

Approved: March 28, 2000
Date

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES.

The meeting was called to order by Chairperson Garry Boston at 1:30 p.m. on March 16, 2000 in Room 423-S of the Capitol.

All members were present except: Representative Peggy Long, Excused
Representative Dale Swenson, Excused

Committee staff present: Emalene Correll, Kansas Legislative Research Department
Norman Furse, Revisor of Statute's Office
June Evans, Secretary

Conferees appearing before the committee: Pam Scott, Kansas Funeral Directors Association
Dr. Charles DeCarli, Director, University of Kansas,
Alzheimer's Disease Center
Cynthia Teel, PhD, RN, University of Kansas, Alzheimer's
Disease Center

Others attending: See Attached Sheet

The Chairperson opened the meeting and stated there were two extra days to work bills i.e., Monday and Tuesday of next week and asked what bills the committee wished to work. The Chairperson asked if the following bills had interest of the Committee: **SB397**, yes; **Sub SB554**, no; **SB555**, no; **SB598**, no; **SubSB599**, yes; **HB2728**, no; **HB2924**, no.

The Chairperson opened the hearing on **SB 556 - Who has right to control disposition of a decedent's remains.**

Staff gave a briefing stating the bill was requested by the Kansas Funeral Directors Association whose representative testified as to the problems that can arise when there is no one person designated to authorize the disposition, to represent the decedent's wishes, or if the decedent has not given directions for disposition. The bill would create a new law that would set out by statute the order of priority of persons who may order the burial, cremation, entombment, or anatomical donation of the remains of the decedent. The funeral director, funeral establishment, or crematory is not to be subject to criminal prosecution or civil liability for carrying out the otherwise lawful instructions of the person or persons authorized by the new statute to give such instruction if the funeral director reasonably believes such person was entitled to control the final disposition of the remains of the decedent.

Pam Scott, Executive Director, Kansas Funeral Directors and Embalmers Association, Inc. testified as a proponent to **SB556** stating the issue of final disposition of the deceased's remains has become very prevalent today. It becomes a divisive issue in situations where family members can not agree over the manner or location of final disposition. Confrontations are more common today than in the past because of an increase in divorce, remarriage and situations where there is no spouse but a "significant other" of the opposite or same sex.

An amendment on page 1, lines 20 and 21 is requested striking "The individual who, at the time of death of the decedent acted as attorney in fact" and replaced with "agent" was requested (See Attachment #1).

Mack Smith, Executive Secretary, Kansas State Board of Mortuary Arts, provided written testimony supporting **SB556** and the amendment requested by the Kansas Funeral Directors and Embalmers Association, Inc. (See Attachment #2).

Representative Bethell moved and Representative Storm seconded to strike language put in by the senate and reinstate "The agent" on page 1, lines 20 and 21. The motion carried.

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES, Room 423-S of the Capitol at 1:30 p.m. on March 16,2000.

Representative Bethell moved and Representative Haley seconded to pass SB556 out favorably as amended. The motion carried.

The Chairperson opened the hearing on **SCR 1636 - Support of Alzheimer's disease pilot program.**

Staff gave a briefing stating the University of Kansas Alzheimer's Disease Center has had some pilot studies going around the state and have looked at the rural areas of the state not diagnosed at an early stage. Sometimes physicians are unaware when it is possible to diagnose alzheimer's at a fairly early stage of the disease because that ability is relatively new and sometimes physicians are reluctant to make that diagnosis or at least put it into words for reasons of affect on the family. People are often admitted to nursing homes before they would have had to be simply because there were not facilities available in the community to assist them and the families to keep them in the home. With early diagnosis there are some drugs that can be used that delay the onset of the most pervasive manifestations of alzheimer's and through medications and treatment they can be self-sustaining and self-functioning for at least a year and perhaps longer. There is also some evidence that is not totally agreed to that the earlier that treatment is begun manifestations may be delayed for a period of time. The Center has proposed a pilot project for which they are requesting funding. The pilot project "Kansas Memory Assessment Program" would actually support a pilot that would be geared toward providing access to dementia diagnosis in specific piloted areas and the access to early treatment for alzheimers. This is to have a two prong approach. One part is to educate physicians in that area of the state and the other is to start treatment. This pilot project is patterned by a project in the state of Maine. It has been so successful it has now been extended statewide in Maine. This would be cost savings for the state and the quality of life for the individual and family. The amount of funding being requested is \$21,035 and this would be for 10 people in the Hays area.

Dr. Charles DeCarli, Director, University of Kansas, Alzheimer's Disease Center, stated a pilot project of the Kansas memory Assessment Program (MAP) is proposed herein. Project staff at the University of Kansas Alzheimer's Disease Center, in collaboration with colleagues in northwest Kansas, would participate in pilot testing, MAP. The purpose of the MAP is to support the diagnosis and treatment of persons with dementia and their families who live in rural areas of Kansas. Overall, the MAP is designed improve access to dementia services and to enhance the expertise of local health care providers in the management of persons with dementia. It was found that the people most vulnerable to alzheimer's is in the midwest with the exception of 2 small East coast states. Kansas is in the middle of the aging belt, but also has its own particular issues and has to do with the combination of demographics and the rural location. There are 41,832 people in Kansas who are 85 years of age and older. That is expected to double in the next 10 years. The majority of these people live in rural areas, 3/4 of them are women and most of them live alone and most of them live in poverty as defined by their income levels; however, some of them have resources. Why is this important? The people that are 85 years or older; 1/2 of them are at high risk for alzheimer's if they don't have alzheimer's disease and this translates into about 20,000 people who are either at the very early stage of alzheimer's, may have alzheimer's are currently living in these rural areas. That is not the only problem in Kansas. Currently there are 64,000 affected by alzheimer's disease and this is again predicted to double in the next two decades. It is important to know this is a terminal illness that lasts about 7 years but assistance is usually required about 1/2 of the time. This has direct impact on some of our current support services. For example, at the present time about 30,000 nursing beds are available with about an 87% occupancy rate. On a per capita basis, in Kansas, the number of people that have been admitted to nursing facilities has doubled than the national average. 92% of these residents are 65 years of age or older and about 80% have dementia. Of those who have dementia, alzheimer's is currently the most common dementia. Estimates based on these statistics for the state of Kansas estimate that the cost for taking care of these individuals is about \$200M in 1998 and \$80M comes from the state general fund and the remainder comes from the Medicaid Titlement IXX. The diagnosis of alzheimer's can be made early and have treatment. Implementation of treatment are known to be cost effective because they keep the person independent and allow the person to stay at home, can use less resources, and improves the quality of life for both the patient and the caregiver.

Project goals will be accomplished through partnerships with the Northwest Area Agency on Aging and the Northwest Area Health Education Center, both located in Hays, Kansas. The executive directors of

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES, Room 423-S of the Capitol at 1:30 p.m. on March 16,2000.

both agencies have offered enthusiastic support for the pilot.

Cynthia Teel, PhD, RN, Director, Education and Information Transfer, University of Kansas, Alzheimer's Disease Center, spoke how they have arrived at this being a reasonable solution for the issues we are facing. When we discovered there was such a high rate of older adults who are in nursing homes, many of whom were in nursing homes with very little disability compared to some of the older adults in institutional settings in other states, we asked ourselves why? What is going on here and what is the problem? As a part of the strategy in trying to find the answer, I traveled the state and visited with family members asking them about the problems they had in trying to get the diagnosis of alzheimer's disease for their loved ones, what were the challenges they faced and the barriers, not only to the diagnostic section, but also getting care and treatment after diagnosis had been made. From that a lot was learned and we started looking for solutions that had been effective in other states and came across a program that had been implemented for a number of years in Maine and putting those pieces together and are proposing today that implementation of a pilot project for Kansas is warranted at this time. The purpose of Kansas MAP is to support the diagnosis and treatment of persons with dementia living in rural Kansas and hope that by implementation of this pilot project we can identify and begin treatment for patients with dementia earlier than is currently happening. Education is a very strong component of this program, education for physicians, care providers and family. We currently have commitments for program partnerships with the Northwest Area on Aging in Hays and also the Northwest Area Education Center in Hays. There are physicians in the rural area who are responsible for diagnosing and treating their patients and many times that works out fine but could be improved. In the project, a physician in a rural area would refer a client who he or she was suspicious of having dementia and wanting assistance in working up the patient with a diagnosis so the patient would be referred to the Kansas MAP project. At that point and time a nurse - social worker team from the Area on Aging who had already been trained by the KU Medical Alzheimer's Center could go out and do an assessment of the patient and family in the home setting. The nurse-social worker assessment team would then go to an Area Health Education Center in Hays and communicate those findings to the dementia consultants at KU. We would deliberate about those findings and communicate with the primary care provider in the rural community and at that point the local physician would make the diagnosis and then implement treatment for the patient in a rural setting using the resources of the assessment team to help carry out and implement that treatment. The patients would benefit because there would be access to earlier diagnosis and that means earlier treatment which means better chance for prolonged independence in the home. The families benefit because when patient gets into the system earlier the families then can also get earlier access to knowledge and education about treating the disease and behavior management in the home (See Attachment #3).

Representative Morrison moved and Representative Toelkes seconded moving SCR1636 out favorably. The motion carried.

The Chairperson asked the Committee what their wishes were on SB513 - Concerning cosmetology.

Representative Bethell moved and Representative Lightner seconded to move SB513 out favorably.

Representative Landwehr stated that Senator Praeger had a concern with the sanitation issue as it has to be addressed and would like to have the authority moved from the Cosmetology to the Behavioral Sciences Regulatory Board.

Representative Lightner moved a Substitute Motion and Representative Storm seconded amending SB513 with HB2875 which allows 49% of total services per week in a residence or office of the person receiving services. There would be a \$15.00 application fee to provide this service

Representative Morrison stated he opposed the Substitute Motion.

The Chair stated if SB513 was taken up again this year, would start at the point of Representative Lightner's Substitute Motion. Might continue after talking to the Board of Cosmetology.

CONTINUATION SHEET

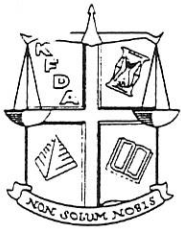
MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES, Room 423-S of the Capitol at 1:30 p.m. on March 16,2000.

The Chairperson stated hearings had not been concluded on **HB 2728**, but had ran out of time so would not be able to continue today.

The Chairperson again asked the Committee which bills they wished to consider.

Representative Showalter moved and Representative Bethell seconded approval of the minutes of March 6, 7, 8, 13 and 14. The motion carried.

The meeting adjourned at 3:10 p.m. Meetings for next week are on call.



KANSAS FUNERAL DIRECTORS AND EMBALMERS ASSOCIATION, INC.

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EXECUTIVE DIRECTOR

PAM SCOTT
Topeka

Date: March 16, 2000

To: House Health and Human Services Committee

From: Pam Scott
Executive Director

Re: Senate Bill No. 556

Mr. Chairman and members of the Committee, I am Pam Scott, Executive Director of the Kansas Funeral Directors and Embalmers Association (KFDA). I appear before you today in support of Senate Bill No. 556.

Senate Bill No. 556 would define who has the right to direct the final disposition of a deceased's remains. This is an issue that has become very prevalent today. The funeral director often encounters this issue when the deceased has not expressed his or her wishes to family members prior to death. It becomes a divisive issue in situations where family members can not agree over the manner or location of final disposition. Confrontations are more common today than in the past because of an increase in divorce, remarriage and situations where there is no spouse but a "significant other" of the opposite or same sex. Also today families are more mobile and often spread around the country. This makes it difficult to obtain consent for disposition from family members located across the country.

Kansas has no statutory law governing who has the right to control disposition of a deceased. The right to control is governed by Kansas case law which has generally recognized that next-of-kin has a personal right to possess the dead body of a relative for the purpose of preserving and burying it. Alderman v. Ford, 146 Kan. at 700 (1937). Typically this right belongs to the surviving spouse. If there is no spouse, then the right passes to other next-of-kin in order of intestate succession. When the issue of who has the right to control disposition has been before Kansas courts, the courts have considered each case in equity, on its own merits, taking into consideration the interest of the public, the wishes of the decedent, religious beliefs, and the feelings of those entitled to be heard by reason of relationship to or association with the deceased. Cordts v. Cordts, 154 Kan. 354 (1941).

Senate Bill No. 556 lists in order of priority, the persons who shall have the right to control disposition. First priority under the legislation goes to an agent appointed pursuant to a Durable Power of Attorney for Health Care Decisions. Kansas law at K.S.A. 58-625 et seq. allows a person to appoint an agent to make decisions concerning disposition of the person's body after death. This gives a person the power to control his or her own manner of disposition even if family members object to the type of disposition the person chooses.

H & H S
3.16.2000
Atch #1

After the agent for health care decisions, the hierarchy of priority follows the order of intestate succession. The surviving spouse has the right to make decisions concerning disposition followed by the surviving adult children and then the deceased's parents.

Under Section 1(a)(3) of the bill, if there is more than one adult child, any adult child who confirms in writing the notification of all other adult children may authorize disposition unless written objection is received by the funeral home or crematory from another adult child.

If there is no next-of-kin available to direct disposition, Section 1(a)(6), provides that the guardian of the decedent at the time of death can direct disposition. This is needed because often the decedent has no family, has been in nursing home care, or institutionalized. In such cases a guardian often has appointed to attend to their affairs. Often the decedent has been on public assistance and funds will be available under the Funeral Assistance Program for disposition. This provision would allow the guardian to authorize disposition including cremation, which is the least expensive means of disposition. Currently such an individual could not be cremated because there is no next-of-kin to authorize cremation.

The final two persons having authority to control disposition are the personal representatives of the deceased and then, in the case of an indigent, the public official charged with arranging final disposition such as a county coroner.

Section 1(b) of the bill protects the funeral home, crematory and funeral director from liability for carrying out the instructions of those legally entitled to make decisions concerning disposition pursuant to this act. This type of provision is found in most, if not all, state statutes dealing with the right to control disposition.

On the floor of the Senate, an amendment was added to the bill because it was thought that the Durable Power of Attorney for Healthcare Decisions was like a general Durable Power of Attorney and would not be effective after death. In fact, the statutes providing for a Durable Power of Attorney for Healthcare Decisions specifically provide in K.S.A. 58-629(f) that death of the principal shall not prohibit or invalidate acts of the agent in arranging for disposition of the body. Therefore, we offer the attached amendment so that the language on lines 20 and 21 of the bill will be as originally drafted and consistent with a Durable Power of Attorney for Healthcare Decisions Act.

Kansas is in need of specific statutes setting forth who has the authority to make decisions concerning disposition of a deceased's remains. Such a law will provide direction to funeral directors and provide clarity to families making arrangements for deceased loved ones.

We urge you to support this legislation to put an end to the uncertainty that currently exists under Kansas law. I would be happy to answer any questions you may have.

[As Amended by Senate Committee of the Whole]

As Amended by Senate Committee

Session of 2000

SENATE BILL No. 556

By Committee on Public Health and Welfare

2-2

12 AN ACT concerning the right to control the disposition of a decedent's
13 remains.

14 *Be it enacted by the Legislature of the State of Kansas:*

15 Section 1. (a) The following persons, in order of priority stated, ~~when~~
16 ~~persons in prior classes are unavailable at time of death,~~ may order any
17 lawful manner of final disposition of a decedent's remains including bur-
18 ial, cremation, entombment or anatomical donation:

19 (1) ~~The agent [The individual who, at the time of death of the~~
20 ~~decedent acted as attorney in fact]~~ for health care decisions estab-
21 lished by a durable power of attorney for health care decisions pursuant
22 to K.S.A. 58-625, *et seq.*, and amendments thereto, if such power of at-
23 torney conveys to the agent the authority to make decisions concerning
24 disposition of the deceased's body;

25 (2) the spouse of the decedent;

26 (3) the decedent's surviving adult children. If there is more than one
27 adult child, any adult child who confirms in writing the notification of all
28 other adult children may ~~serve as the authorizing agent~~ **direct the man-**
29 **ner of disposition** unless the ~~funeral establishment or~~ crematory au-
30 ~~thority receives written objection to the~~ **cremation manner of disposi-**
31 **tion** from another adult child;

32 (4) the decedent's surviving parents;

33 (5) the persons in the next degree of kinship under the laws of de-
34 scendent and distribution to inherit the estate of the deceased. If there is
35 more than one person of the same degree, any person of that degree may
36 direct the manner of disposition;

37 (6) a guardian of the person of the decedent at the time of such
38 person's death;

39 (7) the personal representative of the deceased; or

40 (8) in the case of indigents or any other individuals whose final dis-
41 position is the responsibility of the state or county, the public official
42 charged with arranging the final disposition pursuant to K.S.A. 1999 Supp.
43

1 22a-215 and amendments thereto.

2 (b) A funeral director, funeral establishment or crematory shall not
3 be subject to criminal prosecution or civil liability for carrying out the
4 otherwise lawful instructions of the ~~decedent or the~~ person or persons
5 under ~~this section~~ **subsection (a)** if the funeral director reasonably be-
6 lieves such person is entitled to control final disposition.

7 Sec. 2. This act shall take effect and be in force from and after its
8 publication in the statute book.

The agent

authority conferred shall be exercisable notwithstanding the principal's subsequent disability or incapacity.

History: L. 1989, ch. 181, § 1; July 1.

Cross References to Related Sections:

Natural death act, see 65-28,101 et seq.
Uniform anatomical gift act, see 65-3209 et seq.
Uniform durable power of attorney act, see 58-610 et seq.

Law Review and Bar Journal References:

"Durable Power of Attorney for Health Care Decisions (No. "5")," Marla J. Luckert, 91 Kan. Med. No. 5, 138 (1990).

58-626. Same; acts of agent during disability or incapacity of principal. All acts done by an agent pursuant to a durable power of attorney for health care decisions during any period of disability or incapacity of the principal have the same effect as if the principal were competent and not disabled.

History: L. 1989, ch. 181, § 2; July 1.

58-627. Same; power of court-appointed guardian; principal authorized to nominate conservator or guardian; court appointment. (a) If, following execution of a durable power of attorney for health care decisions, a court of the principal's domicile appoints a guardian charged with the responsibility for the principal's person, the guardian has the same power to revoke or amend the durable power of attorney that the principal would have had if the principal were not disabled or incapacitated.

(b) A principal may nominate, by a durable power of attorney for health care decisions, a conservator or guardian for consideration by the court if protective proceedings for the principal's person or estate are thereafter commenced. The court shall make its appointment in accordance with the principal's most recent nomination in a durable power of attorney for health care decisions except for good cause or disqualification.

History: L. 1989, ch. 181, § 3; July 1.

Cross References to Related Sections:

Act for obtaining a guardian or conservator, or both, see 59-3001 et seq.

58-628. Same; effect of voluntary revocation by principal; actual knowledge required. A voluntary revocation by a principal of a durable power of attorney for health care decisions does not revoke or terminate the agency as to the agent or other person, who, without actual knowledge of the revocation, acts in good faith under the power.

History: L. 1989, ch. 181, § 4; July 1.

58-629. Same; authority of agent; limitations on agent's power; persons not to be designated as agents; witnesses and acknowledgment; effect of death of principal. (a) A durable power of attorney for health care decisions may convey to the agent the authority to:

(1) Consent, refuse consent, or withdraw consent to any care, treatment, service or procedure to maintain, diagnose or treat a physical or mental condition, and to make decisions about organ donation, autopsy, and disposition of the body;

(2) make all necessary arrangements for the principal at any hospital, psychiatric hospital or psychiatric treatment facility, hospice, nursing home or similar institution; to employ or discharge health care personnel to include physicians, psychiatrists, psychologists, dentists, nurses, therapists or any other person who is licensed, certified, or otherwise authorized or permitted by the laws of this state to administer health care as the agent shall deem necessary for the physical, mental and emotional well being of the principal; and

(3) request, receive and review any information, verbal or written, regarding the principal's personal affairs or physical or mental health including medical and hospital records and to execute any releases of other documents that may be required in order to obtain such information.

(b) The powers of the agent herein shall be limited to the extent set out in writing in the durable power of attorney for health care decisions, and shall not include the power to revoke or invalidate a previously existing declaration by the principal in accordance with the natural death act. No agent powers conveyed pursuant to this section shall be effective until the occurrence of the principal's disability or incapacity, as defined in K.S.A. 59-3002 and amendments thereto, as determined by the principal's attending physician, as defined in subsection (a) of K.S.A. 65-28,102 and amendments thereto, unless the durable power of attorney for health care decisions specifically provides otherwise. Nothing in this act shall be construed as prohibiting an agent from providing treatment by spiritual means through prayer alone and care consistent therewith, in lieu of medical care and treatment, in accordance with the tenets and practices of any church or religious denomination of which the principal is a member.

(c) In exercising the authority under the durable power of attorney for health care decisions,

1-4

the agent has a duty to act consistent with the expressed desires of the principal.

(d) Neither the treating health care provider, as defined by subsection (c) of K.S.A. 65-4921 and amendments thereto, nor an employee of the treating health care provider, nor an employee, owner, director or officer of a facility described in K.S.A. 58-629(a)(2) may be designated as the agent to make health care decisions under a durable power of attorney for health care decisions unless:

(1) Related to the principal by blood, marriage or adoption; or

(2) the principal and agent are members of the same community of persons who are bound by vows to a religious life and who conduct or assist in the conduct of religious services and actually and regularly engage in religious, benevolent, charitable or educational ministrations or the performance of health care services.

(e) A durable power of attorney for health care decisions shall be:

(1) Dated and signed in the presence of two witnesses at least 18 years of age neither of whom shall be the agent, related to the principal by blood, marriage or adoption, entitled to any portion of the estate of the principal according to the laws of intestate succession of this state or under any will of the principal or codicil thereto, or directly financially responsible for the principal's health care; or

(2) acknowledged before a notary public.

(f) Death of the principal shall not prohibit or invalidate acts of the agent in arranging for organ donation, autopsy or disposition of body.

(g) Any person who in good faith acts pursuant to the terms of a durable power of attorney for health care decisions without knowledge of its invalidity shall be immune from liability that may be incurred or imposed from such action.

History: L. 1989, ch. 181, § 5; L. 1994, ch. 224, § 1; July 1.

58-630. Same; effect if valid under laws of state of principal's residence; acts by agent in this state. Any durable power of attorney for health care decisions which is valid under the laws of the state of the principal's residence at the time the durable power of attorney for health care decisions was signed, shall be a durable power of attorney for health care decisions under this act. All acts taken by an agent in this state under such a durable power of attorney for health care decisions, which would be

valid under the laws of this state, shall be valid acts. All acts taken by an agent for a principal whose residence is Kansas at the time the durable power of attorney for health care decisions is signed shall be valid if valid under Kansas law.

History: L. 1989, ch. 181, § 6; July 1.

58-631. Same; durable power of attorney executed before July 1, 1989, not affected by this act. A durable power of attorney executed before July 1, 1989, that specifically authorizes the attorney in fact or agent to make decisions relating to the health care of the principal shall not be limited or otherwise affected by the provisions of this act.

History: L. 1989, ch. 181, § 7; July 1.

58-632. Same; form. A durable power of attorney for health care decisions shall be in substantially the following form:

**DURABLE POWER OF ATTORNEY FOR HEALTH CARE DECISIONS
GENERAL STATEMENT OF AUTHORITY
GRANTED**

I, _____, designate and appoint:

Name _____

Address: _____

Telephone Number: _____

to be my agent for health care decisions and pursuant to the language stated below, on my behalf to:

(1) Consent, refuse consent, or withdraw consent to any care, treatment, service or procedure to maintain, diagnose or treat a physical or mental condition, and to make decisions about organ donation, autopsy and disposition of the body;

(2) make all necessary arrangements at any hospital, psychiatric hospital or psychiatric treatment facility, hospice, nursing home or similar institution; to employ or discharge health care personnel to include physicians, psychiatrists, psychologists, dentists, nurses, therapists or any other person who is licensed, certified or otherwise authorized or permitted by the laws of this state to administer health care as the agent shall deem necessary for my physical, mental and emotional well being; and

(3) request, receive and review any information, verbal or written, regarding my personal affairs or physical or mental health including medical and hospital records and to execute any releases of other documents that may be required in order to obtain such information.

In exercising the grant of authority set forth above my agent for health care decisions shall: _____

(Here may be inserted any special instructions or statement of the principal's desires to be followed by the agent in exercising the authority granted).

LIMITATIONS OF AUTHORITY

(1) The powers of the agent herein shall be limited to the extent set out in writing in this durable power of attorney for health care decisions, and shall not include the power to

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Thursday, March 16, 2000

Representative Gary Boston , Chairman
House Health and Human Services Committee
Room 156-E
State Capitol
Topeka, Kansas 66612

Mr. Chairman and Members of the Committee:

Thank you for the opportunity to submit testimony to you today. My name is Mack Smith, and I'm the executive secretary to the Kansas State Board of Mortuary Arts. I write requesting your support of Senate Bill 556.

There is currently no law governing control of disposition of the deceased. Passage of this bill would rectify a situation that is often confusing to both families and funeral homes.

The only amendment to the bill that I would ask the committee to support would be the elimination of "The individual who, at the time of death of the decedent acted as attorney-in-fact" (that can be found on page one, lines 20-21,) replacing those words with the original "The agent."

Thank you in advance for your consideration. I apologize for not being able to meet with you in person today.

Sincerely,

Mack Smith, Executive Secretary
Kansas State Board of Mortuary Arts

MS

H+HS
3-16-2000
A tch #2

Kansas Memory Assessment Program: KS – MAP

Pilot Project Proposal

Presented to:

House Health and Human Services Committee
Rep. Garry Boston, Chair

March 16, 2000

Presented by:

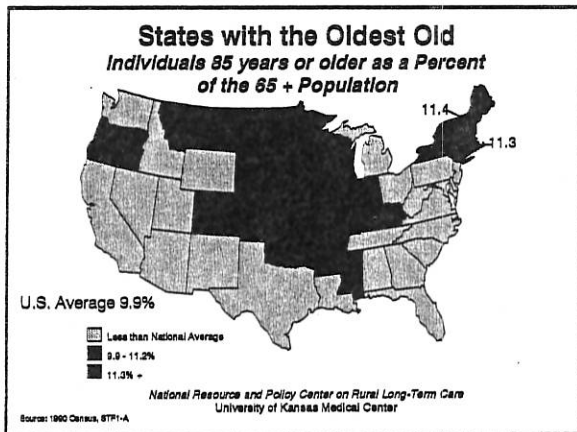
Charles DeCarli, MD
Director
University of Kansas
Alzheimer's Disease Center

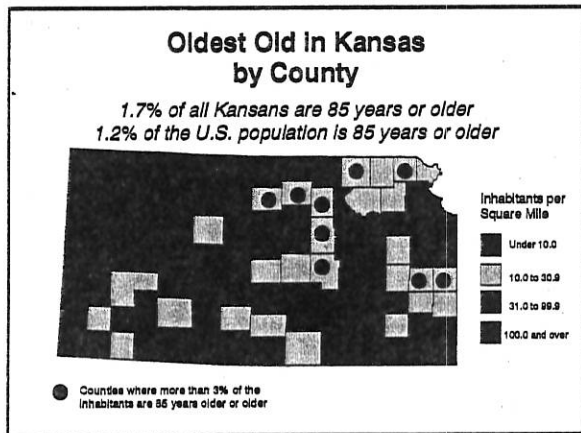
Cynthia Teel, PhD, RN
Director, Education and Information Transfer
University of Kansas
Alzheimer's Disease Center

H&HS
3-16-2000
Atch #3

Kansas MAP
*Approaching the Problem of
 Alzheimer's Disease in Kansas*

Charles DeCarli, MD
 Cynthia Teel, PhD, RN
 Karen Blackwell, MS
 University of Kansas Alzheimer's Disease
 Center

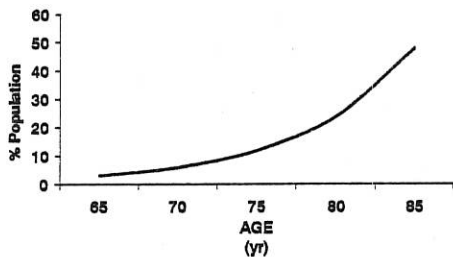




Who are the Oldest Old?

- 41,832 People in Kansas are 85 or older
- 96,000 expected by 2010
- ◆ Majority live in rural areas
- ◆ 3/4 are women
- ◆ Most live alone
- ◆ Most live in poverty

AGE-RELATED PREVALENCE OF AD



Alzheimer's Disease in Kansas

- 64,000 Currently affected
- 128,000 predicted by 2020
- Terminal disease
 - > Average 7 years
- Assistance is required during 1/2 the illness

**Consequence of
Alzheimer's**

- Approximately 30,000 available beds
- 87% occupancy rate
- Double the national average
- 92% of residents > 65 years of age
- ~80 % of residents have dementia

**The Cost of Alzheimer's
Disease in Kansas**

- Alzheimer's Disease is the most common dementia
- \$200 million estimated cost for AD in 1998
 - ◆ \$ 80 million State General Fund
 - ◆ \$120 million Medicaid (Title XIX)

Benefits of Treatment

- Early intervention and treatment
 - ◆ Significantly delays institutionalization
 - ◆ Improves quality of life for
 - > patient
 - > caregivers

Focusing on Solutions

Kansas Memory Assessment Program

Kansas MAP



- Program Purpose
 - Support diagnosis & treatment of persons with dementia living in rural Kansas
- Program Goals
 - Early identification and treatment of dementia
 - Education
- Program Partners
 - Northwest Area Agency on Aging, Hays
 - Northwest Area Health Education Center, Hays

What is Kansas MAP?

- Rural physicians refer patients to project
- Nurse/social worker team conducts in-home assessment
- Nurse/social worker team communicates findings to dementia consultants at KU
- Diagnosis & treatment plan communicated to local physician
- Local physician implements treatment plan

Who benefits with Kansas MAP?

- *Patients* benefit from early diagnosis and treatment
- *Families* benefit from education about dementia & care management
- *Physicians* benefit from access to consultants, which enhances knowledge & skills
- *Community* benefits from better resource utilization

3 Phases in Pilot Project Educating, Examining, Evaluating

■ Phase I - Education

- Information dissemination to physicians re: project and current dementia diagnosis & treatment strategies
- Training for in-home assessment team; nurse & social worker will train at KU Alzheimer's Disease Center



Phase II - Examination

- Physician notifies Northwest AAA of referral
- Assessment team to patient's home
- Assessment data shared with KU consultants using interactive televideo at Northwest AHEC
- KU consultant shares diagnosis & treatment plan with local physician
- Assessment team assists physician in implementation of plan

Phase III - Evaluation

- Processes
 - Communication
- Outcomes
 - Demographics
 - Family satisfaction with intervention
 - Family's ability to manage home care
 - Physician satisfaction with participation
 - Change in physician knowledge about dementia

Alzheimer's Disease in Kansas

- Unique challenges in Kansas
- Alzheimer's disease is a significant health issue now & in the future
- University of Kansas Alzheimer's Disease Center has qualified personnel and is positioned to support innovative solutions

Kansas Memory Assessment Program

Project Summary

A pilot project of the Kansas Memory Assessment Program (MAP) is proposed herein. Project staff at the University of Kansas Alzheimer's Disease Center, in collaboration with colleagues in northwest Kansas, will participate in pilot testing the MAP. The purpose of the MAP is to support the diagnosis and treatment of persons with dementia and their families who live in rural areas of Kansas. Overall, the MAP is designed improve access to dementia services and to enhance the expertise of local health care providers in the management of persons with dementia.

Prior to a statewide implementation of the MAP, a trial of the program is proposed to extend collaborative relationships with health care partners in rural areas and to test program materials for information dissemination, staff training, and program evaluation. The projected timeline for this pilot project is 6 months and at least 10 patients in northwest Kansas will be evaluated during the pilot project. The northwest region of the state has been selected for pilot testing of the MAP because of its rural characteristics and because of the resources that are already in place in the area to support project implementation. More specifically, the Northwest Area Agency on Aging and the Northwest Area Health Education Center are located in Hays and both are enthusiastic partners in this pilot project proposal.

Project team members at the University of Kansas Alzheimer's Disease Center (ADC) include Dr. Cynthia Teel, PhD, RN, Project Leader and Dr. Charles DeCarli, MD, Dementia Specialist. The Kansas City team also includes Karen Blackwell, MA, who will provide administrative support for the project.

Project collaborators in northwest Kansas include Greg Hoover, Executive Director, Northwest Area Agency on Aging (AAA) and Ruby Jane Davis, Director, Northwest Area Health Education Center (AHEC). Both of these agencies are located in Hays, Kansas. The Hays team also includes a nurse and a counselor from the Northwest AAA, who will be trained as primary data collectors for the in-home assessments.

Primary project activities include:

- Sending information to health care providers in areas surrounding Hays regarding pilot project; inviting attendance to a continuing education program on dementia and informational meeting about the Kansas MAP.
- Training nurse/counselor team members regarding in-home memory assessment
- Receiving referrals sent to Northwest AAA from health care providers for in-home memory assessment; forwarding information to MAP team in Kansas City
- Conducting in-home assessments by nurse/counselor team
- Using interactive televideo (ITV) equipment for conferences between Hays assessment team and Kansas City MAP team
- Communicating diagnosis and treatment plan to primary health care provider
- Implementing treatment plan through return home visit by assessment team
- Maintaining follow-up telephone contact with patient and family
- Conducting outcome assessment of Kansas MAP pilot project by documenting process and result of each patient/family evaluation, obtaining input from family caregivers regarding perceived value of intervention, and soliciting input from primary health care providers about program usefulness and interest in continued participation

Overview and Project Aims

The University of Kansas Alzheimer's Disease Center (ADC) has been active in seeking to gain a better understanding of the challenges that family caregivers in rural areas of Kansas encounter when caring for loved ones with Alzheimer's disease. Recently, Dr. Teel has conducted in-depth interviews throughout the state with rural family caregivers to identify their perceptions of barriers in the diagnosis and treatment of dementia. Interviews with professional health care providers are currently underway to further extend understanding about these challenges.

Most family caregivers in Kansas note extreme difficulty in obtaining a diagnosis for their loved one with dementia. The pursuit of a diagnosis often extends over several years and includes evaluations by several physicians. According to these family caregivers, many physicians do not make a diagnosis and instead say that the memory disturbances and unusual behaviors are "just old age." Family caregivers also identify several barriers to care in rural Kansas, some of which include a lack of instruction from the professionals about how to care for their loved one and limited services to support care. In addition, the family caregivers perceive that many health care providers have a poor educational background about Alzheimer's disease.

Clearly, the continuation of strong educational programs about Alzheimer's disease for health care professionals is essential and the University of Kansas ADC will continue an active program to educate health care providers and families about dementia. However, the provision of formal education alone is not enough to meet the needs of families in rural areas. We believe these needs must also be addressed through a concerted outreach effort to facilitate the diagnosis and treatment of persons with dementia who live in rural Kansas. The University of Kansas ADC is proposing a pilot test of the Kansas Memory Assessment Program, which is intended to extend dementia services in rural areas and enhance the diagnostic skills of rural health care providers with regard to dementia and Alzheimer's disease.

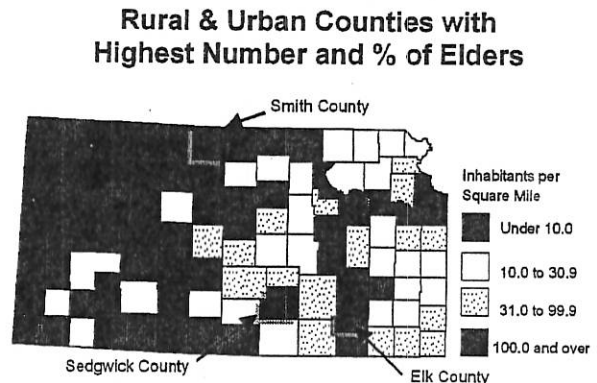
The Kansas MAP is modeled after a similar in-home assessment program in Maine. The Maine geriatric dementia assessment program was developed as a demonstration project to reduce reliance on nursing home care and increase community based services. In this program, a nurse/social worker team conducts an in-home evaluation, communicates the assessment data to a dementia specialist, who then forwards information about the diagnosis and suggested treatment to the community physician. Follow-up consists of at least one home visit and one or more telephone calls to the patient and family. Currently, the program has 7 outreach locations, which cover over 12,000 square miles and serve over 260,000 people in rural areas of the state. The Maine program is supported by state funding, which has increased annually over the 4 years since the program's inception.

In the proposed Kansas MAP pilot project, a memory assessment team (comprised of a nurse and counselor) will conduct in-home evaluations of persons with memory difficulties who live in rural areas and then confer with a dementia specialist at the University of Kansas ADC to develop individualized care plans. Plans will be implemented through communication with the local health care provider and follow-up home visits and telephone contact by the assessment team. Specific aims of the pilot project are to support access to dementia diagnosis and treatment services for rural families and to support the education of rural health care providers in the diagnosis and management of persons with dementia.

Background and Significance

Kansas has a high percentage of older residents; 13.8% of the population in Kansas is age 65 or older. Further, 1.7% of the population in Kansas is age 85 and older. Over the next 20 years, the number and percentage of the oldest old (>85 years) in Kansas is expected to more than double to 96,000. Because this group of elders has a nearly 50% chance of having Alzheimer's disease, Kansas is particularly vulnerable to the personal, social, and economic burdens of dementia that accompany a rapidly growing population of the oldest old.

In addition, Kansas is a rural state with almost one-third of the state's 2.5 million residents living in rural areas. Rural counties generally have the highest percentages of older people while urban counties have the greatest number of elders. For example, Elk County is considered frontier (less than 6 residents/square mile) and 29.6% of its residents are age 65+. In Smith County, also a frontier county, 19% of the residents are 85+ years. On the other hand, Sedgwick County has 45,883 residents age 65+, but this accounts for only 11.4% of the population in this area. Of the older residents in Sedgwick County, only 10% are 85 years and above.



Challenges of rural living often include limited access to health care. More specifically, over half of the counties in Kansas have critically underserved health care needs, with less than one physician per 1,000 residents. Most (72%) of these counties also are quite isolated, with fewer than 10 residents per square mile. The isolation translates into fewer health care providers, more limited access to medical technology, and more hospital admissions.

Among Kansans age 85+, about 30% reside in long term care settings, compared to the national institutionalization rate of approximately 22% for people 85+ years. In several of the frontier counties of Kansas the percent of the oldest old population in nursing homes is extremely high (e.g., 48% in Morton County). The high rate is not, however, found in all frontier areas. For example, in Jewell County (4 persons/square mile), the rate is only 13%. Neither is the high rate found only in rural areas. For instance, in Harvey County, located just north of one of the most densely populated areas in the state, 47% of the oldest old are institutionalized.

The basis for the overall high rate of long term care placement in Kansas is currently unknown, but isolation and lack of resources in the rural setting that may impede diagnosis and treatment are possible causes. The high percentage of older residents coupled with the rural nature of the state and limited resources available in the rural areas may explain the higher use of long term care in Kansas compared to the rest of the country. Further, there may be impediments to learning about current treatment regimens among health care professionals across a variety of settings. The high utilization rate provides both an impetus and justification for concerted outreach efforts by the University of Kansas ADC.

Project Protocol

Project goals will be accomplished through partnerships with the Northwest Area Agency on Aging and the Northwest Area Health Education Center, both located in Hays, Kansas. The executive directors of both agencies have offered enthusiastic support for the pilot project. The memory assessment team personnel will be employees of the Area Agency on Aging (AAA). The Area Health Education Center (AHEC) will support communication between project staff and local health care providers in addition to providing access to interactive televideo equipment for consultations. The pilot will progress in 3 phases, beginning with information dissemination and staff training, followed by data collection, and concluding with project evaluation.

Phase I

Phase I of the pilot project will focus on information dissemination and training for the in-home assessment team. Letters will be sent to health care providers in the communities surrounding Hays to inform them about the project. In addition, they will be notified about a continuing education program that will be provided in Hays to discuss current strategies in the diagnosis and management of dementia. Offering this program is essential to facilitate introduction of the project and the project staff to local physicians and advanced practice nurses. In addition, the program will provide baseline information about diagnosis and treatment to local health care providers. The Northwest AHEC is an important partner in scheduling this educational program for a time and location likely to generate maximum participation by local health care providers.

Training of the in-home assessment team is also planned for Phase I. A nurse and master's prepared counselor from the Northwest AAA will travel to Kansas City for intensive training in the study protocol. The team members will join Dr. DeCarli for at least 2 memory assessment clinics during which they will learn current assessment techniques for the in-home evaluations of rural patients. In addition, the team members also will join Dr. Teel for intensive instruction about assessment of family caregivers and data collection techniques for in-home assessment.

Phase II

Data collection will take place in Phase II of the pilot project. Primary health care providers in the region surrounding Hays will notify the Northwest AAA of a referral and forward pertinent health history data to the dementia specialist at the University of Kansas ADC. The assessment team will schedule a home visit to conduct an in-home evaluation. At least 10 patients will be evaluated during the pilot project.

After the in-home assessment has taken place, an interactive televideo (ITV) conference will be scheduled to communicate the evaluation data to the project staff at the University of Kansas ADC. Using ITV for team meetings between the in-home memory assessment team (based in Hays) and the KS-MAP project director and dementia specialist (based in Kansas City) will greatly enhance communication among project team members. The dementia specialist will contact the local health care provider about the diagnosis and suggested treatment plan. The assessment team will support implementation of the treatment plan by return visits to the patient's home and follow-up telephone communication with the patient and family.

All patient information will be communicated to the primary care provider. The local provider is an essential member of the overall memory assessment team. Further, we anticipate that periodic communication between local health care providers and the KU dementia specialist

using ITV technology will facilitate discussion about diagnoses and treatment plans for dementia patients in the pilot study.

Phase III

A primary emphasis in the pilot project of the Kansas MAP is to develop the infrastructure that will support implementation of a statewide memory assessment program. Phase III of the pilot project will focus on evaluation of the project's success. Several indices will be used to evaluate the project.

Outcomes of Kansas MAP pilot project will be assessed by tracking data about patients and their families, including the number of patients and families who are evaluated, the process of each evaluation, and the results of the evaluations. In addition, input from family caregivers regarding their perceptions of the value of the intervention will be obtained. For example, family caregivers will be asked how participation in the program affected their ability to manage the situation at home. The primary health care providers will be surveyed about their perceptions of the usefulness of the MAP and their interest in continuing participation in the program. These data will be used to modify program protocol prior to future implementation of the Kansas MAP in other areas of the state.