced to seek out more reasonable alternatives.

Trends throughout our nation reflect the same widespread acceptance of the Hospice care concept, as we have seen evidenced in Pinellas County. While only 50 Hospices were operational in the U.S. in 1978, today there are nearly 2000. In 1983, Congress elected to make Hospice care eligible for Medicare reimbursement, and businesses are also beginning to adopt Hospice coverage as a part of employee benefit packages. Indeed, America is welcoming and embracing the Hospice ideal of a more humanistic approach to the family as a unit. To quote from a Hospice Care brochure, "Hospices are developing at an unprecedented rate because they meet the needs of the dying and their families. Hospices are no longer a nice addition to the field of health care; they are a necessity for freedom of choice."

Although I do not share your expertise in health care, as an educator, I, too, have a vision that our two disciplines can work together and succeed as a team in expanding the Hospice concept of understanding and attending the physical, emotional, social and spiritual needs of the dying and their families.

I see a dire need for our schools to begin offering guidance and training on death and dying to the youth of America through school health curriculums. I can think of no more humane service we can provide to our youth than pre-death counseling that will prepare them to accept death as one of life's inevitabilities and teach them coping methods in advance of their being faced with such personal tragedy.
For indeed, all of us experience the deep pain of loss at some point in our lives. And even those among us who are trained in the mental health professions may find themselves lacking in coping strategies when personal tragedy strikes. We know that unresolved pain keeps us from being complete, content people, but unfortunately, few of us know what to do to help ourselves through these times of personal upheaval.

A very poignant account of a young mother's reaction to the drowning death of her two sons was authored by Ruth Lloyd in a recent issue of Thanatos. Since Mrs. Lloyd's experiences draw a very clear picture of the anger and confusion that can afflict grieving persons of all age levels, I would like to share some of the statements in her article with you.

"The empty, lonely, lost feeling, together with an overwhelming sense of being completely isolated in a world where pain is the only emotion you are capable of having, is difficult to convey. Many times I felt like a child on a cold, dark night, searching for relief from this pain that eats away at me. To bear my sons was painful, but the pain of losing them is unbearable.

"Grief...such a little word, but what an impact it has on one's emotions. It will make you cry, it will keep you awake night after night, it can make you think you are going crazy, it can make you lose weight, and it will make you a physical wreck. When grief takes hold of you, it will run the gamut of human emotions.

"I never felt such excruciating pain. My heart felt like it was being torn apart and ached all the time. I ached to the very depths of my soul. I felt as though I had been kicked in the stomach and I had a lost, lonely feeling and look about me. I was so tired all the time...tired of the hurt, tired of the pain, tired of the crying, and tired of the lonely feeling, knowing a big part of me was taken away.

"My mind and whole being went into shock, a shock so deep that nothing seemed real or penetrated for at least two years. I could not remember anything from one day
to the next and often would repeat the same thing over and over to the same person. The simplest decision was so hard to make and seemed so complicated.

"My physical appearance deteriorated rapidly. I'd lost 36 pounds within one month, my skin had a grayish tint to it and dark circles were constantly under my eyes. My nerves were so bad that I could not sit still for more than 10 minutes, and my mind could not retain three-fourths of what was happening around me. My hair began to fall out, I would go for days without having a bowel movement, and had a steady pain in my back and chest. To have hives appear all over my body became almost normal the first two years, and this still occurs."

While reading Mrs. Lloyd's article in conjunction with a number of scholarly papers on the topic of grief, I was struck by the commonality of mental, physical and emotional turmoils that affect all grieving persons to some degree. Although the duration of mourning and symptomatic effects vary from individual to individual, each of us has or will experience the tremendous pain of loss at some time, in some way.

The recurring theme of loneliness among the bereaved is one of the aspects of grief that I find most sad and disturbing. If the experience of loss is common to all human beings, why must we feel so alone in our suffering? From our perspectives as Americans, cultural and societal pressures may well be at the root of this problem.

For the most part, we live in a death-denying society. We use euphemisms such as "passed away" or "gone on" in place of realistic descriptions of death. The value we give to health, youth and fitness serves to prevent comfortable, open discussions of death and dying. And today's pop culture emphasis on achieving our "personal best"--never letting our weaknesses show along with our strengths--forces us to withhold and internalize those emotions that may make us appear to differ from society's ideal.

Yet silence only deprives us of the opportunity to share and learn from our grief. In contrast, when a well-educated, talented writer like Mrs. Lloyd describes her pain in the pages of a magazine, thousands of readers like her—hardworking, professional
people who fear that their associates will brand them as "maladjusted" if they allow their symptoms of grief to show through—can be helped by the awareness that their feelings are neither extreme nor unique, and that what they may be perceiving as signs of mental illness are simply emotional reactions common to all human beings.

The most effective strategy for aiding the grieving, of course, is through the personal sharing of feelings and fears. Hospice leaders have proven to be visionaries in this area as well, as they were among the first health professionals to recognize the value that one-on-one and group sharing has in promoting the healing process among the bereaved, and they took the lead in designing counseling programs to meet the needs of those who are left feeling alone and forgotten in the aftermath of a loved one's death.

In recent years, since the advent of Hospices, more research and literature has been devoted to the study and development of counseling programs for the bereaved. Hospice Care's fine bereavement counseling programs, which are tailored to reach all family members from children through adults, are excellent models of treatment for those who are suffering in the aftermath of death. Programs patterned after these Hospice models are currently being adopted by increasing numbers of community mental health agencies throughout the country. The numbers of self-help books and articles devoted to this topic are increasing as well. A notable example is Living Through Personal Crisis by Ann Kaiser Stearns, a layman's guide to recovery from loss which was published in 1984 and promoted nationally through the Ann Landers column. Counseling programs and self-help publications such as these are indeed critical to guiding the bereaved back to a feeling of normalcy and well-being.

But I reiterate, that a good deal of the suffering experienced by the grieving, could be prevented by educational programs geared toward teaching children to accept the facts of death as part of life, beginning at the kindergarten or first grade level. As it stands, the topic of death has been somewhat of an "educational taboo," a subject
left out of our health curriculums and relegated to our churches for teaching and discussion. Perhaps it is a fear of the ethical and religious implications that may arise that has led to this omission from our list of "accepted" school topics. This stance has some validity, when taken into account the furor that integration of sex education into school curriculums has led to in some communities. But the type of school programs I refer to here would incorporate instruction in the different religious perspectives on death and dying, and the range of associated societal values. These programs would concentrate on disseminating factual information about terminal illness and death, and teaching effective strategies for anticipating and coping psychologically with life's inevitable tragedies.

As with any area of mental health, it is obvious that teaching people strategies for coping with problems in advance of their need is a more positive and productive approach than treating after-the-fact effects. Many school counselors of my acquaintance have been involved with helping distressed children after a death has occurred, but most see precrisis educational efforts directed at aiding children in a better understanding and assimilation of the inevitability of death as a highly preferable situation. They see as an ideal situation, one where death education for very young children would be initiated by the parents, but feel that the schools should share this educational responsibility in a carefully structured program throughout the years of formal education.

For as Rabbi Earl Grollman once noted in an address to the American School Health Association, "Children growing up today are all too aware of the reality of death, perhaps more than we realize. Even at a very young age, our children are confronted with that process when life no longer exists.

"A pet is killed. A funeral procession passes by. A grandfather dies. A leader is assassinated. And, of course, there is television with the picture of death in living color.
"Adults do not understand the complete meaning of death. Professionals continue to wrestle with this thorny question. No mortal has ever pierced the veil of its great mystery. Yet, we have the inescapable responsibility to share with our children the fragments of our experience and knowledge."

Through research and observation, counselors have found that children should be allowed to ventilate fear and apprehension about death, and be dissuaded from common misconceptions such as death always resulting from a lingering illness. Other important factors in pre-death training for the very young are encouraging an open atmosphere for discussion of concerns and preparing children to accept the conflicting feelings implicit in mourning.

As children advance in age, they should be provided with general information, including experiences designed for exploring values that are germane to acceptance and understanding, and promoting a respect for the aged and their contributions to society. Again, as I mentioned earlier, these children should be exposed to and encouraged to discuss the various religious perspectives on death and dying as well.

I suppose, from a religious point of view, the veil of death, and especially what lies beyond death — if anything — will always be a source of wonderment to some and a mystery to everyone. But we must talk about these things openly and deal with death's finality. The uncertainty of anything and everything beyond death, the grief of loss, and words such as eternity, forever, everlasting, immortality, spirit, eternal, and others restricted to certain religious groups, all conjure in some people's minds a bewildering sense of doubt, fear, guilt, anxiety, and a depression beyond belief. I believe this is the heart of the problem.

A group of Florida school counselors who conducted a preliminary study on death education curriculum researched several techniques for use in instructing older children. Their findings pointed out that fantasizing experiences—such as having the students pretend they were dying and writing a last letter to someone significant, or imagining...
the experience of going home from school and finding that a family member has died—led to very effective and supportive group discussions. They noted that sensitivity and compassion on the part of the group leader is essential, since students must feel free to cry or express other emotions that may be evoked from these discussions and exercises.

As those of us in the academic realm continually awaken to the fact that pre-grief training is as important to our youth's development as preventative counseling relating to drug use, sexual behavior, self-esteem and other mental health matters, we are most fortunate to have the resources of the Hospices in our communities to which to turn. For while our interest in providing this information to our children is sincere, our resulting scholarly research and experimental programs have been somewhat limited and geographically isolated. The combined efforts of Hospices' nationwide network of health professionals, however, have yielded a wealth of information, expertise and program models that educators throughout the country may access immediately.

In Pinellas County, for instance, Hospice Care offers the services of a team of experts who share their knowledge about dying, death, and the grieving process with groups of teachers and/or students in both private and public schools. Their discussion groups and presentations draw rave reviews from school personnel, and the materials they have to offer are invaluable tools.

For example, these counselors help teachers identify those students who are suffering silently in their grief. They tell us that the indicators to watch for in young children include nervousness, uncontrollable rages, frequent sickness, accident proneness, depression and compulsive behavior. Those of us working with older children are taught to watch for additional symptoms such as poor schoolwork, reclusiveness or social withdrawal, overeating or undereating, experimenting with drugs or alcohol, sexual promiscuity and talk of suicide. By being more cognizant of these behavioral deviations
as they arise, our teachers can be prepared to intervene before the affected children encounter more serious problems that could lead to tragedy.

The teacher training component of this Hospice Care service provides information on all aspects involved in guiding youth to understand and cope with the effects of death and dying. A fact sheet entitled "Telling Children About Death" details straightforward methods for explaining the death of a loved one to younger children through the use of honest explanations, encouraging participation in and discussion about the rituals of mourning, and reinforcing the idea of the continuity of life after loss. Other reference publications made available through this program include articles detailing children's capacity to understand death and dying at various age levels, guides to the clinical symptoms of the various stages of grief, and tips for helping students of varying ages work through their grief and bereavement. In addition, Hospice Care offers thorough bibliographies of books on death and dying, instructional materials to help teachers and counselors become better listeners, and specific information for sharing with parents on topics such as preparing a child for a last visit to a dying loved one.

To my knowledge there are, regretfully, no schools of education today which incorporate instruction for teachers on death and dying into their academic curriculums, even though an abundance of resources for courses and counseling program models are available to us through the Hospice movement. But what better place can there be to break this cycle of ignorance that ultimately harms each member of our society than to prepare our future educators to train our children to face and cope with life's ultimate inevitability?

To integrate this type of training into our school systems, we educators must follow the lead of Hospice founders and strive to be pioneers who can break new ground. We must take a closer look at the various methods we can use to help prepare our youth to face death and work as a unit to convince school administrators of the
vital contribution that such programs can make to our students' overall mental health. For as author/counselor Charlotte P. Ross quite aptly states, "The facts of death are as essential to the education of the young--and as intensely sought--as the facts of life."

Two years ago, February 14, 1985, a very close friend and a person whom my wife had known since childhood, met with an untimely death. All of us grieved; the unexpected death was shocking! It is what happens to the family which is still cloaked in grief that is of on-going tragedy. The daughter in the family was unable to cope with college upon her return, unable to cope with being away from home, unable to cope with the loss of her father, and sought comfort and refuge in the affection of a male companion whom she hardly knew. She apparently planned and became pregnant, in an attempt as we later understood, to try to replace the love she had lost. Today her problems are compounded. She has no training for a job; she has no preparation and ability to survive; she has no mature experience to be a mother. The son in the family, 17 years old, experienced the loss of will-power, motivation, and self-esteem. The mother, a teacher for the handicapped, has a life that has unravelled. She has long bouts of depression; she does not function well in her job; has a shrine in her living room; and grieves continuously. The family was and is under a siege of grief.

As I noted earlier, because our society has not yet embraced pre-death counseling in the schools, many adults continue to find themselves bewildered and depressed following a loved one's death because they have not had the benefit of learning coping strategies. This, too, is a problem that I feel should be addressed by our upper-level educational institutions. I see a need for our colleges and universities to begin offering continuing education courses, seminars, or discussion groups geared toward the same purpose of teaching healthy methods of dealing with loss.

As you are well aware, the writings of Dr. Elizabeth Kubler-Ross have already done a great deal to alleviate some of the concerns of adults who are facing death. But there is a pressing need to expand our knowledge of what comprises the core of
death anxiety and to support people of all ages in understanding it, coping with it, and possibly changing it before their own death, or that of someone they dearly love, is imminent.

In recent weeks the media have been alive with teenage suicide. As usual, we are reactive rather than proactive. It was after the death of the young people that we began to see the need to counsel students about death and dying. Sometimes, regretfully, it takes a tragedy or a series of tragedies to open our eyes to even elementary realities. We must begin to take a proactive stand -- the study of death and dying must be a part of the education of students because they are an inevitable part of our humanity.

It is my firm belief that educators must follow the lead of Hospice founders and work toward pioneering new programs to help people prepare for and cope with the effects of death. In fact, it is my fervent hope that the very near future will find members of your profession and mine working as a team to integrate such programs into our schools and offer this unique mental health service to the widest possible segment of our society. My admiration for the goals and programs of Hospice is deep-seated, and I hope to experience the satisfaction of knowing someday that our educational system is helping to spread and strengthen the noble, humane objectives of your organization throughout the United States and, therefore, positively contributing to improving the overall mental state of our citizenry.

Let me leave you with three thoughts:

1. We must learn to accept Jonathan Swift's motto:
   "It is impossible that anything so natural, so necessary, and so universal as death, should ever have been designed by Providence as an evil to mankind."

2. We must realize that as _____________ Colton experienced:
"Death is the liberator of him whom freedom cannot release; the physician of him whom medicine cannot cure; the comforter of him whom time cannot console..." and the final episode of human life.

3. And finally, we must remember The Old Testament - Ecclesiastes 3:1-2:

"To everything there is a season and a time to every purpose under the heaven; A time to be born and a time to die...."