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CHOICE in DYING

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CHOICE IN DYING

THE NATIONAL
COUNCIL FOR THE
RIGHT TO DIE

Oseran & Company
COMMUNICATIONS

Laurie S. Oseran

5175 Watson St. NW/Washington DC 20016

202/362/1505

Choice In Dying, Inc.

200 Varick Street
New York, NY 10014

the national
council
for the right
to die

formerly
Concern for Dying
and Society for
the Right to Die

ADVANCE DIRECTIVE FORM FOR:

THE DISTRICT OF COLUMBIA
ARKANSAS

CHOICE IN DYING

Formerly Concern for Dying and the Society for the Right to Die

0790B

Dear CID friend,

Thank you for contacting Choice in Dying.

On June 25, 1990, the Supreme Court ruled in the Nancy Cruzan case that Americans have a constitutional "right to die," and indicated that a Living Will or a Durable Power of Attorney may be the best way to protect that right. As a result, we have increased our distribution of these essential documents.

In this envelope you will find:

A) Two legal documents:

1) A Living Will in the language authorized by your state statute (often called a Directive or a Declaration), and

2) A Living Will in general language, drafted by Choice in Dying.

B) A list of publications available from Choice in Dying.

We recommend that you complete and sign both these legal documents.

Why two Living Wills? Your statutory Living Will is widely recognized and, under the appropriate conditions, may be adequate. However, the Living Will drafted by Choice in Dying covers a wider range of medical situations and treatments than most Living Wills authorized by state law. For example, many state Living Wills only come into effect when you are in a "terminal" condition, which might exclude people with advanced Alzheimer's and vegetative patients like Nancy Cruzan, who could live for many years; other state Living Wills do not allow you to refuse tube feeding. Choice in Dying's Living Will does not impose these restrictions, and the Supreme Court's recent decision in the Cruzan case (Cruzan v. Director, Missouri Health Services) suggests that your personal wishes are entitled to constitutional protection, as long as you express them clearly. For that reason, we suggest that you make your full treatment wishes known by filling out both Living Will documents.

Also, Choice in Dying's Living Will contains a "proxy designation clause." This allows you to appoint another person (known as your "agent") to make health care decisions for you if at any time you become unable to make them yourself. We strongly advise you to do this, assuming you have someone whom you trust to make the decisions you would make if you could, and who is willing to act for you in this way.

We are sending you both these forms, even though they overlap in some cases, because we feel that together they provide the best protection of your right to make your own medical treatment decisions. The law governing this issue is a patchwork right now, and is sometimes confusing. We are working with legislators and courts to try to make the laws consistent.

Please read and follow the instructions carefully, and call or write us if you have any questions or comments. We will be glad to help.

Choice in Dying's publications provide additional information about various aspects of the right to refuse life-sustaining treatment. Please use the enclosed form to order.

(over, please)

Annual membership, currently at a low $15, entitles you to the latest information on right-to-die developments, including any changes in the law that might affect you or your family; a subscription to our Newsletter, published four times a year; a wallet-size Living Will Membership Card to alert people that you have a Living Will, in the event of an emergency; and a discount on all our publications and films.

In addition, by contributing, you will join the ranks of supporters who, for over 50 years, have kept. Choice in Dying in the vanguard of the patients' rights movement. Please remember that we are a not-for-profit group that depends on your contributions. Your donation will help us to distribute more of these documents and so protect the rights of all Americans to a natural and dignified death.

Thank you for your support.

CHOICE IN DYING

Formerly Concern for Dying and the Society for the Right to Die

How to Use the DECLARATION
Authorized by the Arkansas Rights of the
Terminally Ill or Permanently Unconscious Act

The new Arkansas Rights of the Terminally Ill or Permanently Unconscious Act replaces the Arkansas Death with Dignity Act. The new Act recognizes your right as an adult (18 or older) to sign a "Declaration" stating that you do not want your dying artificially prolonged by life-sustaining treatment. It contains two forms:

1) the "Terminal Condition" Declaration, applicable in the event of "an incurable and irreversible condition that, without the administration of life-sustaining treatment, will, in the opinion of the attending physician, result in death within a relatively short time";

2) the "Permanently Unconscious" Declaration, applicable in the event of a "lasting condition, indefinitely without change in which thought, feeling, sensations, and awareness of self and environment are absent."

The document forms enclosed are substantially similar to the suggested forms given in the statute. You may sign one or both. You may, if you wish, add personalized directions, and we have provided space for these. You may want to consider listing the particular treatments to be withheld or withdrawn—for example, "I especially do not want surgery, cardiac resuscitation, a respirator, artificially administered nutrition and hydration, antibiotics." You may want to emphasize your desire to be kept comfortable and pain free, or to die at home if possible.

The statute recognizes your right also to name a **health-care proxy**—age 18 or older—whom you trust to make the treatment decisions you would make if you could. The proxy appointment is optional—not everyone has a close friend or relative to designate—but if you have, such a person can be helpful for consultations with your physician on treatment options with reference to your personal preferences.

Your Declaration must be signed in the presence of two witnesses. Note that execution of both Declarations (front and back of the enclosed) requires your witnesses' and your own signature on each. There are no restrictions as to who may serve as your witnesses.

Discuss your Declaration with your physician, who must place a copy of it in your medical record file. If you change doctors, make sure your new doctor also has a copy. Discuss it not only with your proxy, if any, but with others who would be concerned about your care under the circumstances described in your Declaration. Provide these people with a copy of your Declaration, and keep your own readily available at home, where it can be found if it is needed.

Properly signed and witnessed, your Declaration will remain in effect until or unless you revoke it. As long as you are able to communicate your preferences, your own expressed wishes always supersede your Declaration.

For additional Declaration forms or further information, please contact Choice in Dying.

ARKANSAS
"TERMINAL CONDITION" DECLARATION

If I should have an incurable or irreversible condition that will cause my death within a relatively short time, and I am no longer able to make decisions regarding my medical treatment, I direct my attending physician, pursuant to the Arkansas Rights of the Terminally Ill or Permanently Unconscious Act, to withhold or withdraw treatment that only prolongs the process of dying and is not necessary to my comfort or to alleviate pain.

Other directions:

I direct my attending physician to follow the instructions of

_____, residing at

_____, as my Health

Care Proxy, to make medical treatment decisions on my behalf consistent with my wishes.*

Signed this _____ day of _____, 19_____.

Signature _____

Address _____

The declarant voluntarily signed this writing in my presence.

Witness _____

Address _____

Witness _____

Address _____

*If you do not name a Proxy, it is advisable to draw a line through this portion.

(See other side for Declaration pertaining to Permanent Unconsciousness)

Courtesy of **Choice in Dying**
200 Varick Street, New York, NY 10014 (212) 366-5540

"PERMANENTLY UNCONSCIOUS" DECLARATION

If I should become permanently unconscious, I direct my attending physician, pursuant to the Arkansas Rights of the Terminally Ill or Permanently Unconscious Act, to withhold or withdraw life-sustaining treatments that are no longer necessary to my comfort or to alleviate pain.

Other directions:

I direct my attending physician to follow the instructions of

_____ , residing at

_____, as my Health

Care Proxy, to make medical treatment decisions on my behalf consistent with my wishes*

Signed this_____ day of _____

Signature _____

Address _____

The declarant voluntarily signed this writing in my presence.

Witness _____

Address _____

Witness _____

Address _____

**If you do not name a Proxy, it is advisable to draw a line through this portion.*

ADVANCE DIRECTIVE
Living Will and Health Care Proxy

Death is a part of life. It is a reality like birth, growth and aging. I am using this advance directive to convey my wishes about medical care to my doctors and other people looking after me at the end of my life. It is called an advance directive because it gives instructions in advance about what I want to happen to me in the future. It expresses my wishes about medical treatment that might keep me alive. I want this to be legally binding.

If I cannot make or communicate decisions about my medical care, those around me should rely on this document for instructions about measures that could keep me alive.

I do not want medical treatment (including feeding and water by tube) that will keep me alive if:

- I am unconscious and there is no reasonable prospect that I will ever be conscious again (even if I am not going to die soon in my medical condition), or
- I am near death from an illness or injury with no reasonable prospect of recovery.

I do want medicine and other care to make me more comfortable and to take care of pain and suffering. I want this even if the pain medicine makes me die sooner.

I want to give some extra instructions: *[Here list any special instructions, e.g., some people fear being kept alive after a debilitating stroke. If you have wishes about this, or any other conditions, please write them here.]*

The legal language in the box that follows is a health care proxy.
It gives another person the power to make medical decisions for me.

I name _____, who lives at _____

_____, phone number _____,

to make medical decisions for me if I cannot make them myself. This person is called a health care "surrogate," "agent," "proxy," or "attorney in fact." This power of attorney shall become effective when I become incapable of making or communicating decisions about my medical care. This means that this document stays legal when and if I lose the power to speak for myself, for instance, if I am in a coma or have Alzheimer's disease.

My health care proxy has power to tell others what my advance directive means. This person also has power to make decisions for me, based either on what I would have wanted, or, if this is not known, on what he or she thinks is best for me.

If my first choice health care proxy cannot or decides not to act for me, I name _____

_____, address _____,

phone number _____, as my second choice.

(over, please)

I have discussed my wishes with my health care proxy, and with my second choice if I have chosen to appoint a second person. My proxy(ies) has(have) agreed to act for me.

I have thought about this advance directive carefully. I know what it means and want to sign it. I have chosen two witnesses, neither of whom is a member of my family, nor will inherit from me when I die. My witnesses are not the same people as those I named as my health care proxies. I understand that this form should be notarized if I use the box to name (a) health care proxy(ies).

Signature _____

Date _____

Address _____

Witness' signature _____

Witness' printed name _____

Address _____

Witness' signature _____

Witness' printed name _____

Address _____

Notary [to be used if proxy is appointed] _____

Drafted and Distributed by Choice In Dying, Inc.—the National Council for the right to Die. Choice In Dying is a National not-for-profit organization which works for the rights of patients at the end of life. In addition to this generic advance directive, Choice In Dying distributes advance directives that conform to each state's specific legal requirements and maintains a national Living Will Registry for completed documents.

CHOICE IN DYING INC.—
the national council for the right to die
(formerly Concern for Dying/Society for the Right to Die)
200 Varick Street, New York, NY 10014 (212) 366-5540

5/92

CHOICE IN DYING

Formerly Concern for Dying and the Society for the Right to Die

0790A

Dear CID friend,

Thank you for contacting Choice in Dying.

On June 25, 1990, the Supreme Court ruled in the Nancy Cruzan case that Americans have a constitutional "right to die," and indicated that a Living Will or a durable power of attorney may be the best way to protect that right. As a result, we have increased our distribution of these essential documents.

In this envelope you will find:

A) Three legal documents:

1) A Living Will in the language authorized by your state statute (often called a Directive or a Declaration);

2) A Living Will in general language, drafted by Choice in Dying, and

3) A durable power of attorney for health care form, authorized by either your state's statute or some other legal authority.

B) A list of publications available from Choice in Dying.

We recommend that you complete and sign all three legal documents.

Why two Living Wills? Your statutory Living Will is widely recognized and, under the appropriate conditions, may be adequate. However, the Living Will drafted by Choice in Dying covers a wider range of medical situations and treatments than most Living Wills authorized by state law. For example, many state Living Wills only come into effect when you are in a "terminal" condition, which might exclude people with advanced Alzheimer's or vegetative patients like Nancy Cruzan, who could live for many years; other state Living Wills do not allow you to refuse tube feeding. Choice in Dying's Living Will does not impose these restrictions, and the Supreme Court's recent decision in the Cruzan case (Cruzan v. Director, Missouri Health Services) suggests that your personal wishes are entitled to constitutional protection, as long as you express them clearly. For that reason, we suggest that you make your full treatment wishes known by filling out both Living Will documents.

Why the durable power of attorney for health care? This allows you to appoint another person (known as your "agent") to make health care decisions for you if at any time you become unable to make them yourself. We strongly advise you to do this, assuming you have someone whom you trust to make the decisions you would make if you could, and who is willing to act for you in this way.

We are sending you these three forms, even though in some cases they overlap, because together they provide the best protection of your right to make your own medical treatment decisions. The law governing this issue is a patchwork right now, and can be confusing. We are working with legislators and through the courts to try to make the law consistent.

Please read and follow the instructions carefully, and call or write us if you have any questions or comments. We will be glad to help.

Choice in Dying's publications provide additional information about various aspects of the right to refuse life-sustaining treatment. Please use the enclosed form to order.

(over, please)

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In addition, by contributing, you will join the ranks of supporters who, for over 50 years, have kept Choice in Dying in the vanguard of the patients' rights movement. Please remember that we are a not-for-profit group that depends on your contributions. Your donation will help us to distribute more of these documents and so protect the rights of all Americans to a natural and dignified death.

Thank you for your support.

CHOICE IN DYING

Formerly Concern for Dying and the Society for the Right to Die

How to Use the DECLARATION TO PHYSICIANS
Authorized by the DISTRICT OF COLUMBIA NATURAL DEATH ACT

The District of Columbia Natural Death Act recognizes your right to execute a Declaration stating that you do not want your dying artificially prolonged by the use of life-sustaining procedures. The Declaration will be given effect only after your attending physician and one other doctor have certified that your condition is terminal.

The form we are sending you complies with the suggested Declaration form given in the statute. The Act also permits personalized additions, and we have provided space for these. You might wish to consider listing the particular treatments to be withheld or withdrawn—for example, "I do not want surgery, antibiotics, cardiac resuscitation, a respirator, artificial feeding...." You might want to name a "proxy"—someone you trust to make the treatment decisions you would make if you could. You might want to emphasize your desire to be kept comfortable and pain free, even though medication might shorten your life.

Your Declaration must be signed in the presence of two witnesses, neither of whom may be:

1) related to you by blood or marriage;
2) entitled to any part of your estate, by inheritance or other claim;
3) directly financially responsible for your medical care;
4) your attending physician, or his/her employee, or an employee of the health facility in which you are a patient.

Note: A nursing home patient executing a Declaration must have one witness who is a patient advocate or ombudsman.

We suggest that you discuss your Declaration with your doctor and ask that a copy of it be made part of your medical record. If you change doctors, make sure your new doctor has a copy. Discuss it also with family members or others close to you, and provide copies to anyone who might someday have to make medical decisions for you. Keep one signed Declaration at home, among your important papers and readily available.

Properly signed and witnessed, your Declaration will remain in effect until or unless revoked. As long as you are able to express your preferences, your own expressed wishes always supersede your Declaration.

DISTRICT OF COLUMBIA HEALTH CARE DECISIONS ACT OF 1988

On December 12, 1988, the Mayor signed a new Act, effective March 3, 1989, which allows you to appoint an "attorney in fact" to make health-care decisions on your behalf if you are ever unable to make or communicate them yourself. Your attorney in fact can be authorized to make decisions to withhold or withdraw life-prolonging care. The new act is an important additional protection. Two physicians, one of whom must be a psychiatrist, must certify that you are unable to make medical decisions yourself. But they do not have to certify that you are in a "terminal condition" before your attorney in fact can act on your behalf.

To obtain the power of attorney for health care or additional Declaration forms as authorized by the Natural Death Act, please contact Choice in Dying.

Choice in Dying is a not-for-profit organization which depends on the support of individuals. Members of Choice in Dying receive our Newsletter and information on any changes in the law that might affect them.

DISTRICT OF COLUMBIA

DECLARATION

Declaration made this _____ day of _____(month, year).

I, _____, being of sound mind, willfully and voluntarily make known my desires that my dying shall not be artificially prolonged under the circumstances set forth below, and do declare:

If at any time I should have an incurable injury, disease or illness certified to be a terminal condition by two (2) physicians who have personally examined me, one (1) of whom shall be my attending physician, and the physicians have determined that my death will occur whether or not life-sustaining procedures are utilized and where the application of life-sustaining procedures would serve only to artificially prolong the dying process, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort care or to alleviate pain.

Other directions:

In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this declaration shall be honored by my family and physician(s) as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

I understand the full import of this declaration and I am emotionally and mentally competent to make this declaration.

Signed _____

Address _____

_____

I believe the declarant to be of sound mind. I did not sign the declarant's signature above for or at the direction of the declarant. I am at least eighteen (18) years of age and am not related to the declarant by blood or marriage, entitled to any portion of the estate of the declarant according to the laws of intestate succession of the District of Columbia or under any will of declarant or codicil thereto, or directly financially responsible for declarant's medical care. I am not the declarant's attending physician, an employee of the attending physician, or an employee of the health facility in which the declarant is a patient.

Witness _____

Witness _____

Courtesy of **Choice in Dying**
200 Varick Street, New York, NY 10014 (212) 366-5540

DISTRICT OF COLUMBIA

POWER OF ATTORNEY FOR HEALTH CARE

INFORMATION ABOUT THIS DOCUMENT

This is an important legal document. Before signing this document, it is vital for you to know and understand these facts:

This document gives the person you name as your attorney in fact the power to make health-care decisions for you if you cannot make the decisions for yourself.

After you have signed this document, you have the right to make health care decisions for yourself if you are mentally competent to do so. In addition, after you have signed this document, no treatment may be given to you or stopped over your objection if you are mentally competent to make that decision.

You may state in this document any type of treatment that you do not desire and any that you want to make sure you receive.

You have the right to take away the authority of your attorney in fact, unless you have been adjudicated incompetent, by notifying your attorney in fact or health-care provider either orally or in writing. Should you revoke the authority of your attorney in fact, it is advisable to revoke in writing and to place copies of the revocation wherever this document is located.

If there is anything in this document that you do not understand, you should ask a social worker, lawyer or other person to explain it to you.

You should keep a copy of this document after you have signed it. Give a copy to the person you name as your attorney in fact. If you are in a health-care facility, a copy of this document should be included in your medical record.

I, _____, hereby appoint:

_____ (name)

_____ (home address)

_____ (home telephone number)

_____ (work telephone number)

as my attorney in fact to make health-care decisions for me if I become unable to make my own health-care decisions. This gives my attorney in fact the power to grant, refuse, or withdraw consent on my behalf for any health-care service, treatment or procedure. My attorney in fact also has the authority to talk to health-care personnel, get information and sign forms necessary to carry out these decisions.

If the person named as my attorney in fact is not available or is unable to act as my attorney in fact, I appoint the following person to serve in the order listed below:

1. _____ (name)

_____ (home address)

_____ (home telephone number)

_____ (work telephone number)

2. _____ (name)

_____ (home address)

_____ (home telephone number)

_____ (work telephone number)

With this document, I intend to create a power of attorney for health care, which shall take effect if I become incapable of making my own health care decisions and shall continue during that incapacity.

My attorney in fact shall make health-care decisions as I direct below or as I make known to my attorney in fact in some other way.

(over, please)

STATEMENT OF DIRECTIVES CONCERNING
LIFE-PROLONGING CARE, TREATMENT, SERVICES AND PROCEDURES:

_____

_____

_____

_____

_____

SPECIAL PROVISIONS AND LIMITATIONS:

_____

_____

_____

_____

_____

BY MY SIGNATURE I INDICATE THAT I UNDERSTAND THE PURPOSE AND EFFECT OF THIS DOCUMENT.

I sign my name to this form on _____
(date)

at: _____
(address)

_____
(signature)

WITNESSES

I declare that the person who signed or acknowledged this document is personally known to me, that the person signed or acknowledged this durable power of attorney for health care in my presence, and that the person appears to be of sound mind and under no duress, fraud, or undue influence. I am not the person appointed as the the attorney in fact by this document, nor am I a health-care provider of the principal or an employee of the health-care provider of the principal.

First Witness	Second Witness
Signature: _____	Signature: _____
Home Address: _____	Home Address: _____
Print Name: _____	Print Name: _____
Date: _____	Date: _____

(AT LEAST 1 OF THE WITNESSES LISTED ABOVE SHALL ALSO SIGN THE FOLLOWING DECLARATION.)

I further declare that I am not related to the principal by blood, marriage or adoption, and, to the best of my knowledge, I am not entitled to any part of the estate of the principal under a currently existing will or by operation of law.

Signature: _____

Signature: _____

ADVANCE DIRECTIVE
Living Will and Health Care Proxy

Death is a part of life. It is a reality like birth, growth and aging. I am using this advance directive to convey my wishes about medical care to my doctors and other people looking after me at the end of my life. It is called an advance directive because it gives instructions in advance about what I want to happen to me in the future. It expresses my wishes about medical treatment that might keep me alive. I want this to be legally binding.

If I cannot make or communicate decisions about my medical care, those around me should rely on this document for instructions about measures that could keep me alive.

I do not want medical treatment (including feeding and water by tube) that will keep me alive if:

- I am unconscious and there is no reasonable prospect that I will ever be conscious again (even if I am not going to die soon in my medical condition), or
- I am near death from an illness or injury with no reasonable prospect of recovery.

I do want medicine and other care to make me more comfortable and to take care of pain and suffering. I want this even if the pain medicine makes me die sooner.

I want to give some extra instructions: *[Here list any special instructions, e.g., some people fear being kept alive after a debilitating stroke. If you have wishes about this, or any other conditions, please write them here.]*

The legal language in the box that follows is a health care proxy.
It gives another person the power to make medical decisions for me.

I name _____, who lives at _____

_____, phone number _____,

to make medical decisions for me if I cannot make them myself. This person is called a health care "surrogate," "agent," "proxy," or "attorney in fact." This power of attorney shall become effective when I become incapable of making or communicating decisions about my medical care. This means that this document stays legal when and if I lose the power to speak for myself, for instance, if I am in a coma or have Alzheimer's disease.

My health care proxy has power to tell others what my advance directive means. This person also has power to make decisions for me, based either on what I would have wanted, or, if this is not known, on what he or she thinks is best for me.

If my first choice health care proxy cannot or decides not to act for me, I name _____

_____, address _____,

phone number _____, as my second choice.

(over, please)

I have discussed my wishes with my health care proxy, and with my second choice if I have chosen to appoint a second person. My proxy(ies) has(have) agreed to act for me.

I have thought about this advance directive carefully. I know what it means and want to sign it. I have chosen two witnesses, neither of whom is a member of my family, nor will inherit from me when I die. My witnesses are not the same people as those I named as my health care proxies. I understand that this form should be notarized if I use the box to name (a) health care proxy(ies).

Signature _____

Date _____

Address _____

Witness' signature _____

Witness' printed name _____

Address _____

Witness' signature _____

Witness' printed name _____

Address _____

Notary [to be used if proxy is appointed] _____

Drafted and Distributed by Choice In Dying, Inc.—the National Council for the right to Die. Choice In Dying is a National not-for-profit organization which works for the rights of patients at the end of life. In addition to this generic advance directive, Choice In Dying distributes advance directives that conform to each state's specific legal requirements and maintains a national Living Will Registry for completed documents.

CHOICE IN DYING INC.—
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(formerly Concern for Dying/Society for the Right to Die)
200 Varick Street, New York, NY 10014 (212) 366-5540

5/92

Long Island, NY
Newsday
New York City Met Area
Wednesday
D 476,000

NY Has to Update End-of-Life Laws

By Karen Orloff Kaplan

IN A MAJOR BLOW to the rights of people to refuse unwanted medical treatment, the New York State Court of Appeals ruled unanimously last month that a Lake Success man must pay $100,000 to a Great Neck nursing home for keeping his permanently unconscious wife on life support, even though he had evidence that she never would have wanted that to happen.

According to the Oct. 14 ruling, Grace Plaza of Great Neck Inc. was entitled to be paid for keeping Jean Elbaum alive from 1987 to 1989 after her husband, Murray Elbaum, had, according to a lower court decision, presented them with "clear and convincing" evidence that she had made repeated requests not to be maintained on artificial life support. The Court of Appeals, however, said documentation of Jean's Elbaum's wishes was lacking.

New York is one of just two states that prohibits family members from making medical decisions on behalf of loved ones without clear and convincing evidence of their end-of-life wishes.

The Elbaum ruling also is a glaring example of the failure of the law in New York and elsewhere to impose penalties on health-care institutions for providing unwanted care, and to prevent health institutions from making massive raids on family finances.

Since the Karen Ann Quinlan case in 1976, state laws throughout the country overwhelmingly recognized the rights of patients and their families to refuse medical treatment at the end of life. Yet, the courts consistently have been reluctant to give teeth to these rights, and they leave people with no recourse but to fight health-care institutions that impose the unwanted care.

Newsday / Bernie Cootner

The New York State Court of Appeals "message" was that people who would not wish to be kept alive in a permanently unconscious condition should protect themselves by filling out advance directives — the general term for a living will — and a durable power of attorney for health care.

A living will allows individuals to indicate their preferences about the kind and degree of care they wish to receive at the end of life. A health-care proxy allows someone whom the individual appoints to make medical decisions on behalf of that individual when he or she becomes incapacitated.

Jean Elbaum was being fed through a tube implanted in her stomach. She was permanently unconscious, had no hope of recovery and previously had told her husband that she would never want to be kept alive under such circumstances.

When the nursing home refused to withdraw the tube, Elbaum refused to pay for the unwanted treatments. In 1987, the nursing home sued him for payment and he sued the nursing home to have her feeding tube removed.

After winning his suit on appeal to end treatment, Elbaum was able, in 1989, to have his wife transfered to another facility where the tube was removed and Jean Elbaum was allowed to die peacefully. Yet, Murray Elbaum and his family were left with their grief over Jean Elbaum's prolonged death — and $100,000 in medical bills from Grace Plaza.

New York's state law has been modified since 1987 to permit health-care proxies, and cases like Nancy Cruzan's in Missouri have modified the way courts view these issues. Yet, New York's unanimous Court of Appeals ruling highlights the need for the State Legislature to create a "safety net" for those who fail to take full advantage of their

— Continued on Next Page

Karen Orloff Kaplan is executive director of Choice In Dying, a Manhattan-based organization that distributes state-authorized advance directives ("living wills") and powers of attorney for health care.

New York's End-of-Life Laws

— Continued from Preceding Page

right to refuse medical treatment at the end of life, by passing a surrogate decision-making statute.

This type of statute would allow families a voice in making decisions for incapacitated patients who do not have any advance directives. In fact, following the Elbaum decision, Court of Appeals Judge Stewart Hancock Jr., who offered a concurring opinion on this case, explicitly criticized the legal standard adopted by the Court of Appeals in earlier cases. This requires "clear and convincing" evidence of a patient's wishes before life support can be withheld or withdrawn.

Believing that this standard is "unworkable," Hancock called for "legislative attention" that would enable family members in New York to make end-of-life decisions for each other.

Nowadays, many health-care professionals are reluctant to rely on informal decision making about end-of-life choices in the absence of advance directives, since they are afraid of professional or criminal liability. Surrogate or family decision-making statutes provide authorization for next-of-kin to make treatment choices for the incompetent patient who has not executed a living will or appointed an agent through a health-care proxy.

The best protection against unwanted medical treatment remains a written advance directive. The nation's problem is that so few people have completed their advance directives. No one hesitates about getting life insurance, fire insurance, flood insurance, etc. The insurance against the anguish that advance directives provides loved ones should likewise be high on the list.

IA-0078
WATERLOO DAILY COURIER
WATERLOO, IA
CIRC-(E)49,006 (S)54,758
DAILY NEWSPAPER
NOVEMBER 14, 1993

A question for the living: How do you prepare to die?

Group launches nationwide campaign to promote living wills.

By RUTH SHURMAN
Courier/Medill News Service

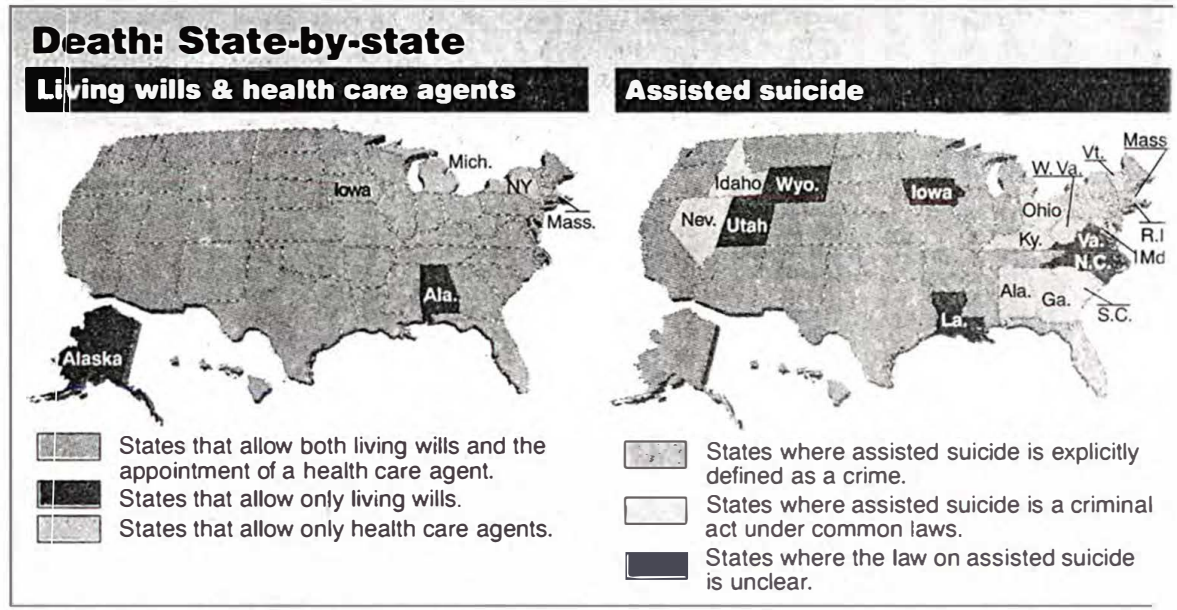
WASHINGTON — From Hillary Rodham Clinton, who plans to sign a living will, to Dr. Jack Kevorkian assisting in 19 deaths, "to be or not to be" is still the question.

Death is the last great taboo. Two million people die in America every year, more than 27,000 of them in Iowa. Eighty percent die in institutions such as hospitals, hospices, or nursing homes. Two-thirds die of cancer, heart disease and other chronic illness, but we are remarkably ill-prepared for coping with these statistics.

According to a 1991 Gallup poll, 48 percent of Americans have written a will to dispose of their property, 34 percent have made their own funeral or burial arrangements, but only 20 percent have written a living will or "advance directive" instructing family and doctors about health-care decisions in case they have a terminal or debilitating illness or injury.

This week, a national campaign to educate the public and health care workers about advance directives was launched by Choice in Dying Inc. (CID). The campaigners aim to close the gap between the 75 percent of Americans who think living wills are a good idea, and the 20 percent who actually have one.

See WILLS / page A8



Group promotes using living wills

Continued from page A1

"We're going to bring this conversation out of the hushed corridors of the hospitals and into the living rooms," said Judith Ahronheim of the American Geriatrics Society Ethics Committee.

What they do

Living wills spell out how patients wish to be treated should they be unable to communicate those wishes, including the right to refuse or terminate treatment. Living wills apply to patients in end-of-life situations, medically labeled "terminally ill", "permanently unconscious," or "imminently dying."

Another form of advance directive confers a durable power of attorney for health care, also known as a health-care agent or proxy. This person can make all the patient's medical decisions, not only end-of-life ones.

Failure to make an advance directive can have agonizing results, according to people forced to watch a family member's life deteriorate in pain prolonged by fruitless medical procedures.

Christy Cruzan White's sister, Nancy, lay in a coma for seven years until the U.S. Supreme Court decided in 1990 that Missouri doctors could end tube feeding, in accordance with Nancy's wishes, as expressed informally to family and friends before a car accident reduced her to permanent unconsciousness.

Cruzan White joined other living will advocates who had to battle in the courts because their relatives never formalized advance directives.

"We feel that these are things that apply only to seniors or the very ill," Cruzan White said Tuesday, "But young people can be the most vulnerable to being held hostage to medical technology simply because their wishes are not known."

The states

All 50 states and the District of Columbia have some kind of living will law. Iowa's statute permits individuals to refuse tube feeding, or gives their health care agent the authority to do so. If the patient is pregnant, a physician may not withhold or withdraw life support under a living will, though a health care agent may instruct the physician to do so.

Under the federal Patient Self-Determination Act (PSDA) of 1991, all health-care facilities that receive Medicare or Medicaid funds must inform patients of their right to refuse treatment and to sign advance directives. But the measure may not be as widespread as lawmakers intended.

Last year, state inspectors in California revealed some hospitals and nursing homes were erratic in informing patients of their rights; doctors sometimes did not comply with patients' wishes; and many patients under the stress and pain of emergency hospital admission failed to fill out their advance directives.

Some of those failings could be due to fear of malpractice litigation or to the medical profession's reticence toward mortality.

"The health-care system views death as the No. 1 failure," said Ann Fade, director of legal services at CID and a former nurse of cancer patients.

Now Choice in Dying is calling on Hillary Rodham Clinton to commission a full study on the effectiveness of the Patient Self Determination Act. CID also recommends that advance directives be included as a check-off item on the proposed National Health Security Card.

The fear of critics

But critics fear that advance directives are the first step on a road that leads to "Dr. Death" (the Kevorkian scenario) and government-financed euthanasia.

"It is very important to have some objective sense of standards of care," said Rishard Doerflinger, editor of the euthanasia-watching newsletter, Life At Risk.

"Catholic teaching is that one should never directly attack innocent life," he said. "The support of life has intrinsic worth... We should continue care with all ordinary means."

Opinion differs over the definition of ordinary means. For some it may exclude tube feeding for the permanently unconscious; for others, it could exclude flu shots for the elderly in the final stages of Alzheimer's disease.

These terms are sinister euphemisms to Rita Marker, the director of the International Anti-Euthanasia Task Force.

"The living will is a very vague document," Marker said. "I think it's very dangerous to have a public policy that gives one person the power to kill another."

Marker approves of clear advance directives to appoint a "trusted individual," rather than "a doctor who may be (following) his or her own views," to make health care decisions. She deplores the PSDA, as it asks patients to make decisions about their destiny in the flustered moment of arrival at the hospital.

Both supporters and opponents of living wills point out that intensive care [illegible] hugely expensive, and advance directives can eliminate some of that financial burden. While CID and legal aid workers save families from spending limited resources on futile treatment, Julie Grimstad of the Center for the Rights of the Terminally Ill in Texas takes a cynical view of the PSDA. She called it "purely and simply a cost-containment measure" intended to accrue savings to Medicaid and the Veterans Administration.

"If you have a dead patient," Grimstad said, "it doesn't cost you anything in medical care."

Assisted suicide

Marker and Doerflinger's main concern, however, is that the increase in living wills and advance directives will spur on the separate movement in favor of assisted suicide.

Advance directives do not permit assisted suicide, whereby doctors provide patients with the drugs or instructions necessary for suicide. This is different from euthanasia, whereby doctors, or any third party, physically helps the consenting patient to commit suicide. Euthanasia, as Dr. Kevorkian has found, is tantamount to homicide in every state.

"Assisted suicide is a nice soothing term for what is first-degree murder," according to Marker.

Assisted suicide is explicitly a crime in 32 states, and criminalized under common law in 12 others. In Iowa, the law is unclear concerning the legality of assisted suicide.

However, when a 1991 Gallup poll asked: "When a person has a disease that cannot be cured, do you think doctors should be allowed by law to end the patient's life by some painless means if the patient and his family request it?" 65 percent of Americans answered, "Yes."

Iowa State Sen. Al Sturgeon, a Democrat, introduced a bill to legalize assisted suicide two years ago, after watching his uncle die slowly and painfully of cancer.

The bill was defeated, although it applied only to terminally ill patients who made the decision independently when they were of sound mind, said Sturgeon, chairman of the Iowa Judiciary Committee.

Extreme views tend to put off the mainstream majority, but whatever patients decide is appropriate — from continued life support at all costs, to the withholding of all treatment — they should put it in writing, CID said.

CID has a toll free number 1–800–989–WILL and will send advance directive forms and information packets.

Nashville, TN
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NOV 14 1993

Living Will can provide death with dignity

By LISA FAYE KAPLAN
Gannett News Service

When Hugh Rodham lay comatose from a stroke last spring, Hillary Rodham Clinton sat at his bedside wondering how best to help her father live or die with dignity.

The answers may have been clearer if her father had signed an "advance directive" — commonly called a living will — telling his family and physicians what he wanted done to prolong his life or let it pass in peace.

Mrs. Clinton's personal experience has made her an advocate of advance directives: She and President Clinton plan to sign their own living wills publicly, an action they hope will "encourage other Americans to do the same," says Neel Lattimore, a spokesman for Mrs. Clinton.

Every state now has passed legislation recognizing some sort of advance directive. Basically, two kinds exist:

- A living will, where an individual specifies treatment he or she will accept or refuse at the end of life.
- Durable power of attorney, where a person appoints an agent to make medical decisions.

Both types of advance directives go into effect only if the person is rendered incompetent and unable to speak for himself.

Learn more

Every state has passed legislation legalizing advance directives.

Many religious groups customize advance directives to reflect their teachings and they distribute their own forms to followers.

Choice In Dying, based in New York City, distributes state-specific advance directives and instructions on how to fill them out.

To receive the free forms write: Choice In Dying, Dept. W, 200 Varick Street, 10th Floor, New York, N.Y. 10014-4810.

Or call: 1-800-989-WILL.

"You have a constitutional right to refuse treatment," says Ann Fade, director of legal services for Choice In Dying, a New York City-based group that distributes advance directive forms. "But the question then is what happens if you are no longer able to communicate your wishes to refuse treatment? The only way to be sure that your wishes will be honored is if you have them written down."

The federal Patient Self-Determination Act, enacted in 1991, requires most health care facilities to inform adult patients of their right to refuse treatment and formulate advance directives.

Living wills were conceived in 1967 by the Society for the Right to Die. (The group is now known as Choice in Dying.) Each state decides which advance directive it will recognize, under what circumstances, and what constitutes patient competence, terminal illness, or a persistent vegetative state.

"These living wills reinforce the common law that doctors can't do procedures you don't agree with," says James Hoefler, author of the upcoming *Deathright: Culture, Medicine, Politics and the Right to Die*, (Westview Press; $49.95 hardcover; $16.95 softcover), due out in February, 1994. Hoefler is professor of political science at Dickinson College in Pennsylvania.

Still, passage of advance directive legislation was slow and controversial.

"The health care community until recently has always done everything to keep (patients) alive as a general rule," says Hoefler. "The living will generally is thought of as something that would contravene that general predisposition."

That bioethical evolution is troublesome to some "pro-life" groups that view advance directive legislation as a dangerous ideological shift away from the presumption that all life is sacred. Some of those groups distribute their own customized living wills.

The health care community now believes "if someone is severely and permanently disabled and can't speak for herself that she should not receive life-saving procedures," says Burke Balch, state legislative director for the National Right To Life Committee. "For those of us who think life with disability is worth living, we're creating a legal document that will help to protect our right to live."

Right To Life's advance directive is called "Will To Live," and it instructs health care providers to make decisions consistent with the patient's desire to preserve life "without discrimination based on my age or physical or mental disability or the 'quality' of my life,'" it says.

Anti-euthanasia groups and the Roman Catholic Church also oppose some parts of advance directive legislation.

For example, the Catholic Church has fought legislation that allows doctors to withdraw artificial feeding and hydration from terminally ill patients, although the church endorses the general idea of living wills.

"Under the church teaching no one is obliged to undergo extraordinary treatment or care," says Bernard Shire, spokesman for the Pennsylvania Catholic Conference, a state lobbying group. However, the church believes feeding and hydrating a dying patient is "ordinary" care and should be continued unless it "presents a grave, intolerable or unbearable burden and offers a reasonable hope of benefit."

"We don't want to see people starve to death," Shire says.

Rita Marker, director of the International Anti-Euthanasia Task Force, based in Steubenville, Ohio, doesn't support living wills, which she calls "a blank check to an unknown physician." She does, however, endorse signing a durable power of attorney.

A random 1991 Gallup survey found that 80% of U.S. adult respondents approve of living wills, though only 20% have executed one.

"Death is still in the closet in our society," says Ann Fade of Choice in Dying. "People are just very reluctant to face and think about their own death and what they want it to be like."

Hoefler, however, predicts advance directives will become popular as the population continues to age.

"As more of us see our parents, siblings and spouses deteriorate and be kept alive by advance medical technology when the quality of life is irreversibly (over), you'll see the number of people executing living wills jump," he says. "They're going to skyrocket." ■

New Orleans, LA
TIMES – PICAYUNE
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NOV 10, 1993

NATIONAL NEWS

Group begins drive for living wills

By The Associated Press

WASHINGTON — A private group launched a drive Tuesday to persuade more Americans to sign living wills to spare their relatives the decision of when to stop medical treatment for them.

"These choices about end-of-life treatment are ours to make. Every American has the right to request or refuse treatment," said Karen Orloff Kaplan, executive director of Choice in Dying. "But most Americans don't know that they have that right, or ... they don't know how to exercise it."

The group's effort has gotten a boost from the White House, where both President Clinton and his wife, Hillary, have said they intend to sign living wills and hope others will follow their example.

Mrs. Clinton, whose father died last April, said Monday that signing a living will was "the fairest and most responsible action to take on behalf of those who are going to be ... asked hard questions when a loved one is in a comatose situation."

Kaplan said the group, which has distributed 18 million advance directives since 1967, hopes to get 1 million Americans to sign living wills in 1994. The slogan of its effort is: "Choose ... or someone else will."

Several people who fought protracted court battles to end extraordinary care for comatose relatives endorsed the drive.

Among them were Christy Cruzan White, sister of Nancy Cruzan, an auto accident victim whose right-to-die case went to the Supreme Court in 1990; Pete Busalacchi, who fought the Missouri legal system to allow his 17-year-old comatose daughter to die; and Murray Elbaum, who won a court battle in New York to stop a nursing home from feeding his wife by tube.

In the Cruzan case, the Supreme Court held that Missouri could require "clear and convincing evidence" that Nancy Cruzan would have decided on her own to forgo life support. A state court subsequently allowed removal of her feeding tube, and she died Dec. 26, 1990, almost eight years after the accident that left her in a vegetative state.

Busalacchi's daughter died last spring after a six-year legal fight. She had been incapacitated by a car crash when she was 17.

Although Elbaum prevailed in court, New York's highest court last month ordered him to pay more than $100,000 for the unwanted treatment at a Long Island nursing home. Jean Elbaum died in 1989 in a hospice after three years on a feeding tube in the nursing home.

A free, state-specific copy of a living will is available from Choice in Dying by calling 1-800-989-WILL or writing: Choice in Dying, 200 Varick St., New York, N.Y. 10014-4810.

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DAILY NEWSPAPER
NOVEMBER 10, 1993

2254

Right To Die Group Seeks Role In Medical Care Issue

By Kathleen Best
Post-Dispatch Washington Bureau

WASHINGTON — President Bill Clinton's proposed national health insurance card should include a check-off box for people who have signed living wills, says a national advocacy group for dying patients and their families.

Choice in Dying Inc. issued the call Tuesday in a news conference designed to inject medical treatment of the dying into the national debate on health care.

The conference featured Peter Busalacchi of St. Charles, Mo., who fought to have treatment ended for his daughter Christine, and Christy Cruzan White of Carterville, Mo., sister of Nancy Cruzan.

The Cruzan family's fight to allow Nancy to die led the U.S. Supreme Court to rule that people have a constitutional right to refuse medical treatment.

But White said too few Americans are exercising that right.

"I think people are reluctant to confront their own mortality," White said. "It's imperative we accept reality and confront these issues."

Busalacchi said he signed a power of attorney two weeks ago giving his daughter and a close friend the power to make medical decisions for him should he become incapacitated.

"Tragedy can strike at any time," he said. "It's important — especially in Missouri — to say what you can have done."

Christine Busalacchi died eight months ago after Missouri officials dropped their challenge to her father's efforts to withhold food and water. Busalacchi said former Gov. John Ashcroft and former Attorney General William Webster "tried to take over as her dad."

"There is no room, no place at bedsides, for strangers," he said.

Christine Busalacchi was 17, a minor, when she suffered irreversible brain damage in a car accident in 1987. She was too young to sign a binding living will or power of attorney. But Busalacchi said that in such cases, decisions should be left to families.

Choice in Dying wants to urge 1 million Americans to sign living wills or powers of attorney within the next year. The organization also wants information on such "advance directives" to be included along with other information presented by regional health alliances under Clinton's health-care program.

Karen Orloff Kaplan, executive director of Choice in Dying, said that with health-care reform on the table, Americans are primed to think about health-care choices.

And one of those choices, she said, should be whether to continue care.

Clintons to sign 'living wills'

Treatment would stop if no hope for recovery

5307

By R.A. ZALDIVAR
Herald Washington Bureau

WASHINGTON — Hillary Rodham Clinton said Monday she and President Clinton would soon sign "living wills" to tell family and doctors to stop medical treatment if either of them is being kept alive artificially with no hope of recovery.

"It's the fairest and most responsible action to take on behalf of those who are going to be asked hard questions when a loved one is in a comatose situation," the first lady said in an interview with reporters.

'Hard decisions'

Clinton said society must eventually face "hard decisions" about expensive and futile treatments for people on the threshold of death. But she stressed that the sensitive issue cannot be addressed fairly until all Americans have health-insurance coverage.

"I am very torn about this," she said. "Anyone who has looked at it can see that there are expenditures that are made in situations where it is perhaps inappropriate. It's only prolonging the inevitable.

"But on the other hand," she continued, "there's a figure which just haunts me: an uninsured person who shows up at the hospital with the same ailment as an insured person is three times more likely to die."

"Until everyone is in the system, to have a conversation about who we will make judgments about strikes me as inappropriate," she said.

Personal conviction

Mrs. Clinton said the decision to sign a living will is a matter of personal conviction for her and the president.

"Nobody likes talking about death, but if we do it in the context of providing guidance to help those who are left behind make the right decision, it becomes an easier conversation," she said.

About 25 percent of adults now have some form of living will, said Patrick Hill, a spokesman for Choice in Dying, a New York-based organization that advocates the right of dying patients to refuse unnecessary life-prolonging procedures.

MAKING HARD DECISIONS: Hillary Rodham Clinton.

Federal law now requires al hospitals to inform patients o their right to have a living will

Patients can also draw up power of attorney designating family member, friend or othe representative to make deci sions in a medical crisis.

MIAMI HERALD, Miami. FL, Nov. 9
(c. 404,679)

TIME

Clinton at the Top of His Game

The Political Interest/Michael Kramer

Pulling the Plug

"I HAVEN'T TOLD MY HUSBAND YET," HILLARY CLINTON SAID AS THE President wolfed rice beside her at a luncheon with journalists last week, "but we're going to have a living will."

"I need one in my line of work," Clinton cracked. His guests laughed, and a discussion about living wills, in which the signer declares that his dying life should not be artificially prolonged, was deftly deflected. The Clintons deny that their reform program would limit medical services in any way, but their own recent brush with what the First Lady calls "a crazy system" supports the experts' view: serious rationing is coming.

Last March, as the White House rushed to craft its health-care proposals, Mrs. Clinton had to leave Washington abruptly to be with her ailing father. The victim of several strokes, Hugh Rodham had been failing for some time. With the end near, the President's 82-year-old father-in-law was admitted to St. Vincent's hospital in Little Rock, where he remained until he died three weeks later. "There was really nothing to do for him," says an Arkansas physician familiar with the case. "He would normally have been discharged after a week because that's all the treatment Medicare would cover for someone in his condition, but he stayed on because of who he was. The hospital ate the bill, about $10,000."

Roughly 30% of all U.S. health costs are incurred in the last six months of life, far more than in other countries, a consequence, largely, of the American notion that there is no such thing as too much health care. But there's something else, something pernicious. "A lot of defensive medicine is practiced in those last six months," says Mrs. Clinton, "extraordinary efforts used on patients who doctors know will not recover, because of fears that families will think they should have done something they didn't do"—and who then sue if it wasn't done.

Malpractice reform would help, but the Administration's new proposals are essentially lame since Clinton has refused to adopt a California-style cap on awards for pain and suffering. On the other hand, Clinton's plan to extend at-home and nursing-home benefits *will* lower costs. As the First Lady points out, Medicare does not pick up those tabs now, "so that doctors, as favors to families, keep people in hospitals."

Mrs. Clinton with her parents in 1992

The Clintons' true goal is the most ambitious of all, a change in the culture of dying. "That's why Hillary's talking up living wills and advance directives," says an Administration official. "She hopes to spur others to get comfortable with pulling the plug."

Choice in Dying, the nation's largest distributor of living wills, sent out 400,000 forms last year. But no one knows how many living wills have actually been signed or executed, and doctors are often reluctant to act even when the document is in order, lest a relative sue. "And even if the family bows to the patient's wishes as expressed in the will, it often takes days or weeks to get agreement," says Stephen Sullivan, a physician on the clinical faculty at Stanford University Hospital, "during which time costs continue to rise."

While some health-care rationing is already a fact of life, more people will feel its bite as universal coverage leads to lower reimbursements. Insuring all Americans will be easier only if more people come to grips with the expense of prolonging life artificially. The Clintons can lead, but no symbolism and no legislation will suffice unless others follow. ■

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NEW YORK POST

SATURDAY, OCTOBER 23/SUNDAY, OCTOBER 24, 1993 /

HILLARY CLINTON

Hillary & Bill: Where there's a living will . . .

By KYLE SMITH

First Lady Hillary Clinton says she and the president will publicly sign "living wills" to instruct doctors what to do in case either should be incapacitated while terminally ill.

Speaking in Chicago on Thursday, Mrs. Clinton said it is essential for people to talk about their deathbed wishes with their loved ones.

A White House official did not know when the First Couple would sign their living wills, or what instructions the wills would contain.

Mrs. Clinton, who was in Chicago to promote the administration's health care reform proposals, talked about living wills during a question and answer period.

Mrs. Clinton said that by signing the documents, she and the president hoped to inspire others to do the same.

A spokeswoman for Choice in Dying, the New York-based organization that claims to have invented living wills, said the First Lady's remarks will encourage people who have been putting off signing the documents to go ahead with it.

The problem with procrastinating is "you never know when you're going to need it. It's like an insurance policy," said Ann Fade, director of legal services for the group.

A spokesman for a pro-life group called Mrs. Clinton's remarks "dangerous."

"I don't think anybody is capable of drafting a living will that could cover all of the various sorts of situations a person could face," said Brian Young of the American Life League of Stafford, Va.

Mrs. Clinton's views on living wills are believed to have been shaped by her excruciating vigil at the deathbed of her father, Hugh Rodham, who died April 7 after suffering 19 days from a stroke.

USA TODAY
NO. 1 IN THE USA . . . FIRST IN DAILY READERS

USA WEEKEND • *October 15-17, 1993*

Thy (living) will be done

Sixteen states last year changed their laws to legalize living wills — legal documents that spell out a person's wishes regarding medical treatment at the end of life. And a recent Gallup Poll shows that although 75 percent of U.S. adults say they approve of living wills, only 25 percent have one. Now anyone can get free, preprinted, state-specific living will forms from Choice In Dying, a New York City-based non-profit advocacy group for the terminally ill. While a few other organizations offer generic living-will formats (at nominal cost), Choice In Dying tracks state legislation and updates its documents continually. This is necessary because living wills that do not conform to state laws aren't recognized by health-care providers. Choice In Dying also provides information for families struggling with end-of-life medical treatment decisions. For more information, call 1-800-989-WILL.

A SPECIAL ISSUE

HEALTH

OCTOBER 1993 • $2.95

LIVING WILLS: HOW TO MAKE THEM STICK

ALL 50 STATES now recognize the right of terminally ill patients to refuse life-prolonging treatment. But in the confusion and trauma of an illness, those rights, and the patient's wishes, can be ignored. Family members not ready to say good-bye, doctors who see their mission as preserving life at all costs, hospitals worried about litigation, all may undermine the law and drown out the lone voice of the patient.

Unfortunately, that means there is no guaranteed way to avoid the nightmare scenario: a parent hooked up against his or her will to a respirator or dialysis machine, disoriented, depressed, with little or no chance of recovery or a decent quality of life. Still, you and your parents *can* greatly increase the chances that their wishes will be respected—if you plan ahead and keep on top of the doctors.

Involve the Whole Family

All too often, parents fill out a living will—the main legal document that instructs a physician to stop or not start certain kinds of treatment—without consulting every family member. That's a mistake. If even one family member says, "I don't care what the living will says, treat him," the doctor usually will.

In your family discussions about the living will, try to be very specific. Ask your parents whether they'd want treatment that prolonged their lives but offered no chance of a decent quality of life. Define decent. Would they want lifesaving surgery if they had a chronic illness such as cancer or diabetes and then suffered a heart attack? What if they were to suffer irreversible brain damage? Would they want to be kept alive on a respirator? "There's no way to anticipate every health circumstance," says Terry Barnett, author of *Living Wills and More*. "Your objective should be to discuss the topic well enough that each family member can apply your parents' wishes to whatever situation is at hand."

Find a Doctor Who Will Be Your Parent's Advocate

A living will means nothing if a physician won't act on it. Make sure your parent's doctor understands *and agrees* with the end-of-life wishes and would be willing to fight to make sure they are heeded. If the doctor won't agree, find one who will. That's especially important when a parent is hospitalized under the care of specialists whose training biases them in favor of aggressive treatment. Even when a parent can still make decisions, he or she may feel steamrollered by what Barnett calls "the technological imperative run amok"—unless the family doctor weighs in.

Have Your Parents Appoint a Health Care Proxy

A durable power of attorney for health care decisions is a document by which parents can name a trusted friend or relative—usually called a health care proxy—to make medical decisions for them if they become incapacitated. It also details what the person named can and cannot do under what circumstances. In making decisions about end-of-life issues, most doctors prefer talking face-to-face with a proxy to having to interpret a living will.

You can get the necessary forms from medical societies, bar associations, and the New York–based nonprofit organization Choice in Dying. "The document should be only the opening gambit in a conversation that lasts a lifetime," says Patrick Hill of Choice in Dying.

Distribute Both Documents

Hospitals or nursing homes cannot honor a living will or power of attorney if they don't have a copy of it. Make sure family members, your parents' doctors, and any medical facility your parent might go to have both.

Think Before You Call 911

If your parent is seriously ill at home or in a nursing home, ask whether she would want Emergency Medical Services called should she go into cardiac arrest. In most states, EMS personnel will try to revive the patient—whatever her living will might say.

Of course, asking a parent whether she wants you to call 911, like discussing a living will itself, is easier said than done. "It's hard," says Patrick Hill, "but it can save a lot of grief later on."

Consider Hospice Care

Terminally ill patients who fear the intrusion of high-tech machines may prefer hospice care to hospitalization. Although hospice workers can administer medication, their primary task is to ease —not forestall—death and provide emotional support to patient and family.

—Teo Furtado

FOR MORE HELP

Choice in Dying **(200 Varick St., New York, NY 10014; 212/366-5540) will send you sample health care documents and advise you how to correctly fill them out.**

National Hospice Organization **(1901 N. Moore St., Ste. 901, Arlington, VA 22209; 703/243-5900) will help you find hospice care in your area.**

Living Wills and More, **written by Terry J. Barnett and published by John Wiley & Sons, Inc. (605 Third Ave., New York, NY 10158-0012), is an excellent guide to filling out a living will and appointing a health care proxy.**

CHOOSE . . .
OR SOMEONE ELSE WILL!

PARTICIPANT BIOGRAPHIES

KAREN ORLOFF KAPLAN, M.P.H., SC.D.
EXECUTIVE DIRECTOR, CHOICE IN DYING

Karen Orloff Kaplan, Sc.D., is the Executive Director of Choice In Dying (CID). Dr. Kaplan has special expertise in health and aging issues, and in developing health and social policy.

Prior to her appointment as Executive Director of CID, Dr. Kaplan served as founding Executive Director of the National Center for Social Policy and Practice, the research and policy arm of the 140,000-member National Association of Social Workers.

Dr. Kaplan also served as a health staff associate to Congressman Ron Wyden (D-Oregon). Dr. Kaplan advised the Congressman about health and social issues, particularly as they related to the elderly. Dr. Kaplan served as spokesperson for Representative Wyden with the Health Care Financing Administration (HCFA), the U.S. Public Health Service, the National Institutes of Health (NIH) and various Congressional committees.

Dr. Kaplan's work has also included spearheading a non-profit research and consulting group with projects that included health care cost containment and inpatient utilization studies.

Dr. Kaplan's previous academic positions included posts as Clinical Instructor at Tufts University and the University of Cincinnati School of Medicine.

Listed among Who's Who of American Women, Dr. Kaplan's professional memberships include the Academy of Certified Social Workers, the American Public Health Association, Association for Health Care Quality, and American Medical Peer Review Association.

Dr. Kaplan received her Doctorate in Science and Masters in Public Health degrees from the School of Hygiene and Public Health, the Johns Hopkins University. She received her Masters in Social Work from Ohio State University.

# # #

ANN E. FADE, R.N., J.D.
DIRECTOR OF LEGAL SERVICES, CHOICE IN DYING

Ann E. Fade, J.D., R.N., the Director of Legal Services at Choice in Dying (CID), has professional training and expertise in both law and health care.

At Choice In Dying, Ms. Fade supervises the organization's legal department. During this past year, Ms. Fade has expanded CID's free legal counseling service, prepared several friend-of-the-court briefs for DeGrella v. Elston, (KY); in re Busalacchi (MO) and Elbaum v. Grace Plaza of Great Neck, (NY), and successfully intervened on scores of legal cases where the legal rights of individuals in end-of-life decisionmaking were in jeopardy. In addition, Ms. Fade and her staff keep legal and medical professionals up-to-date on changing right-to-die law through CID's quarterly publication, Right To Die Law Digest.

Prior to her appointment at CID, Ms. Fade worked as an Associate in the Litigation Department of Kaye, Scoler, Fierman, Hays, and Handler, a law firm in New York City. She also worked for several years as an oncology nurse at Mt. Sinai Medical Center, New York City, where she specialized in treating terminally ill patients. Her publications include a number of articles on the status of advance directive law across the United States.

Ms. Fade graduated from the University of Oregon with a Bachelor of Arts degree, Phi Beta Kappa. Ms. Fade then received her Bachelor of Science degree in Nursing, University of Rochester, and her Juris Doctorate from Yale Law School, New Haven Connecticut.

Ms. Fade is a member of the American Association of Nurse Attorneys.

# # #

JUDITH C. AHRONHEIM, M.D.

Judith C. Ahronheim, M.D., a nationally-recognized specialist in geriatrics, is attending physician and Chief of Consultation and Liaison Service in the Department of Geriatrics and Adult Development at Mount Sinai Medical Center. Dr. Ahronheim also holds positions as Associate Professor of both Medicine and Geriatrics, Mount Sinai School of Medicine in New York.

Previously, Dr. Ahronheim was Clinical Assistant Professor of Medicine and Director of Geriatric Education at New York University School of Medicine, and attending Physician at Bellevue Hospital and Geriatric Clinic. Dr. Ahronheim was also Physician-in-Residence of the Society for the Right to Die.

Dr. Ahronheim serves on the Ethics Committee of the American Geriatrics Society, and is Ad Hoc reviewer for several medical journals. She is a member of the Gerontological Society of America, a Fellow of the American College of Physicians, and immediate past-president of the New York Metropolitan Area Geriatrics Society.

Dr. Ahronheim lectures widely and has written several books and numerous articles on geriatrics and end-of-life issues. She is co-author of Final Passages: Positive Choices for the Dying and Their Loved Ones, and the soon to be released Clinical Ethics in Medical Practice.

Dr. Ahronheim received her M.D. degree from the Abraham Lincoln School of Medicine, University of Illinois, Chicago.

# # #

CHRISTY CRUZAN WHITE

Christy Cruzan White was 27 years old when her sister Nancy, then 25 years old, was found lying unconscious near her overturned car -- the victim of a devastating accident on January 11, 1983. Nancy Cruzan suffered irreversible neurological trauma and never regained consciousness after the accident. Christy and her family then embarked on a pioneering legal battle, eventually decided by the U.S. Supreme Court, which now sets precedent for right-to-die law.

The Cruzan's battle began shortly after their daughter Nancy, sustained only by tube feedings, was transferred to the Missouri Rehabilitation Center in February, 1983. Nancy's parents asked the employees of the Missouri Rehabilitation Center to end the tube feedings of their daughter. When their request was refused, the Cruzan's asked for a court ruling on their request to have Nancy's feeding tube removed and allow her to die.

The trial court approved the Cruzan's request. The court found there was strong evidence suggesting that Nancy Cruzan "would not wish to continue with nutrition and hydration." The state of Missouri appealed to the Missouri Supreme Court which reversed the lower court's decision. The Missouri Supreme Court ruled there was no legal authority to grant the Cruzan's request.

Following this decision, the Cruzan's appealed to the U.S. Supreme Court. In December 1989 -- six years after Nancy's accident -- the U.S. Supreme Court heard arguments in the Cruzan case. This was the first time that a right-to-die case was considered by the nation's highest court. On June 25, 1990, the U.S. Supreme Court upheld the decision of the Missouri Supreme Court. It ruled that Missouri, if it chooses, can require "clear and convincing evidence" that Nancy Cruzan would decide to forgo life support before allowing the exercise of her constitutionally protected right to refuse unwanted medical treatment.

On November 1, 1990, the Cruzan family returned to the trial court in Missouri with additional evidence from three new witnesses who testified to Nancy's previously expressed wishes about end-of-life medical treatment. Based on this new clear and convincing evidence presented by witnesses, authorization was given to remove tube feeding for Nancy Cruzan on December 14, 1990. After seven years of emotional trauma and court battles, the Cruzans said goodbye to Nancy, who died on December 26, 1990.

As the Cruzan case tortuously moved through the courts -- capturing newspaper headlines across America -- Christy Cruzan White's commitment to patient rights at the end of life was sealed. Ms. White has said that "No one should ever be put through this trauma. Nancy's case symbolized that everyone should have a living will."

Today Christy Cruzan White is the Executive Director of the Nancy Cruzan Foundation, headquartered in Carterville, Missouri. This foundation provides support and assistance to families faced with crisis situations at the end of life. It also provides education for the public and health care providers on end-of-life decisionmaking and advance directives.

According to Ms. White, her work with the Foundation has "helped to ease the loss of Nancy."

# # #

MURRAY ELBAUM

Jean Elbaum, a resident of Long Island, New York, suffered a debilitating brain hemorrhage in June, 1986, which left her in a persistently vegetative state. Murray Elbaum knew his wife did not want to be kept alive unaware of her surroundings and unable to communicate. Jean had told her husband and children on countless occasions that she did not want to be sustained by artificial means. Murray Elbaum began a six-year battle with the nursing home where Jean Elbaum languished to win her release from death-prolonging treatment. Now Murray Elbaum may take his case before the U.S. Supreme Court.

After Jean Elbaum's admission in September, 1986, to Grace Plaza, a Long Island nursing home, Murray Elbaum implored the nursing home to remove his wife's feeding tube, consistent with his wife's previously expressed wishes. The nursing home officials refused, citing state law which required "clear and convincing evidence" of Jean Elbaum's end-of-life preferences. The nursing home continued to provide medical treatment for Jean Elbaum and continued billing Murray Elbaum.

When Mr. Elbaum stopped paying Grace Plaza for unwanted medical care, Grace Plaza filed suit against him. Murray Elbaum countersued, asking the state courts to demand that Grace Plaza remove Jean Elbaum's feeding tube. In June, 1988, an intermediate appeals court ruled in Murray Elbaum's favor. Jean Elbaum was transferred to a hospice where she died peacefully a week later.

Murray Elbaum and his family were left with their grief over Jean Elbaum's prolonged death -- and $100,000 in medical bills from Grace Plaza.

On October 14, 1993, just two weeks ago, the Court of Appeals in New York dealt a major blow to patient rights at the end of life. The unanimous ruling by the Court of Appeals required that Murray Elbaum pay the medical bills for his wife's unwanted medical care.

Following this decision, Judge Stewart Hancock, Jr., who offered a concurring opinion on this case, publicly criticized New York's current right-to-die statute. Judge Hancock called for new legislation which would enable family members to make end of life decisions for each other.

New York is one of just two states which prohibits family members from making medical decision on behalf of loved ones without clear and convincing evidence of their end-of-life wishes.

# # #

PETE BUSALACCHI

Peter Busalacchi, a native of St. Charles, Missouri, battled the legal system and right-to-life groups for over six years to uphold his right as a father to allow his 17-year-old daughter to die with dignity after she was left in a permanent vegetative state following a serious car accident.

In May 1987, Christine Busalacchi, a high school senior, suffered devastating neurological trauma resulting from a car accident. At the primary care hospital where Christine was treated, a large portion of her brain was removed to relieve pressure and save her life. This procedure left Christine in a permanent vegetative state. She was subsequently transferred to a state medical facility where she was sustained by a ventilator and a feeding tube in her stomach.

Three months after the accident, Christine's physicians and family painfully concluded that her chances for recovery were non-existent. The Busalacchi family also knew that Christine would not want to live in a vegetative condition without hope for recovery. For this reason, Pete Busalacchi attempted to move Christine to a facility outside Missouri in December, 1990, where her feeding tube could be removed legally. While an action was filed by Christine's medical facility and the Missouri Department of Health to block her transfer, the trial court ruled in Pete Busalacchi's favor.

Following this ruling, the Missouri Department of Health appealed the court's decision. The trial court found that Christine was in a persistent vegetative state and that her condition was permanent with no chance for significant improvement. The court denied the Department of Health's request to declare Christine a "developmentally disabled person" entitled to special legal protection, and also denied the request to restrict her father's authority to discontinue her tube feeding.

In January, 1993, a right-to-life advocate petitioned to replace Christine's father as Christine's guardian, and obtained a temporary restraining order to prevent removal of Christine's feeding tube. The guardianship petition was dismissed shortly after it was filed, and the courts refused to extend the restraining order.

Under the ruling of the trial court, the guardian of a minor patient has the authority to make life-sustaining medical treatment decisions on the patient's behalf. As a result, Pete Busalacchi exercised his authority as the guardian of his daughter Christine, and removed the feeding tube. On March 8, 1993, Christine Busalacchi died peacefully.

# # #

S. JEANNE HALL, ESQ.

Ms. Jeanne Hall is the President and Vice-Chairperson of the Board of Choice In Dying. She is also Vice President/Manager Estate Administration and Trust Settlement Departments with the United States Trust Company of New York.

Previously, Ms. Hall was an Associate of Trusts and Estates Department at the law firm of Skadden, Arps, Slate, Meagher, and Flom. She is currently a member of the Committee on Trusts, Estates and Surrogates' Courts at the Association of the Bar of the City of New York.

Ms. Hall's presentations include serving as a panelist, where she addressed "Right to Die--Living Wills" at St. John's University School of Law Alumni Association Homecoming. She has also been a panelist discussing Living Wills and Health Care Proxies at St. John's University School of Law Continuing Legal Education Program.

Ms. Hall's professional memberships include the American Bar Association, and the New York State Bar Association Trusts and Estates Law Section. She is on the editorial board of Estate Planning Magazine.

Ms. Hall received her Bachelor of Arts from Queens College, City University of New York and her Juris Doctorate from St. John's University School of Law, New York.

# # #

EVAN R. COLLINS, JR., M.B.A, B.S.

Evan R. Collins, Jr., is the Chairman of the Board of Choice In Dying. He also is the Vice President, Branch Manager of Prudential Securities in Mesa, Arizona.

Prior to his appointment as Chairman, Mr. Collins served as the Treasurer of Choice In Dying. Previous charitable experience includes serving as volunteer, Special Gifts Chairman, overall Campaign Chairman, member of the Executive Committee and President of the United Way of Northern Westchester, New York.

Mr. Collins has served as a member of the New Castle, New York, Town Planning Board and is a member of the Union League Club.

Mr. Collins received a Bachelor of Science from Dartmouth College and a Masters of Business Administration from the Amos Tuck School of Business.

# # #

CASES

ELBAUM V. GRACE PLAZA OF GREAT NECK

148 A.D.2d 244, 544 N.Y.S.2d 840 (2d Dep't 1989)
New York Supreme Court Appellate Division, 2d Department

SIGNIFICANT FACTORS

- Persistent vegetative state
- Artificial nutrition and hydration
- DNR
- Clear and convincing evidence
- Financial responsibility for unwanted treatment

THE CASE

On June 30, 1986, Jean Elbaum, then sixty years old, was admitted to North Shore University Hospital suffering from headaches, memory difficulties and confusion. A CAT scan revealed subarachnoid bleeding. Within 48 hours Mrs. Elbaum fell into a deep coma. On July 28 she was diagnosed as being in an irreversible persistent vegetative state with no hope of recovery. During this time a nasogastric tube was used to provide nutrition and hydration.

Some time before August 6, 1986, Mrs. Elbaum's husband and two adult children were informed of her diagnosis. They were informed that gastrointestinal tube feeding would be preferable to nasogastric feeding, and that Mrs. Elbaum would need long-term nursing care. The family was told that no nursing home would accept her unless the gastrostomy were performed. Mr. Elbaum asked what would happen if he refused to give consent and was told that if he did refuse, the hospital would begin legal proceedings to authorize the procedure. The family was extremely reluctant because Mrs. Elbaum had expressed her wishes to the contrary, but they finally consented to the procedure after repeatedly being told that legal proceedings would result unless consent was given. The gastrostomy was performed on September 2, 1986, and two and a half weeks later Mrs. Elbaum was transferred to Grace Plaza.

On the eve of the transfer Mr. Elbaum and his daughter met with Dr. Lester Corn, the nursing home's medical director. According to the Elbaums, they told Dr. Corn that Mrs. Elbaum had specifically stated that she did not wish to be kept alive by ventilator, antibiotics or tubes if she were in a "vegetative-like" state with no hope of recovery. Dr. Corn testified, however, that although he was advised that the family did not wish him to intervene or perform any heroic measures to prolong Mrs. Elbaum's life, he was not asked to remove the gastrointestinal tube.

On September 22 Mr. Elbaum wrote to the nursing home authorizing a Do Not Resuscitate order and also requesting that no antibiotics or drugs be used if Mrs. Elbaum should develop an infection. According to Mr. Elbaum, his wife nonetheless received antibiotics, even though on at least six to twelve different occasions he reiterated that his wife would not want antibiotics or any other form of treatment, including tube feeding. Dr. Corn

stated that antibiotic treatment was necessary to prevent the possible spread of infection to other patients.

On October 6, 1987, Mr. Elbaum wrote to Dr. Corn and Grace Plaza's administrator, Ms. Celia Strow, asking that the gastrointestinal tube be removed in keeping with his wife's expressed wishes. On October 9 Dr. Corn wrote back that withdrawal of the gastrointestinal tube was contrary to the "dedication to the law and to the policies and philosophy of Grace Plaza." From that date on, Mr. Elbaum stopped making payments for his wife's care.

The nursing home attempted, unsuccessfully, to transfer Mrs. Elbaum. In February 1988 Ms. Strow advised Mr. Elbaum that even if there had been irrefutable evidence of Mrs. Elbaum's wishes to forgo tube feeding (which she did not accept), the nursing home would not remove it. She advised Mr. Elbaum that he was in arrears $18,500 and that unless payment was received, legal proceedings would be begun. In June 1988 Mr. Elbaum began a legal action to prevent Grace Plaza and Dr. Corn from providing any life-sustaining treatment, including tube feeding, to his wife. The trial court held a hearing at which Mrs. Elbaum's family testified to the statements she had made about medical treatment.

Mr. Elbaum said that his wife had begun to express her views in response to Karen Ann Quinlan's case. She had stated that if she were in Quinlan's condition, "she would not want to be on a respirator or any other mechanical means, she wanted to die." She had also talked about Sunny Von Bulow and, according to her husband, had said, "I do not want to be sustained as a vegetable, I want to die with some dignity." Her husband also testified that, in response to a family friend's stroke, Mrs. Elbaum had said, "If I am ever in a similar state and it is hopeless, I don't want to be sustained by any tubes or machines or antibiotics." Mrs. Elbaum's sister testified to similar conversations and stated that when their mother, terminally ill with cancer, had been fed through a nasogastric tube, Jean had made her "pledge," that similar measures would not be administered to her if she were ill with no hope of recovery. The pledge had been reiterated after their mother's death and most recently when their mother's tombstone was unveiled, only two weeks before Mrs. Elbaum became ill. Mrs. Elbaum's daughter and son also testified to similar conversations.

The trial court ruled that there was not sufficient evidence to prove that Mrs. Elbaum had made a firm decision not to have tube feeding in her current condition. It also ruled initially, in a separate decision (subsequently reconsidered), that Mr. Elbaum must pay Grace Plaza the amount outstanding, and that the Elbaums could not sustain a legal action alleging that the nursing home had committed a battery by treating Mrs. Elbaum against her wishes.

THE OPINION

The Appellate Division reversed the trial court's decision on the sufficiency of the evidence and held that Mrs. Elbaum's statements of her wishes were enough to satisfy the New York standard of "clear and convincing" evidence that she would not want tube feeding in this condition. The court stated that the fact that Mrs. Elbaum had, while competent, repeatedly extracted a series of promises from her husband and family members, was "highly significant," since it reflected a serious and consistent purpose of mind and an intent to "bind others to effectuate her desires in futuro." The court found

these statements constituted solemn pronouncements similar to those made by Brother Fox (See Choice In Dying fact sheet, In re Eichner (In re Storar), 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266, cert. denied, 454 U.S. 858 (1981).) They also found that the medical conditions and forms of treatment Mrs. Elbaum was contemplating when she made her statements were qualitatively similar to her present condition and the treatment she was receiving.

The court specifically rejected the assertion that Mr. Elbaum was motivated solely by economic factors when he directed ending treatment. And it wrote that the evidence "reflects that despite the receipt of Mr. Elbaum's DNR order and despite Mr. Elbaum's complaints concerning the administration of antibiotics and the use of feeding tubes on his wife, the defendants [Dr. Corn and the nursing home] ignored Mr. Elbaum's demands while simultaneously insisting upon payment for their services." The court rejected Grace Plaza's contention that its interest in maintaining its "ethical integrity" outweighed Mrs. Elbaum's wishes, noting that prevailing ethical standards do not require medical intervention at all costs. The court found it significant that Grace Plaza failed to make its policy known to the Elbaum family until after the family requested removal of the feeding tube.

Finally, the court ruled that if either the Elbaums or Grace Plaza failed within 10 days to effectuate Mrs. Elbaum's transfer to a suitable facility which would accede to her wishes, then Grace Plaza would be required to comply with them.* If no member of its staff was prepared to assist, then Grace Plaza was ordered to permit a physician selected by the Elbaums to enter the facility for the purpose of disconnecting the gastrointestinal tube.

IMPLICATIONS

The case makes clear that thoughtful, repeated oral statements about not wishing to have life-sustaining treatment can constitute "clear and convincing" evidence of a competent decision, as required by New York law. The case also stands for the proposition that, particularly when the nursing home has failed to give notice of a policy against stopping treatment, it may be required to carry out a patient's wishes if no transfer can be arranged.

POSTSCRIPT

Mrs. Elbaum was transferred to a New York hospice where the tube feeding was ended. She died peacefully on August 11, 1989. The trial court, in light of language in the opinion to the effect that families should not have to pay for unwanted treatment, reconsidered its decision on Grace Plaza's application for medical charges and held on January 9, 1990, that the Elbaums did not have to pay for unwanted treatment. It adhered to its original ruling dismissing the battery claims.

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* Mr. Elbaum's health precluded the transfer of his wife home. He had been advised that bringing her home would have a deleterious effect on his physical and psychological well-being.

IN RE BUSALACCHI

No. 73677 (Mo. January 26, 1993)
Missouri Supreme Court

SIGNIFICANT FACTORS

- Persistent vegetative state
- Minor patient

THE CASE

On May 29, 1987, seventeen-year-old Christine Busalacchi was involved in a serious car accident. In the days that followed, a large portion of her brain was removed to relieve pressure and a gastrostomy tube was inserted into her stomach to provide her with nutrition and hydration. In December of 1987, Christine was transferred from the hospital to the Missouri Rehabilitation Center (MRC), a state facility. At MRC Christine was diagnosed as being in a persistent vegetative state.

In December of 1990, Christine's father, Peter Busalacchi, attempted to move Christine to a facility outside of Missouri where her feeding tube could be removed legally. MRC officials and the Missouri Department of Health (MDOH) filed this action to prevent Christine's transfer. The trial court ruled in favor of Mr. Busalacchi on three grounds. First, the court ruled that Missouri law does not prohibit a father from moving his daughter to another state. Second, the court ruled that Christine was entitled to the protection of other states' laws under the full faith and credit clause of the federal constitution. Finally, the court held that a minor patient's family and physician may determine what constitutes appropriate medical treatment for the child.

The MDOH appealed, arguing that the court should have required clear and convincing evidence that Christine would not want to continue to receive the tube feeding. In a confusing move, the Supreme Court of Missouri remanded the case for a determination of Christine's medical condition, including whether she was in a persistent vegetative state. Additionally, it ordered the trial court to make "such additional findings as the court may deem necessary to dispose of all related issues. . . ."

On remand, the trial court found that Christine was in a persistent vegetative state and that her condition was permanent, with no chance of significant improvement. The trial court denied the MDOH's request to declare Christine a "developmentally disabled person" entitled to special legal protection, and also denied the MDOH's request to restrict her father's authority to discontinue her tube feedings.

The Attorney General, William L. Webster, appealed this ruling to the Missouri Supreme Court. However, before the appeal could be heard, Missouri held elections for attorney general, and Webster was defeated. The new Attorney General, Jay Nixon, petitioned the Supreme Court to dismiss the appeal voluntarily. This motion was granted in January, 1993. Three days later, a woman describing herself as a right-to-life advocate petitioned to replace Christine's father as Christine's guardian and obtained a temporary restraining

order to prevent removal of Christine's feeding tube. The guardianship petition was dismissed shortly after it was filed and the court refused to extend the restraining order.

IMPLICATIONS

Because the Missouri Supreme Court dismissed the appeal, the decision of the trial court is left standing. Under this ruling, the guardian of a minor patient has the authority to make life-sustaining medical treatment decisions on the patient's behalf; the clear and convincing standard does not apply to minor patients. However, because this is only a trial court ruling, it is not binding on subsequent court decisions.

497 U.S. 261(1990)
United States Supreme Court

SIGNIFICANT FACTORS

- Persistent vegetative state
- Artificial nutrition and hydration
- Clear and convincing evidence
- Constitutional right to refuse treatment

THE CASE

On January 11, 1983, Nancy Beth Cruzan, then twenty-five, was found lying unconscious near her overturned car. Paramedics began efforts to revive her and transported her to Freeman Hospital in Joplin, MO. There she was diagnosed as having a lacerated liver and probable cerebral contusion compounded by anoxia (deprivation of oxygen) estimated at twelve to fourteen minutes. A gastrostomy tube was implanted on February 7 to supply nutrition and hydration, and rehabilitation efforts were begun, but without success. Ms. Cruzan was then transferred to the Missouri Rehabilitation Center in Mount Vernon, where she remained in a persistent vegetative state, in which it was estimated she could live for some thirty years. Her parents (as co-guardians) asked hospital employees to end the gastrostomy feedings. The request refused, the Cruzans filed a declaratory judgment action seeking judicial sanction of their instructions. They were represented by a volunteer attorney from the American Civil Liberties Union,,William Colby, who is a member of a Kansas City law firm.

The trial court approved the parents' request, finding that there was evidence that strongly suggested Ms. Cruzan "would not wish to continue with nutrition and hydration," that she had a "right to liberty," and that to deny her co-guardians authority to act would deprive her of equal protection of the law. The state and Ms. Cruzan's guardian ad litem* appealed to the Missouri Supreme Court, which reversed in a 4-to-3 decision.

The Missouri Supreme Court viewed the case as presenting a single issue: May a guardian order that food and water be withheld from an incompetent ward who is in a persistent vegetative state, but who is otherwise alive and not terminally ill? The court stated that this was a case "in which we are asked to allow the medical profession to make Nancy die by starvation and dehydration." Ruling that a guardian could not order tube feeding stopped, the court held that the evidence offered at trial as to Ms. Cruzan's wishes was inherently unreliable.

* The guardian ad litem appealed because it was the first case of its kind in Missouri, although he believed it was in Ms. Cruzan's best interest to have the tube feeding discontinued.

THE OPINION

On June 25, 1990, the United States Supreme Court, by a 5-4 vote, upheld the Missouri Supreme Court's decision. It ruled that Missouri, if it chooses, can require clear and convincing evidence that Nancy Cruzan would have decided to forgo life support before allowing the exercise of her constitutionally protected right to refuse unwanted medical treatment.

In so ruling the Court "assumed" for the purposes of the case that a person's right to refuse treatment (including tube feeding) is guaranteed by the liberty clause in the United States Constitution.* The Court noted that "the principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions." The majority specifically refused to analyze the case in terms of a constitutional right to privacy. While giving the right to refuse treatment a constitutional dimension for the first time, it acknowledged that the state also has a general interest in preserving the life of its citizens and a particular interest in safeguarding the personal element in a "right to die" case. "The choice between life and death is a deeply personal decision of obvious and overwhelming finality." The Court's majority ruled that the state may legitimately seek to ensure that the choice is the patient's by imposing heightened evidentiary requirements. This meant, in Ms. Cruzan's case, that the federal Constitution would not forbid Missouri's decision that she had not left adequate evidence of her wishes. The state of Missouri is permitted to ask for more detail and certainty than there was in Ms. Cruzan's case.

The Court asserted that the requirement of "clear and convincing" evidence is a "procedural safeguard to assure that the action of the surrogate conforms as best it may to the wishes expressed by the patient while competent." The only question the Supreme Court addressed was "whether the United States Constitution forbids the establishment of this procedural requirement by the State. We hold that it does not."

The Court advanced a number of legitimate state interests implicated in the clear and convincing standard, such as the general interest in the preservation of life and guarding against potential abuses by ensuring that the choice was the patient's. The court held that the evidentiary requirements permissibly furthered these legitimate state interests. Observing that the standard of proof reflects a decision about how to allocate the risk of error, the Court held that a state may permissibly place the burden on those seeking to terminate treatment. Acknowledging that the standard may "frustrate the effectuation of the not-fully-expressed desires of Nancy Cruzan," the majority observed that other legal rules, such as requiring that property wills be in writing, may sometimes not work "faultlessly," but they do further other important interests.

The majority opinion rejected the argument that the Constitution required "substituted judgment" as the best approximation of the patient's wishes. In an important footnote, the majority opinion specifically said that they were not addressing the question of whether a state might be required to defer to the decision of a surrogate if there was evidence that the patient had chosen that individual to make life-support decisions. This footnote suggests that a

* By "assuming" rather than "holding" or ruling, the Court left itself room to refine or adapt the statement in future cases.

majority of the Court would require, as a matter of constitutional law, that the instructions of a formally appointed health care agent be followed.

There were four separate opinions by the Court. Chief Justice Rehnquist delivered the majority opinion, in which White, O'Connor, Scalia and Kennedy joined. Brennan filed a dissenting opinion in which Marshall and Blackmun joined and Stevens filed a separate dissenting opinion. In addition, Justices O'Connor and Scalia filed separate opinions concurring with the majority (i.e. agreeing with the result but for different reasons). The reasoning of the opinions provides guidance to the lower courts and for that reason bears some analysis.

Justice O'Connor wrote separately to clarify why she agreed with the majority that the refusal of what she called "artificially delivered food and water" is encompassed within the liberty interest, as well as to emphasize that the Court was not addressing whether a state could be compelled to follow the directions of a surrogate. Her opinion is particularly important because she was the "swing vote" in this case, providing the fifth vote for the majority opinion.

With more color than the majority opinion, O'Connor described the Supreme Court's and the Constitution's repugnance for state incursions into the body. A seriously ill or dying patient whose wishes are not honored may "feel a captive of the machinery required for life-sustaining measures or other medical interventions." She noted that whether or not the artificial provision of nutrition and hydration is called medical treatment, the methods of providing it all "involve some degree of intrusion or restraint." She also wrote separately to emphasize that the court had not decided whether the state must give effect to a decision by a proxy who had been appointed by the patient. In her view, a proxy's decision might well be constitutionally protected, a significant reiteration of Justice Rehnquist's footnote. Finally, she emphasized that this opinion had held only that one state's (Missouri's) practice did not violate the Constitution. The "more challenging task" of crafting appropriate procedures for safeguarding liberty interests in this area is, in the first instance, "entrusted to the laboratory of the States."

Justice Scalia's concurring opinion was quite different. He would have preferred the Court to announce that federal courts have no business deciding this case, and that the issue of the "right to die" is solely a state matter. Unlike all eight of the other Justices, Scalia simply did not see any constitutional dimension to the issue. He noted that there is nothing in the Constitution which would determine where to draw lines: "[T]he point at which life becomes 'worthless' and the point at which the means necessary to preserve it become 'extraordinary' or 'inappropriate' are neither set forth in the Constitution nor known to the nine Justices of this Court any better than they are known to nine people picked at random from the Kansas City telephone directory." The general thrust of Justice Scalia's opinion was to equate all refusal of treatment with suicide.

THE DISSENT

Justice Brennan dissented, joined by Marshall and Blackmun. Brennan asserted that the "improperly biased procedural obstacles imposed by the Missouri Supreme Court" acted to prevent the exercise of Ms. Cruzan's "fundamental right to be free of unwanted artificial nutrition and hydration." For Brennan, Marshall and Blackmun, the question is whether

Missouri's action prevented the exercise of a fundamental individual right. If a state requirement "significantly interferes" with the exercise of a right, that requirement must be supported by sufficiently important state interests and must be closely tailored to effectuate *only those interests*. To Brennan there is no legitimate general state interest in someone's life that could be abstracted from the interest of the person living that life: therefore Missouri, or any other state, may impose only those procedural requirements that are designed to accurately determine Ms. Cruzan's wishes.

Brennan also pointed out that in other Supreme Court cases it was *the state* which was required to show clear and convincing evidence before an individual's rights could be curtailed, and that in this case the majority had turned that rule on its head by requiring clear and convincing evidence from *the person* before her individual fundamental rights could be exercised.

To Brennan, the rule adopted by Missouri and upheld by the Supreme Court which discounts both the opinions of those closest to the patient and that of a state appointed guardian ad litem, *lessens* the likelihood of an accurate determination of the patient's wishes. Brennan noted that, "Where, as here, the family members, friends, doctors and guardians ad litem agree, it is not because the process has failed, as the majority suggests ... it is because there is no genuine dispute as to Nancy's preference." Discretion to determine an incompetent patient's treatment choice should be left to the state so long as the state is seeking in a reliable manner to determine what the person would want. But states cannot impose procedures that would prejudice the decision. They can require court proceedings or the appointment of an impartial guardian ad litem. To Brennan, if the patient's wishes are not known, states are also constitutionally required to either repose the choice with the person whom the patient would most likely have chosen as a proxy, or leave the decision with the patient's family. Brennan here goes further than O'Connor, who suggested only that there would be constitutional protection for an *appointed* proxy's decision.

Justice Stevens wrote a separate dissent to voice his view that the Constitution requires the state to care for Nancy Cruzan's life in a way that gives appropriate respect to her own best interests. In so doing, Stevens moved completely away from the rest of the Court. The eight other Justices had, in one way or another, looked to subjective individual choice as the guiding principle. Stevens instead grounded his approach in the objective determination of what would be best. He wrote movingly about death and the difficulty of fitting a discussion of it into the structure of legal analysis.

To Stevens, Missouri's policy is fundamentally an effort to define life rather than to protect it. He questions seriously whether the mere persistence of the bodies of patients like Nancy Cruzan (who have no consciousness and no chance of recovery) is "life" as the word is commonly understood. He also questions the way in which the term "life" is used in both the Constitution and the Declaration of Independence. To Stevens, the critical question is not how to prove the controlling facts but rather what proven facts should be controlling. To him the factual information needed is clear: what constitutes the best interest of the individual when buttressed by the interests of all related third parties.

Stevens would define "life" from Ms. Cruzan's point of view. Her life would expire when her biological existence ceased serving any of her own interests,

unless there was any evidence that she herself defined "life" to encompass every form of biological persistence by a human being. He also expressed concern about the possibility of a shifting state definition of "quality of life," which could result in a denial of care.

IMPLICATIONS

For the first time, by an 8-1 vote, the Supreme Court articulated the existence of a constitutionally protected liberty interest that encompasses a right to refuse life-sustaining treatment, including tube feeding. For competent patients it would appear that any limitation on the individual's right to refuse treatment would be very carefully scrutinized. For incompetent patients, the majority left the job of crafting the procedures to the states and found Missouri's evidentiary standard permissible.

The Court treated tube feeding as one of many forms of life-sustaining medical treatment, which can cause an invasion of a liberty interest. In so doing it accepted the statements of the American Medical Association and other leading medical organizations, as well as of the majority of courts, which had taken the same approach. State statutes that do not include tube feeding as a medical treatment that may be rejected, and that purport to be the only method for refusing treatment, may now be unconstitutional.

Both the majority opinion and Justice O'Connor's concurrence suggested that an appointed surrogate would have the same right to refuse treatment as a competent patient. This means that a majority of the court would probably find it unconstitutional to ignore the treatment directives of a health care agent. This language raises serious questions about the constitutionality of durable power of attorney for health care statutes that attempt to limit the agent's powers to certain conditions or treatments.

The court suggested that requiring judicial proceedings would be constitutionally permissible and seemed to condone the appointment of a guardian ad litem as a protection against potential abuse. None of these procedural possibilities would be constitutionally required, but it was implied that they would be a matter of state discretion.

POSTSCRIPT

On November 1, 1990, the Cruzans returned to the trial court with additional evidence from three new witnesses concerning Nancy's previously expressed wishes. In those discussions Nancy indicated that she did not want to be force-fed or machine dependent "like a vegetable." The guardians ad litem did not oppose the removal of tube feeding and elicited testimony from her doctor that her best interests were not being served by continued feeding. The Attorney General's office no longer opposed the request of the family, asserting that the state's interest in clarifying the law had been satisfied.

On December 14, 1990, Judge Teel, upon finding by clear and convincing evidence that Nancy Cruzan, if mentally able, would terminate her nutrition and hydration, authorized the removal of tube feeding. Her feeding tube was removed two hours later. Nancy Cruzan died peacefully on December 26, 1990.

IN RE QUINLAN

70 N.J. 10, 355 A.2d 647, cert. denied sub nom. Garger v. New Jersey, 429 U.S. 922 (1976), overruled in part, In re Conroy, 98 N.J. 321, 486 A.2d 1209 (1985)
New Jersey Supreme Court

SIGNIFICANT FACTORS

- Persistent vegetative state
- Ventilator
- Constitutional right of privacy

THE CASE

Karen Ann Quinlan, twenty-one, a New Jersey resident, was in a persistent vegetative state as a result of respiratory arrest in April 1975. Her father, Joseph Quinlan, sought court appointment as her guardian. In addition, he asked for the power to authorize the "discontinuance of all extraordinary procedures" for sustaining his daughter's "vital processes."

The lower court refused to grant the requested relief, arguing that decisions should be left in the hands of the medical profession. The father appealed the decision to the New Jersey Supreme Court.

THE OPINION

In a landmark decision handed down on March 31, 1976, the New Jersey Supreme Court reversed the lower court and granted the relief sought by Karen Quinlan's father. It upheld Karen Quinlan's constitutional right of privacy,* ruling that the "termination of treatment pursuant to the right of privacy is, within the limitations of this case, ipso facto lawful." In balancing any state interest in regard to such a right, the court cited Miss Quinlan's dim prognosis and noted:

> We think that the State's interest [in preservation of life] weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's rights overcome the State interest.

The court further concluded that "Karen's right of privacy may be asserted on her behalf by her guardian under the peculiar circumstances here present."

The court addressed the arguments Mr. Quinlan advanced on other constitutional grounds and found inapplicable those based on free exercise of religion and 8th Amendment protection against cruel and unusual punishment.

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*There has been judicial disagreement as to the exact constitutional source of the right of privacy. In its 1973 decision in Roe v. Wade (410 U.S. 113), the U.S. Supreme Court preferred to find the right of privacy in the 14th Amendment's concept of personal liberty and restriction upon state action, but it also noted that the Court and individual Justices have found such a right in the 1st, 4th, 5th and 9th amendments and in the "penumbra" of the Bill of Rights.

The court appointed Mr. Quinlan his daughter's guardian, transferring to him the choice of attending physician. The court then summarized its relief by stating that if Karen's guardian, family, and attending physicians concur that "there is no reasonable possibility of Karen ever emerging from her present comatose condition to a cognitive, sapient state and that life-support apparatus... should be discontinued, they shall consult with the hospital 'Ethics Committee' or a like body of the hospital where Karen is being hospitalized." If that consultative body agrees with the prognosis, life-support may be withdrawn "without any civil or criminal liability...on the part of any participant...."

IMPLICATIONS

The Quinlan case represents the first judicial decision to enunciate the constitutional right of privacy as the basis for withholding or withdrawing life-support from a terminal patient. It leaves decisionmaking to the guardian, family, and physician, with review by a hospital "Ethics Committee" but without the need for automatic judicial review.

The court declared: "Decision-making within health care...should be controlled primarily within the patient-doctor-family relationship." The necessity of applying to the courts to confirm such decisions would be "inappropriate" and "impossibly cumbersome."

POSTSCRIPT

Karen Quinlan was removed from the respirator in May 1976 and was transferred to a New Jersey nursing home. For nine years she remained there in a vegetative state, reportedly weighing under seventy pounds and sustained by nasogastric feedings and antibiotics. She died in June 1985.

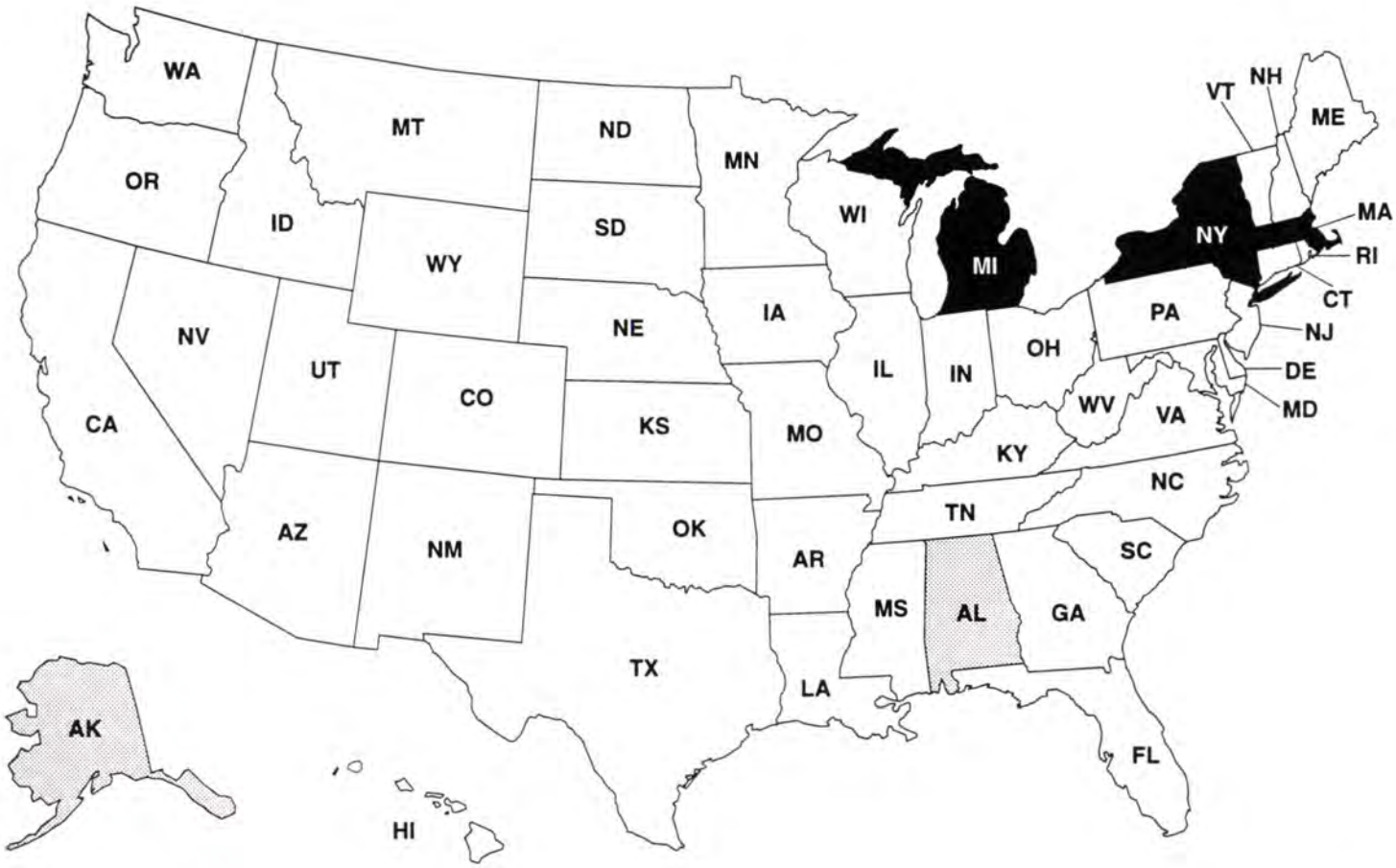
CHOOSE . . .
OR SOMEONE ELSE WILL!

STATE MAPS

CHOICE IN DYING 1-800-989-WILL

June 1993

State Statutes Governing Living Wills and Appointment of Health Care Agents



Jurisdictions with legislation that authorizes both living wills and the appointment of a health care agent (**the District of Columbia and 45 states: Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin and Wyoming**).

States with legislation that authorizes only living wills (**2 states: Alabama and Alaska).**

States with legislation that authorizes only the appointment of a health care agent (**3 states: Massachusetts, Michigan and New York**).

Note: The specifics of living will and health care agent legislation vary greatly from state to state. In addition, many states also have court-made law that affects residents' rights. For information about specific state laws, please contact Choice In Dying.

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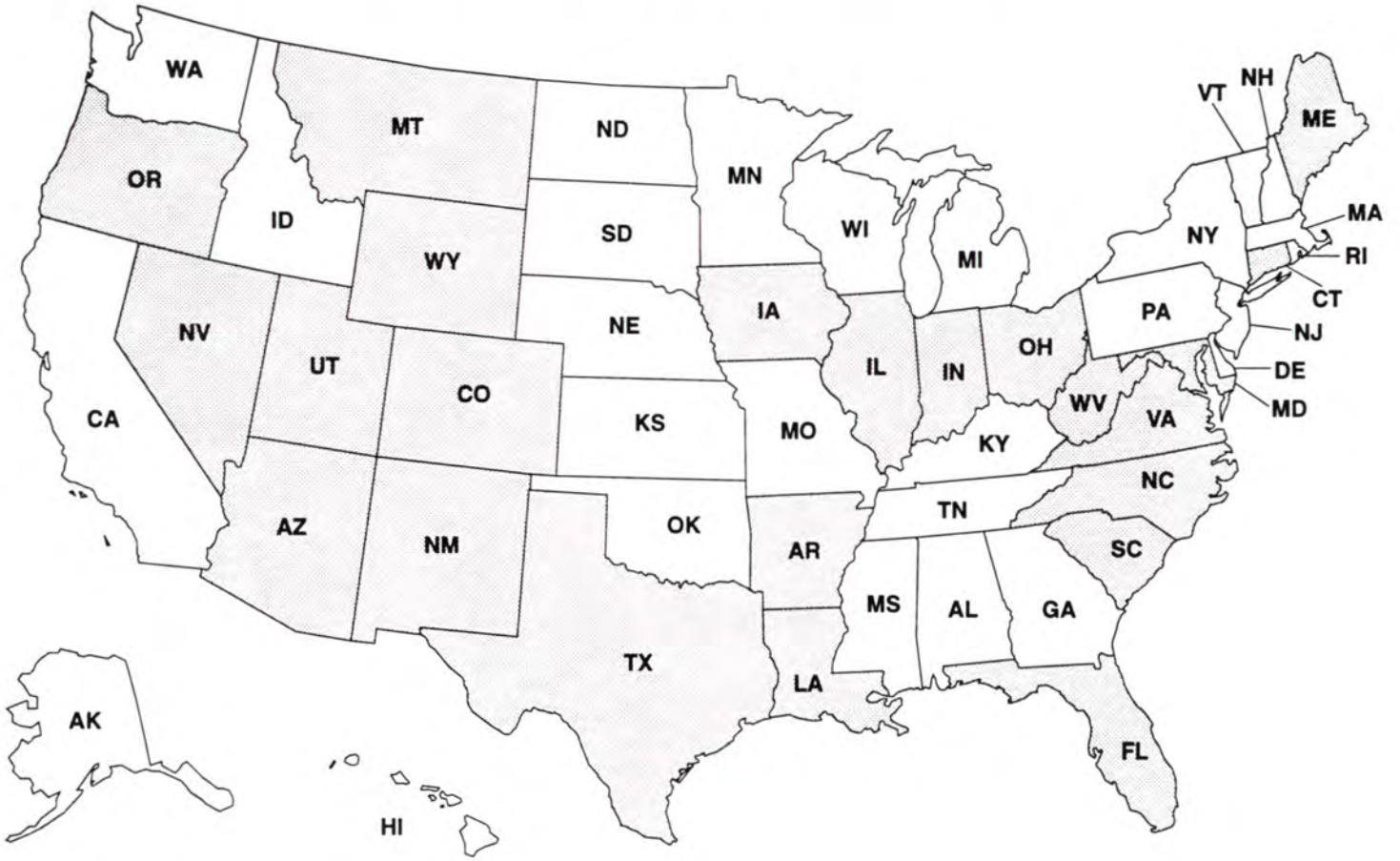
June 1993

State Statutes Governing Surrogate Decisionmaking



Jurisdictions with statutes authorizing surrogate decisionmaking in the absence of advance directives (**the District of Columbia and 23 states: Arizona, Arkansas, Colorado, Connecticut, Florida, Illinois, Indiana, Iowa, Louisiana, Maine, Maryland, Montana, Nevada, New Mexico, North Carolina, Ohio, Oregon, South Carolina, Texas, Utah, Virginia, West Virginia and Wyoming**).

States without statutes authorizing surrogate decisionmaking (**27 states: Alabama, Alaska, California, Delaware, Georgia, Hawaii, Idaho, Kansas, Kentucky, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nebraska, New Hampshire, New Jersey, New York, North Dakota, Oklahoma, Pennsylvania, Rhode Island, South Dakota, Tennessee, Vermont, Washington and Wisconsin**).

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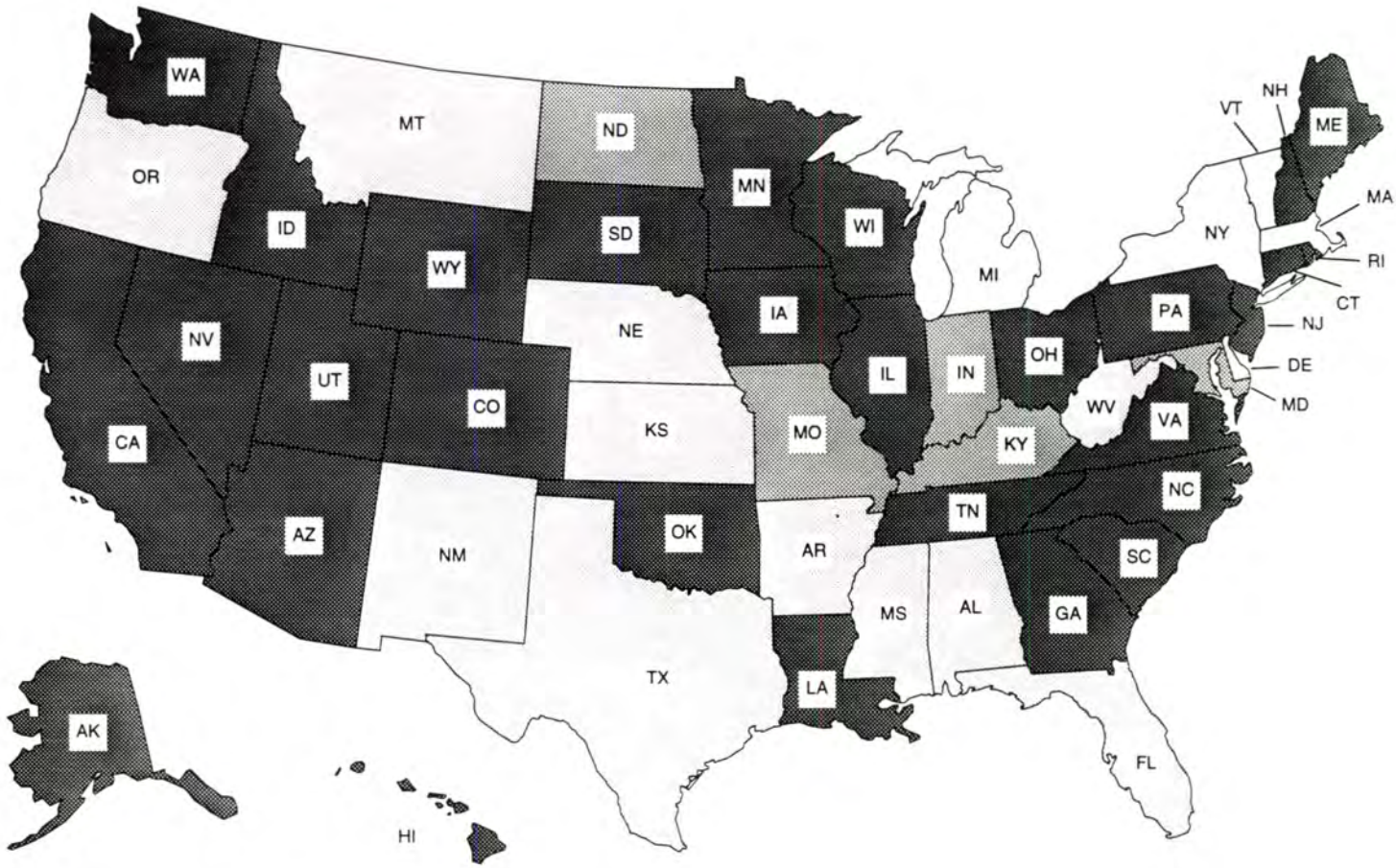
March 1993

Artificial Nutrition and Hydration in Living Will Statutes



States with living will statutes that **permit** individuals to refuse artificial nutrition and hydration through their living wills (**29 states: Alaska, Arizona**[1]**, California, Colorado, Connecticut, Georgia, Hawaii, Idaho, Illinois**[2]**, Iowa, Louisiana, Maine, Minnesota, Nevada, New Jersey, New Hampshire, North Carolina, Ohio, Oklahoma, Pennsylvania, Rhode Island, South Carolina, South Dakota, Tennessee, Utah, Virginia, Washington, Wisconsin and Wyoming**).

States with living will statutes that **require** the provision of nutrition and hydration except in very limited circumstances (**5 states: Indiana**[3]**, Kentucky, Maryland**[4]**, Missouri**[3] **and North Dakota**).

Jurisdictions whose living will statutes do not explicitly permit the refusal of, or explicitly require the application of artificial nutrition and hydration (**the District of Columbia and 13 states: Alabama, Arkansas, Delaware, Florida, Kansas, Mississippi, Montana, Nebraska, New Mexico, Oregon, Texas, Vermont and West Virginia**).

States without living will statutes (**3 states: Massachusetts, Michigan and New York**).

[1] The authority to withhold or withdraw artificial nutrition and hydration is only explicitly mentioned in the sample document.
[2] Artificial nutrition and hydration cannot be withheld or withdrawn if the resulting death is due to starvation or dehydration.
[3] The medical power of attorney statutes in Indiana and Missouri permit appointed agents to refuse artificial nutrition and hydration on behalf of the principal.
[4] Although the act requires the "administration of food and water," a Maryland Attorney General's Opinion has stated that artificial nutrition and hydration may be refused through a living will.

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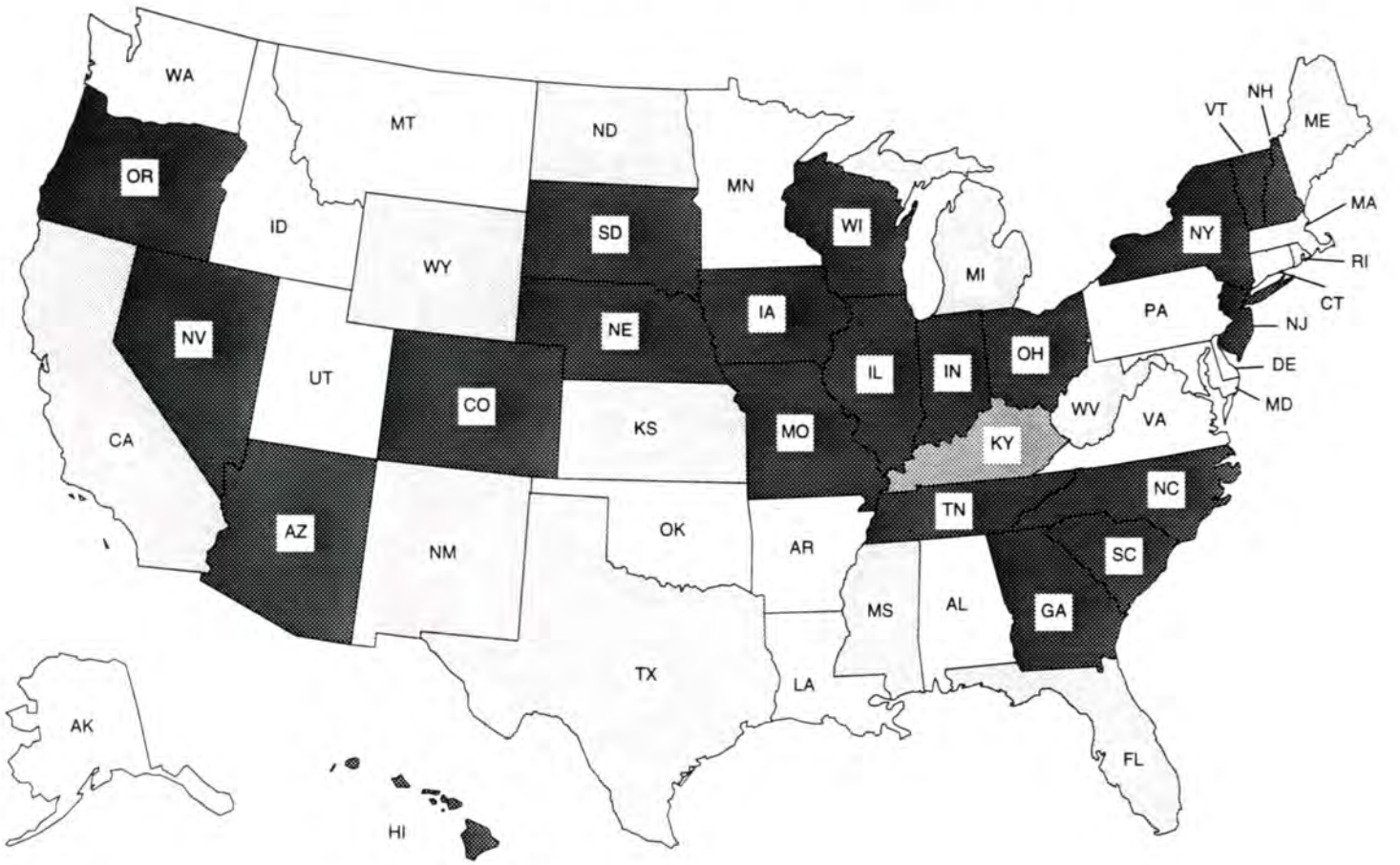
March 1993

Artificial Nutrition and Hydration in Medical Durable Power of Attorney Statutes



States with medical power of attorney statutes that **permit** health care agents to order the withholding or withdrawal of artificial nutrition and hydration (**21 states: Arizona, Colorado, Georgia, Hawaii, Illinois, Indiana, Iowa, Missouri, Nebraska, Nevada, New Hampshire, New Jersey, New York[1], North Carolina, Ohio, Oregon[2], South Carolina, South Dakota, Tennessee, Vermont and Wisconsin**).

States with medical power of attorney statutes that explicitly **require** the provision of nutrition and hydration except in very limited circumstances (**1 state: Kentucky**).

Jurisdictions whose medical power of attorney statutes do not explicitly permit the refusal of, or explicitly require the application of artificial nutrition and hydration (**the District of Columbia and 13 states: California, Florida, Kansas, Maine, Massachusetts, Michigan, Mississippi, New Mexico, North Dakota, Rhode Island, Texas, West Virginia and Wyoming**).

States without medical power of attorney statutes (**15 states: Alabama, Alaska, Arkansas, Connecticut, Delaware, Idaho, Louisiana, Maryland, Minnesota, Montana, Oklahoma, Pennsylvania, Utah, Virginia and Washington**).

1 Agents are permitted to order the withholding or withdrawal of artificial nutrition and hydration only if they know the wishes of the principal concerning such action.

2 Agents are permitted to order the withholding or withdrawal of artificial nutrition and hydration only if the principal had expressly rejected artificial nutrition and hydration before incompetence.

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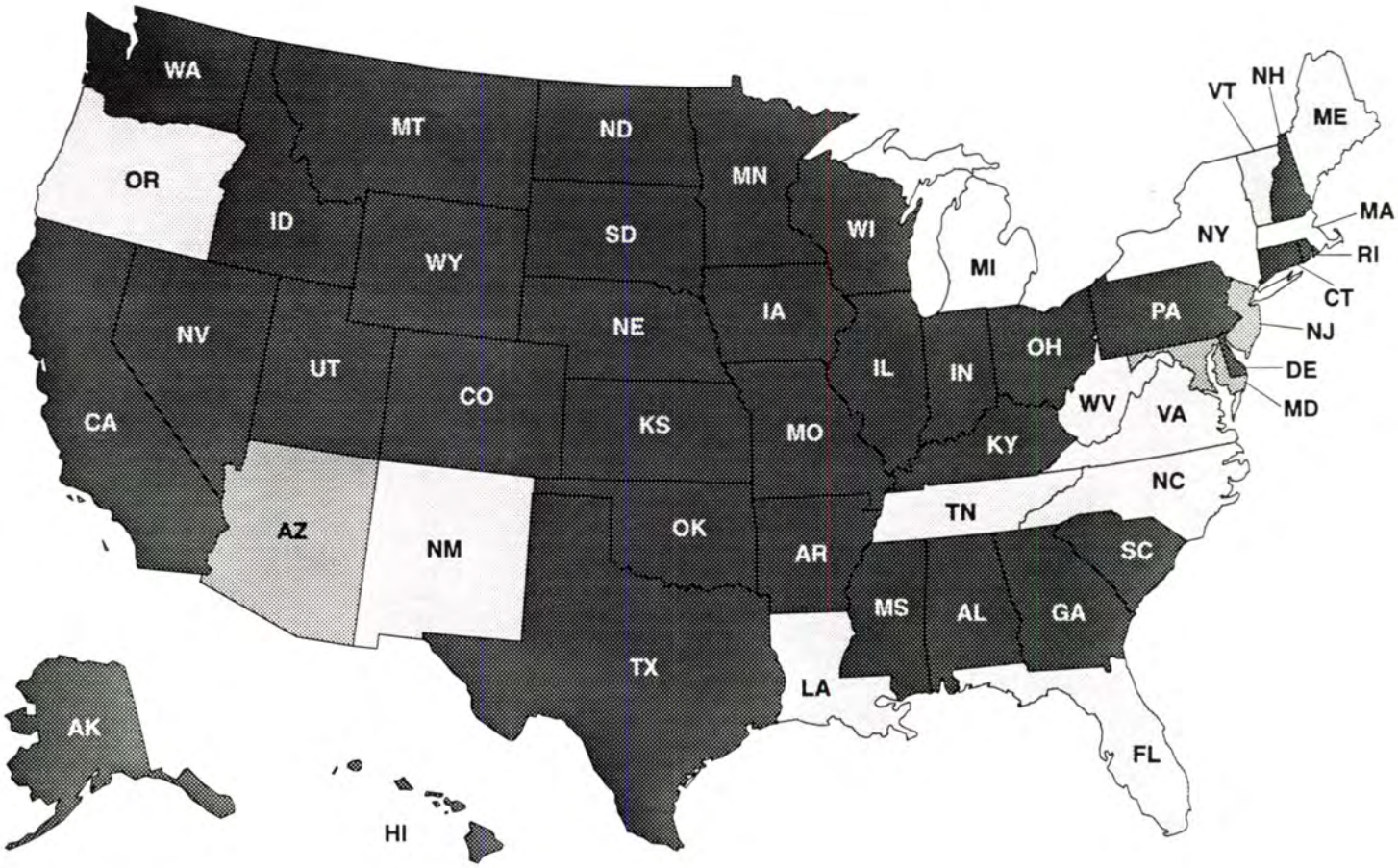
September 1993

Pregnancy Restrictions in Living Will Statutes



States with living will statutes that explicitly forbid the withholding or withdrawal of life support from pregnant patients (**34 states: Alabama, Alaska[1], Arkansas[1], California, Colorado[2], Connecticut, Delaware, Georgia[3], Hawaii, Idaho, Illinois[1], Indiana, Iowa[1], Kansas[1], Kentucky, Minnesota[1], Mississippi, Missouri, Montana[1], Nebraska[1], Nevada[1], New Hampshire, North Dakota, Ohio, Oklahoma, Pennsylvania[1], Rhode Island[1], South Carolina, South Dakota[1], Texas, Utah, Washington, Wisconsin and Wyoming**).

States with living will statutes that permit the principal to choose to refuse life support if she is pregnant (**3 states: Arizona, Maryland and New Jersey**).

Jurisdictions whose living will statutes make no mention of pregnancy (**the District of Columbia and 10 states: Florida, Louisiana, Maine, New Mexico, North Carolina, Oregon, Tennessee, Vermont, Virginia and West Virginia**).

States without a living will statute (**3 states: Massachusetts, Michigan and New York**).

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[1] Life support cannot be withheld/withdrawn if the fetus can develop to the point of live birth with continued life support.

[2] Life support cannot be withheld/withdrawn if the fetus is viable.

[3] Explicitly permits individuals to choose to have living will honored during pregnancy, but only until the point of viability.

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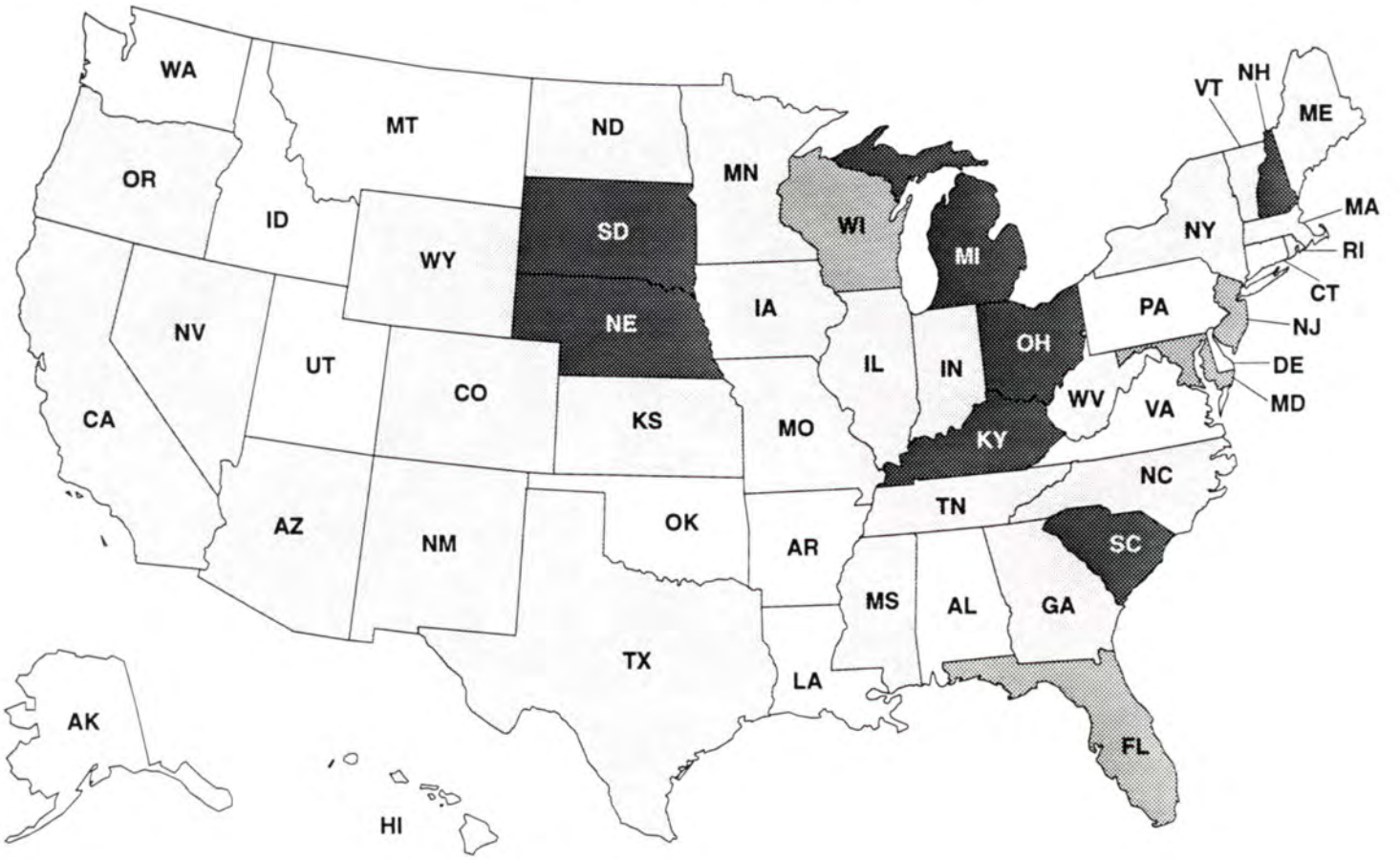
September 1993

Pregnancy Restrictions in Medical Power of Attorney Statutes



States with medical power of attorney statutes that explicitly forbid a health care agent from ordering the withholding or withdrawal of life support from pregnant patients (**7 states: Kentucky*, Michigan, Nebraska*, New Hampshire*, Ohio*, South Carolina and South Dakota**).

States with medical power of attorney statutes that permit the principal to choose whether her agent can withhold or withdraw life support if she is pregnant (**4 states: Florida, Maryland, New Jersey and Wisconsin**).

Jurisdictions whose medical power of attorney statutes make no mention of pregnancy (**the District of Columbia and 26 states: Arizona, California, Colorado, Georgia, Hawaii, Illinois, Indiana, Iowa, Kansas, Maine, Minnesota, Massachusetts, Mississippi, Missouri, Nevada, New Mexico, New York, North Carolina, North Dakota, Oregon, Rhode Island, Tennessee, Texas, Vermont, West Virginia and Wyoming**).

States that do not have medical power of attorney statutes (**13 states: Alabama, Alaska, Arkansas, Connecticut, Delaware, Idaho, Louisiana, Montana, Oklahoma, Pennsylvania, Utah, Virginia and Washington**).

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* Life support must be continued unless it is unlikely that the fetus will develop to the point of live birth.

Note: This publication addresses only health care agents appointed through medical power of attorney statutes. Some living will statutes also permit the appointment of health care agents; however, these agents would then be bound by any pregnancy restriction contained in the living will act.

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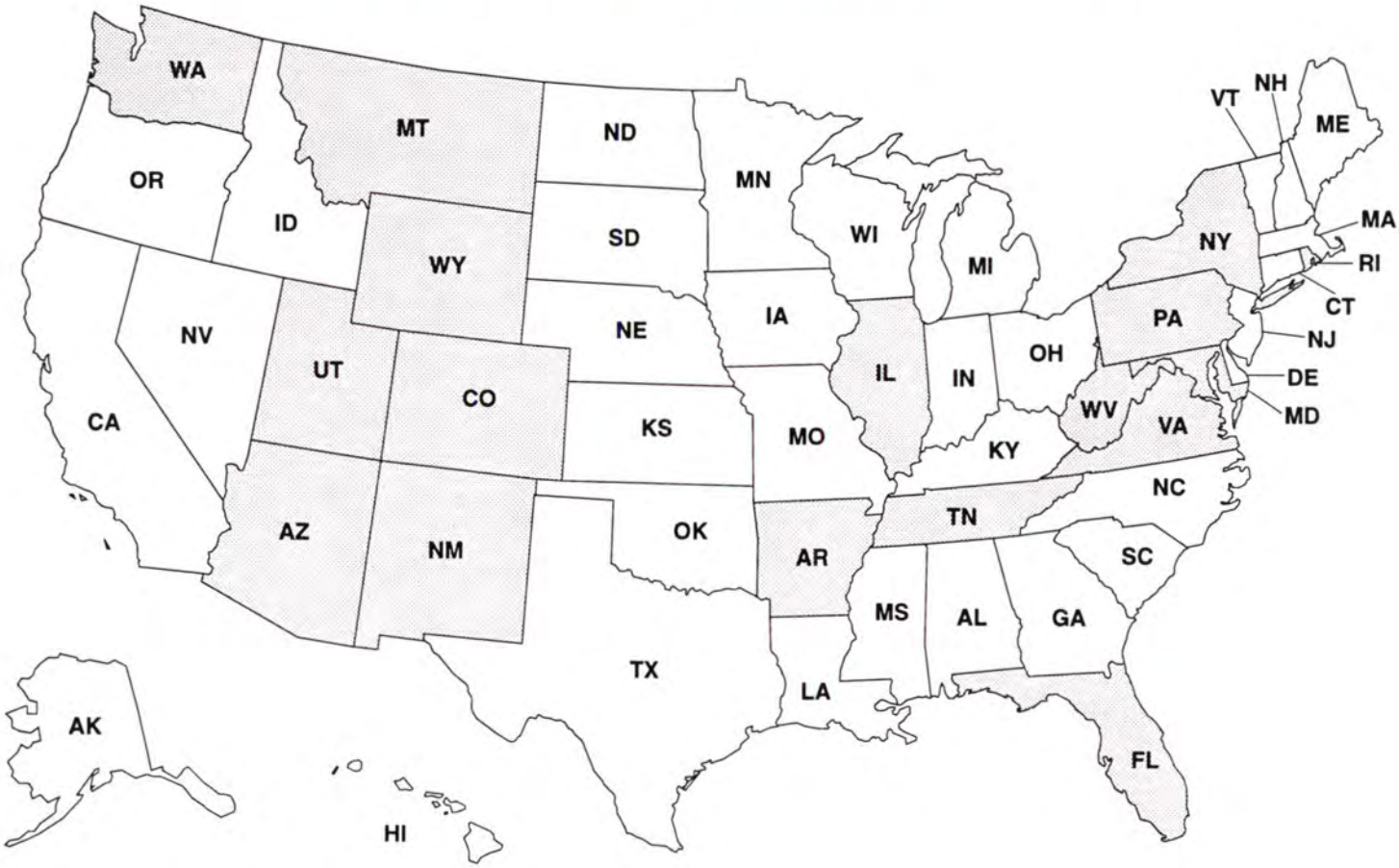
June 1993

State Statutes Governing Nonhospital Do-Not-Resuscitate Orders



States with statutes authorizing nonhospital DNR orders (**17 states: Arizona, Arkansas, Colorado, Florida, Illinois, Maryland, Montana, New Mexico, New York, Pennsylvania, Rhode Island, Tennessee, Utah, Virginia, Washington, West Virginia and Wyoming**).

Jurisdictions without statutes authorizing nonhospital DNR orders (**the District of Columbia and 33 states: Alabama, Alaska, California, Connecticut, Delaware, Georgia, Hawaii, Idaho, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Hampshire, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, South Carolina, South Dakota, Texas, Vermont and Wisconsin**).

Note: This map refers to statutes that address DNR orders in the nonhospital and interfacility settings only. Some of these same statutes explicitly apply also to inpatient situations. However, most hospitals already have institutional policies regarding DNR orders, in compliance with the accreditation standards of the Joint Commission on Accreditation of Hospitals. Thus, we have not provided any information in this publication concerning DNR orders within health care institutions. For information about specific state laws, please contact Choice In Dying.

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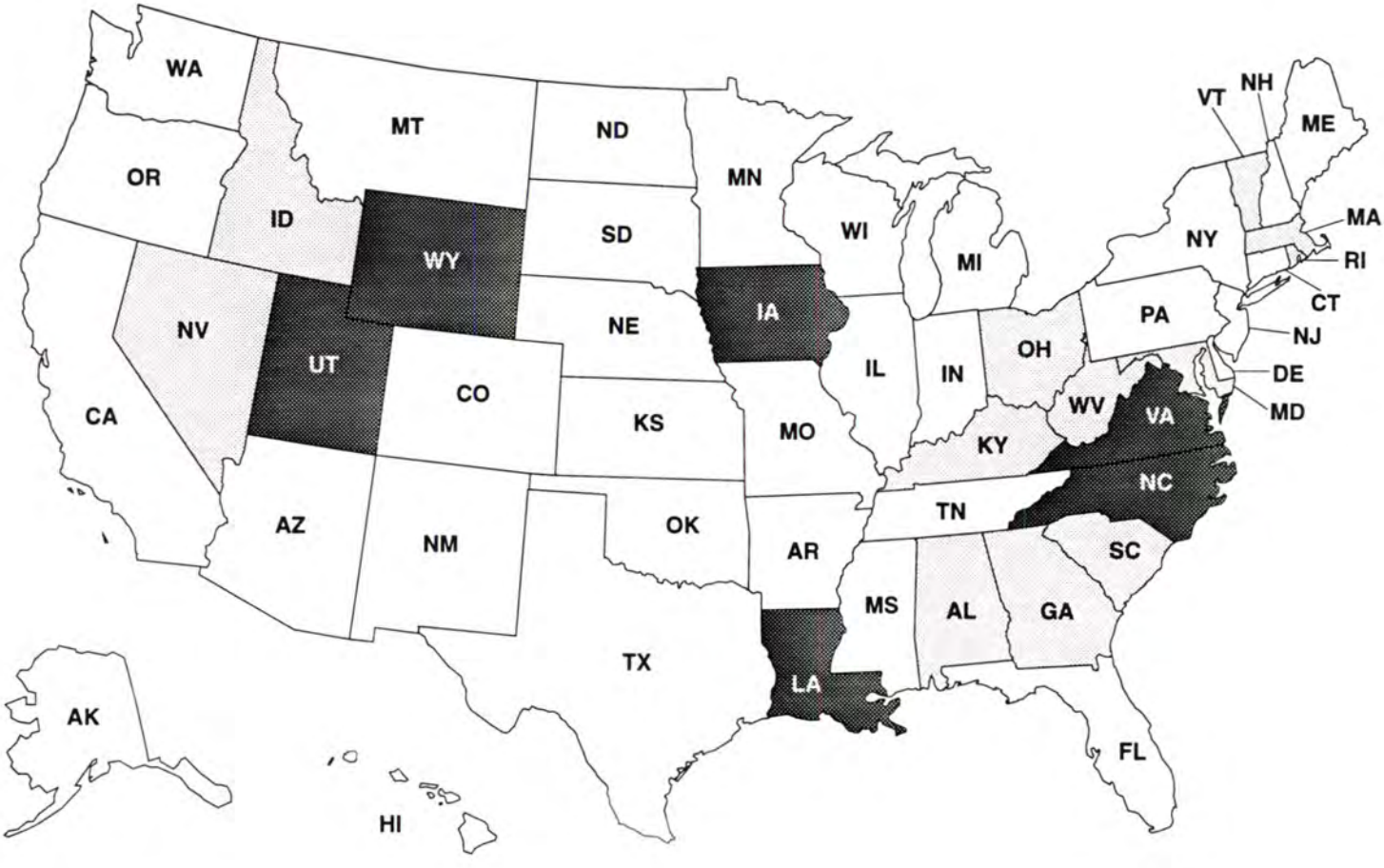
October 1993

Assisted-Suicide Laws in the United States



States with statutes that explicitly criminalize assisted suicide: (**32 states: Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Hawaii, Illinois, Indiana, Kansas, Maine, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, New Hampshire, New Jersey, New Mexico, New York, North Dakota, Oklahoma, Oregon, Pennsylvania, South Dakota, Tennessee, Texas, Washington and Wisconsin**).

Jurisdictions that criminalize assisted suicide through the common law of crimes (**the District of Columbia and 12 states: Alabama, Georgia, Idaho, Kentucky, Maryland, Massachusetts, Nevada, Ohio, Rhode Island, South Carolina, Vermont and West Virginia**).

States in which the law is unclear concerning the legality of assisted suicide (**6 states: Iowa[1], Louisiana[2], North Carolina[3], Utah[3], Virginia[1] and Wyoming[3]**).

---

[1] Case law exists which may or may not be applicable to assisted suicide.

[2] State constitution stipulates that "no law shall subject any person to euthanasia."

[3] State has abolished the common law of crimes and therefore do not explicitly prohibit assisted suicide.

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MEDICARE TO STOP PUSHING PATIENTS TO ENTER H.M.O.'S

GREATER COSTS ARE SEEN

In Discovery With Bearing on Health Plan, Study Finds Flaw in Setting Payment

By ROBERT PEAR
Special to The New York Times

WASHINGTON, Dec. 26 — In a significant policy change, Clinton Administration officials say they will not prod elderly Medicare patients to join health maintenance organizations, in part because they have discovered that the Government loses money on people enrolled in such private health plans.

Bruce C. Vladeck, head of the Federal Health Care Financing Administration, which runs Medicare, said he would not aggressively promote H.M.O.'s for beneficiaries until he could guarantee consistent high-quality care and had a better way of paying for it.

"Our payment methodology is so primitive that it doesn't save money," Mr. Vladeck said in an interview. "We are losing money on H.M.O. patients. Before we undertake aggressive promotion of H.M.O.'s for Medicare beneficiaries, we have to make progress on both issues: payment methodology and quality assurance."

The Problem With H.M.O.'s

In the Reagan and Bush Administrations, Medicare officials insisted that H.M.O.'s would both raise the quality of care for elderly people, by coordinating services, and save money for the Government.

But a new study by Mathematica Policy Research, a private consulting concern, said the Government paid 5.7 percent more for Medicare patients in H.M.O.'s than it would have paid if those people had been in the regular Medicare program. Medicare "is not achieving its goal to save money" through H.M.O.'s, said the study, done under contract to the Government.

The problem, essentially, is this: while Medicare paid the H.M.O.'s a per-capita fee close to the cost of services used by the average Medicare beneficiary, the patients who enrolled in the H.M.O.'s tended to be healthier than the average, meaning that they would probably have used fewer services anyway.

The report does not discuss President Clinton's plan to remake the nation's health care system, which seeks to hold down health spending by inducing large numbers of consumers to enroll in H.M.O.'s and other forms of managed care. But the findings suggest that it may be difficult to achieve the large savings that his plan envi-

Continued on Page A14, Column 4

Continued From Page A1

sions.

"H.M.O.'s reduce utilization and don't seem to cut the quality of care," said Randall S. Brown, chief author of the Mathematica study. "But if you want to reap any savings, you better set the payments right."

Under Mr. Clinton's plan, organizations known as regional alliances would buy coverage for large numbers of people in a particular area. Just as the Government has not found a reliable way of adjusting its payments to H.M.O.'s to reflect the expected health needs of Medicare beneficiaries, so the alliances may have difficulty adjusting their payments to networks of insurers, doctors and hospitals to reflect the needs of alliance members.

Proponents of an alternative to the President's plan argue that instead of seeking elusive savings through managed care, all Americans should be lumped into a Government-run "single payer" plan like the one in Canada.

But Administration officials argue that the nation is not yet ready for a health care system financed entirely by taxes — or the tax increases such a system would require — and that the market forces that would be unleashed by the President's plan would succeed in holding down costs.

Health maintenance organizations normally charge a flat sum, fixed in advance, for each member, regardless of how much care the person uses. By contrast, under traditional fee-for-service arrangements, which most Medicare beneficiaries use, doctors are paid separately for each service or procedure. Many health policy experts say these arrangements give doctors a financial incentive to perform extra services.

The four-year Mathematica study said that the Medicare payment rates to the H.M.O.'s did not fully reflect the makeup of the people who chose to enroll. Had these people obtained their care through fee-for-service, the Government would have paid less than it

After more than a decade of experience with H.M.O.'s in the Medicare program, the study said, the Government has not found a completely satisfactory way of adjusting payments to reflect the health status and medical needs of the people who join a particular plan. Under Mr. Clinton's proposal, the Government would devise a formula to make such adjustments, but actuaries and other experts say this will not be easy, and many H.M.O.'s complain that Medicare payments are already too low.

The study said that H.M.O.'s appeared to reduce the intensity and frequency of medical services used, especially hospital stays, without harming the quality of care. But it found that Medicare paid an average of $413 a month for each person in an H.M.O., or $22 more than it would have paid for the same person in the regular Medicare program, even taking into account the additional services that that patient would presumably have used in a fee-for-service arrangement.

H.M.O.'s provide Medicare beneficiaries with all the services covered under the standard Medicare program and may offer additional benefits like preventive care or prescription drugs, at little or no additional cost.

The Government does not approach Medicare with the actuarial sophistication of private insurance companies, which often refuse to cover people

THE NEW YORK TIMES **NATIONAL** MONDAY, DECEMBER

Medicare to Stop Urging Membership in H.M.O.'s

deemed to have a high risk of costly illness. Medicare covers everyone entitled to benefits, regardless of illness or disability, and one of Mr. Clinton's major goals in his health plan is to end the widespread practice of discrimination against sick people by private insurers.

Under Federal law, Medicare beneficiaries still have the option of joining H.M.O.'s, and the Government is not discouraging this option. Indeed, Medicare officials say beneficiaries may get excellent care from some H.M.O.'s. But elderly people have been reluctant to join. Fewer than 2.5 million of the 36 million Medicare beneficiaries are in H.M.O.'s, and Mr. Vladeck said the Government would not "actively recruit elderly folks" for such plans at this time.

Disclosure of the Mathematica study comes two months after the General Accounting Office, an investigative arm of Congress, said there was "little

A hard look at H.M.O.'s topples a long-held hope for cutting costs.

empirical evidence" of savings from H.M.O.'s and other forms of managed care used by employers for their workers. Two trade groups that represent H.M.O.'s, the Group Health Association of America and the American Managed Care and Review Association, dispute those findings. They say that prepaid group plans achieve substantial savings.

There is some evidence that people under 65 behave like people 65 and over. The data are open to different interpretations, but Mr. Brown of Mathematica said, "Some employers have found that younger, healthier workers are more likely to choose H.M.O.'s than older, sicker workers."

Medicare patients with a history of cancer, heart disease and stroke are less likely to join H.M.O.'s, apparently because they want complete freedom to consult doctors they have used in the past, the study said.

The Government's primary goal in establishing the H.M.O. program for Medicare beneficiaries was to save money for the Government while expanding choices for patients. By design, the program should lower Federal costs 5 percent because, under a statutory formula, the Government pays health maintenance organizations 95 percent of the average per capita cost for people enrolled in the regular Medicare program.

But the Mathematica study said the people in H.M.O.'s were so healthy that the Government would have spent even less — about 90 percent of the average per capita cost — if they had been in the regular Medicare program.

"Thus," the study said, "rather than saving 5 percent as intended, the Health Care Financing Administration spends 5.7 more" when Medicare beneficiaries get their care through H.M.O.'s.

Mr. Vladeck was deeply involved in developing President Clinton's proposal to control health costs and guarantee coverage for all Americans. Before he took office in May, Mr. Vladeck was president of the United Hospital Fund of New York, a philanthropy that does health services research.

'We Are Not Ready'

"The Bush Administration invested heavily in the marketing of H.M.O.'s," Mr. Vladeck said. "We are not ready to do that. I don't want to get into a big marketing campaign until we can tell beneficiaries that quality is really good, that every H.M.O. is doing a good job by our beneficiaries.

"We're trying to get past the idea that managed care is good or evil," Mr. Vladeck said. "The question is: How do we tell the good from the bad, and eliminate the bad?"

Mr. Vladeck said he wanted to encourage new hybrid forms of managed care that would attract elderly people. "H.M.O.'s earned their spurs taking care of young employed populations," he observed. "They do a lot of maternity care and pediatrics." But to serve Medicare beneficiaries, he said, "they need to enlist more orthopedists, cardiac surgeons, ophthalmologists, urologists and oncologists."

Gail R. Wilensky, head of the Health Care Financing Administration under President George Bush, said that increasing Medicare enrollment in H.M.O.'s had been a major goal for her and her predecessor, Dr. William L. Roper.

"The quality and coordination of care can be much better in managed care than when services are provided a la carte, on a fee-for-service basis," she said.

Choice In Dying, Inc.

formerly
Concern for Dying
and Society for
the Right to Die

the national
council
for the right
to die

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January 13, 1994

Mr. Bart Handford
Office of Scheduling and
Advance
The White House
Old Executive Office Building
Room 184
Washington, D.C. 20500

Dear Mr. Handford;

Many thanks for taking the time to speak with me earlier today about Choice In Dying (CID) and advance directives (ie. living wills and durable powers of attorney for health care).

Per our conversation, I had the opportunity to speak briefly with Mrs. Clinton and Ms. Melanne Verveer about Choice In Dying and living wills at a health care forum for Congressional spouses prior to the holidays. At that time, Mrs. Clinton said that she would be interested in meeting with me and suggested that I contact your office to set up a meeting with her. Given Mrs. Clinton's recent comments about advance directives, I am extremely interested in having the opportunity to meet with her to discuss this issue in greater detail.

Choice In Dying--a national, not-for-profit organization which pioneered living wills in the U.S.--has distributed over 18 million free advance directives. As the nation's oldest and largest champion of patient rights at the end of life, Choice In Dying has helped enact legislation in 50 states and the District of Columbia about advance directives enabling Americans to direct their care at the end of their lives. We also worked hard to gain federal enactment in 1991 of the Patient Self Determination Act (PSDA) which was designed to raise public awareness of individual rights in end-of-life decisionmaking. CID routinely counsels thousands of Americans each year about completing advance directives and how to get them enforced.

Fewer than 20 percent of Americans have completed advance directives. Therefore, as I mentioned, I am delighted that Mrs. Clinton is interested in engaging Americans in a

conversation about end-of-life medical issues and would look forward to meeting with her as she moves forward on this sensitive and crucial matter.

I will messenger to you an information kit which provides additional background on CID's activities tomorrow morning. Should you have any questions, please don't hesitate to call me at (202) 362-1505.

Again, thank you for your interest and consideration.

Sincerely,

Laurie Oseran Wyden

Laurie Oseran Wyden

Clinton Presidential Records
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27 Pages
Choice in Dying
Booklet

QUESTIONS+ANSWERS

ADVANCE DIRECTIVES AND END-OF-LIFE DECISIONS

CHOICE IN DYING

Choice In Dying, Inc.

formerly
Concern for Dying
and Society for
the Right to Die

the national
council
for the right
to die

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**CHOICE IN DYING LAUNCHES NATIONAL LIVING WILL CAMPAIGN:
NEW PROPOSALS FOR NATIONAL HEALTH LEGISLATION TO BE ANNOUNCED**

WASHINGTON, D.C. (November 9) -- Choice In Dying (CID), the nation's leading advocacy group for patient rights at the end of life, will unveil its 50 state strategy to urge one million more Americans to sign living wills in 1994 at a news conference on Tuesday, November 9. CID's new proposals about end-of-life care that should be included in national health legislation now pending before Congress also will be announced. The November 9 news conference will be held at 10 a.m., the National Press Club, the First Amendment Room, 13th Floor, 529 14th Street N.W., Washington, D.C.

"CHOOSE....or someone else WILL," is the theme of CID's national public education campaign on advance directives (i.e., living wills, durable powers of attorney for health care) and end-of-life medical treatment issues. Choice In Dying (CID), the 50-year-old, not-for-profit organization which pioneered living wills, is the nation's largest distributor of them. CID recently initiated a toll-free consumer hotline, 1-800-989-WILL, for individuals to call and receive free, state-authorized advance directives and end-of-life information.

While all 50 states have passed some type of legislation enabling Americans to sign advance directives, few people exercise this legal right. A recent poll reveals that 75 percent of Americans approve of living wills, although only 20 percent actually sign them.

"We're working to bring end-of-life issues into the mainstream -- from the hushed confines of hospital corridors to the living rooms of America. Americans need to begin this conversation with their friends and family to make sure their end-of-life wishes are honored, and their loved ones don't suffer outrage in addition to grief," stated Dr. Karen Orloff Kaplan, Executive Director, Choice In Dying.

"Our goal in this campaign is to help guarantee that Americans -- whether 18 or 80 -- know how to exercise their legal rights in end-of-life decisionmaking," continued Dr. Kaplan.

Mrs. Clinton announced just a week ago that she and the President plan to sign their living wills to "help stir a national debate" and encourage Americans to discuss with their families "these difficult life and death issues before they arise."

Call 1-800-989-WILL for more information

Speakers for the November 9 news conference include:
Dr. Karen Orloff Kaplan, Executive Director, CID; **Judith Ahronheim**, M.D., nationally recognized specialist in geriatric medicine and expert on how advance directives work in a health care setting; **Ms. Christy Cruzan White**, sister of Nancy Cruzan, who was the subject of only right-to-die case decided by U.S. Supreme Court; **Mr. Pete Busalacchi**, who fought the Missouri legal system and right-to-life groups to allow his 17-year-old comatose daughter to die with dignity; **Mr. Murray Elbaum**, who fought a nursing home to have the wishes of his comatose wife upheld; and attorney **Ann Fade**, Director, Legal Services, CID, who provides ongoing legal advocacy for families confronted with end-of-life decisions.

Speakers will be available for interviews at news conference.

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RECOMMENDATIONS FOR NATIONAL HEALTH LEGISLATION

The Patient Self-Determination Act (PSDA) is a legislative attempt to broaden public understanding among Americans of their legal rights to direct their health care at the end of life. This statute has fallen short of its legislative mandate to educate the public about advance directives. For this reason, Choice In Dying has proposed that the following recommendations be included in any health care reform legislation.

- Encourage all health care clinicians to discuss end-of-life medical choices and preferences with their patients during a standard medical history. Clinicians should be encouraged to ask whether a patient has completed an advance directive and thus beginning what must be an ongoing conversation with the patient about end-of-life medical choices and decisions.

- Establish "advance directives" as a check-off item on the proposed National Health Security Card. Since the health security card is an ideal vehicle to reflect vital patient data such as health insurance or organ donor preferences, it is appropriate to include a check-off for advance directives. This information will give health care providers essential direction about the end-of-life medical wishes of a patient.

- Include facts about advance directives in the information made available to eligible enrollees by regional alliances. Public education is an integral component of effective implementation of PSDA. Laws regarding end-of-life decisions vary from state to state and health care facilities alone should not bear the full burden of public education.

- A definitive study to assess whether the PSDA is being effectively implemented. The research has been limited and results are conflicting. While the PSDA continues to be hailed as breakthrough legislation, early returns indicate that providers are either confused by or reticent to comply with the requirements of the statute. In addition, there is considerable concern that health care facilities are not fulfilling their mandate to educate staff and local communities about advance directives.

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CHOICE IN DYING--SAFEGUARDING END-OF-LIFE CHOICE

Choice In Dying Facts

Choice In Dying (CID) is a national, not-for-profit organization dedicated to protecting the rights and serving the needs of dying patients and their families, caregivers and health providers. Choice In Dying is the largest organization in the world concerned with the rights of the dying and terminally ill, and has been working for more than 55 years to ensure individual choice and compassionate care at the end of life.

The work of Choice In Dying made "living wills" a household term -- now, all 50 states and the District of Columbia recognize some type of advance directive. The importance of advance directives has been recognized at the federal level, with the passage of the Patient Self-Determination Act (PSDA) in 1991. The PSDA requires health care facilities to inform incoming patients about their rights to have advance directives.

Choice In Dying has more than 150,000 members and 200,000 other contributors.

Choice In Dying: Your Source for Living Wills

Choice In Dying distributes more than a quarter of a million copies of free, state-specific advance directives (the general term for living wills and durable powers of attorney for health care) each year. The legal department of Choice In Dying is continuously monitoring legislation nation-wide that can affect the rights of individuals to determine end-of-life medical treatment choices. In 1992-1993, more than 18 states changed their statutes governing advance directives. Choice In Dying informed individuals in the affected states about these changes, and provided assistance in updating advance directives to ensure that their voices will be heard at the end of life.

Choice In Dying: Safeguarding Your Legal Rights

Choice In Dying provides free legal information and counseling for families, caregivers, and providers about issues pertaining to end-of-life decisionmaking. The organization tracks state and federal right-to-die legislation and provides quarterly updates about right-to-die legal activity.

The group provides free and low-cost educational brochures and other information to

patients, families, and providers about completing and enforcing advance directives.

Choice In Dying developed several "Friend of the Court" (amicus curiae) briefs to help families engaged in courtroom battles to allow their loved ones to die with dignity.

Education Outreach

Choice In Dying provides educational information about end-of-life decisionmaking and:

- Publishes a quarterly newsletter that reaches more than 200,000 people and organizations.
- Processes 50-1000 requests a day through 1-800-989-WILL, a toll-free information hotline.
- Offers the Living Will Registry -- the most comprehensive computerized registration service that provides 24-hour access to an individual's advance directives.
- Produces educational publications and videos, such as A Good Death, a comprehensive guide to planning for dying, and Medical Treatments & Your Living Will, a guide to making decisions about life-sustaining and choices at end of life. Questions and Answers: Advance Directives and End-of-Life Decisions is a new comprehensive booklet addressing the most commonly asked questions about advance directives and end-of-life decisionmaking.
- Sponsors professional conferences, workshops, and presentations.
- Promotes public education through use of community advocates, other volunteer speakers, and national and local media.

Choice In Dying: Grassroots Successes

The organization effectively educates individuals about their rights by providing information about end-of-life decisionmaking. To support this objective, Choice In Dying developed the Community Advocates Program in two pilot cities: New York and Dallas.

Community Advocates are volunteer speakers trained by Choice In Dying to speak to community groups about advance directives and end-of-life decisionmaking. Advocates present this information to interested community groups, and also provide free advance directives and other educational materials during the course of community meetings. The Advocates have helped give people the communication tools, in the form of advance directives, to express their end-of-life decisions.

Choice In Dying also has reached out to the professional and consumer community by making close to 200 presentations since 1987 to various public and professional audiences.

Presentation topics ranged from how to treat the dying patient to how an advance directive can be used to express end-of-life treatment decisions.

Grassroots efforts in 1994 will expand to a state-by-state educational campaign. State legislators, as well as state volunteers, will help Choice In Dying expand educational messages at the state level throughout the next year.

Choice In Dying History

Choice In Dying was created in 1991 by a merger of the nation's two oldest organizations advocating the rights of dying patients, Concern for Dying and Society for the Right to Die. The two organizations were best known for pioneering patients' rights to refuse unwanted life support and for creating the first living will document in 1967.

Choice In Dying Philosophy

The mission of Choice In Dying is to advocate for the rights of individuals to make their own decisions about medical care at the end of life. Choice In Dying accomplishes this by educating the public, health care providers, and lawmakers about the needs of dying patients and their loved ones.

Choice In Dying recognizes the need to foster the debate about assisted suicide and active euthanasia. To meet this objective, CID offers educational materials and forums to help individuals consider various points of view.

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WOMEN AND END-OF-LIFE DECISIONS

The right to refuse medical treatment at the end of life is not the same for women as it is for men. Advance directive laws in individual states often explicitly limit the applicability of living wills or durable powers of attorney for health care during the course of a woman's pregnancy. Even when the law is the same for men and women, there is evidence to suggest that the courts apply that law differently for the two sexes.

Pregnancy Exclusions

"Pregnancy exclusion" -- the definition given to state law restricting a woman's choice to refuse unwanted life support through a living will or durable power of attorney for health care while she is pregnant -- illustrates this imbalance.

In the landmark right-to-die case Cruzan v. Director, Missouri Department of Health, the United States Supreme Court recognized that competent adults have the constitutional right to refuse medical treatment, even if that treatment is necessary to sustain life. This right can be preserved through advance directives such as living wills and durable powers of attorney for health care in the event the individual loses the ability to make decisions for herself.

Roe v. Wade and more recently, Planned Parenthood of Southeastern Pennsylvania v. Casey, the U.S. Supreme Court ruled that a woman's decision to end her pregnancy is a "liberty interest" protected against state interference by the Fourteenth Amendment prior to viability of the fetus.

Combined, these cases clearly state that, at least prior to viability of the fetus, no state may force a pregnant woman to receive unwanted medical treatment.

State laws do not follow suit:

Of the 47 states and the District of Columbia that have living will statutes,

- Thirty-four states explicitly forbid withdrawal of or withholding life support under a woman's living will if the woman is pregnant;

- Ten states and the District of Columbia make no mention of pregnancy in their living will statute, implicitly allowing her to refuse life support during pregnancy;

- Only three states permit the woman to choose to refuse life support if she is pregnant.

Of the 37 states and the District of Columbia that have durable power of attorney for health care or health care proxy statutes:

- Seven states explicitly forbid a health care agent from ordering the withholding or withdrawal of life support from pregnant patients;

- Twenty-six states and the District of Columbia are silent on the issue of whether an agent may order the withholding or withdrawal of treatment from a pregnant patient, implicitly allowing her to refuse life support during pregnancy;

- Only four states permit the woman to choose whether her agent can withhold or withdraw life support in the event she is pregnant.

Right-to-Die Court Cases

Women may also be subject to unequal treatment by the courts when end-of-life medical treatment is at issue. Two researchers (Miles and August, 1990) studied the outcomes of all right-to-die cases decided by state appellate courts involving patients without advance directives.

This study found:

- Out of eight cases involving men, the court found sufficient evidence of the patient's treatment wishes from prior statements in six cases;

- Out of 14 cases involving women, the court found sufficient evidence of the patient's treatment wishes from prior statements in only two cases;

- Many courts characterized past statements made by male patients as "rational." The female patients' statements were characterized as "unreflective, emotional, or immature;"

- Some of the courts never even mentioned the women's prior statements.

Other Facts

- Approximately 60 percent of Choice In Dying's membership is female.
- Of the 10,000 individuals registered in Choice In Dying's Living Will Registry, 70 percent are female.

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FACTS ABOUT END-OF-LIFE CARE

- Every year 2 million people die in America -- 80 percent in hospitals, hospices, or nursing homes. Chronic illness, such as cancer or heart disease, account for two out of every three deaths. It is estimated that approximately 70 percent of these people die after a decision to forgo life-sustaining treatment. (Louis Harris and Associates)

- It has been estimated by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research that 5,000 patients per year are kept alive in a permanently vegetative state (PVS) by ventilators and artificial feeding tubes.

- In 1988 the American Academy of Neurology concluded that patients in a persistent vegetative state do not have the capacity to experience pain. Hence, removal of a hydration or feeding tube cannot cause suffering.

- Medical, legal and ethical authorities agree that there is no difference between withholding unwanted life support and withdrawing life support when it has already been started. Not one of the 50 states' advance directive statutes makes a distinction between withholding or withdrawing life support treatment.

- In 1990, the U.S. Supreme Court ruled that the right to refuse unwanted life-prolonging treatment is protected by the Constitution. This landmark decision is the result of the Nancy Cruzan right-to-die case. The ruling stated that competent adults have the right to refuse treatment including artificial hydration and nutrition.

- The American Medical Association (AMA) adopted the position in 1989 that, with informed consent, physicians could withhold or withdraw treatment from patients who are close to death. The AMA also concluded that physicians could discontinue life support if a patient is in a permanent coma.

- Results of a 1988 American Medical Association poll of physicians revealed that 80 to 90 percent of American physicians agree that withholding and withdrawing of feeding and hydration is permissible in certain circumstances.

Call 1-800-989-WILL for more information

- Fifty states have laws authorizing the use of some type of advance directive. Laws that govern living wills and health care proxies vary from state to state. Forty-five states have a combination of laws recognizing advance directives (i.e., living wills, durable power of attorney for health care). Of the remaining five states, two authorize only living wills (Alabama and Alaska); three only authorize durable power of attorney for health care (Massachusetts, Michigan and New York). An advance directive must reflect the most recent changes in state law to be valid.

- According to a 1991 Gallup poll, 75 percent of all Americans approve of living wills. This poll also indicated that more than 20 percent of all Americans presently have a living will or durable power of attorney for health care designation.

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FEDERAL LAW ON ADVANCE DIRECTIVES: THE PATIENT SELF-DETERMINATION ACT

Background

In December of 1991, the U.S. Congress passed the Patient Self-Determination Act (PSDA), requiring all health care facilities that receive Medicare or Medicaid funds to inform patients about their right to refuse medical treatment and to sign advance directives (i.e., living will, durable power of attorney for health care.) Increased public awareness and concern about the "right to die" issue generated by the 1990 U.S. Supreme Court decision on Nancy Cruzan prompted Congress to step in and clarify the state's role on this complicated issue.

Prior to the Cruzan decision, state courts and legislatures tried to answer the difficult question of whether individuals have a "right to die" and, if so, how that right should be exercised. While the Cruzan decision said that a competent adult has a constitutional right to refuse medical treatment (including artificial nutrition and hydration), the Court delegated regulation of this right (as it applies to incompetent patients) to the "laboratory of the states."

Passage of this law marked a significant advance in patient rights at the end of life. The law also guaranteed that providers could not discriminate against individuals based on whether or not they had an advance directive.

Provisions of PSDA

The PSDA requires that health care facilities comply with the following:

- Provide written information to patients about their right to make decisions concerning treatment and to formulate advance directives
- Ensure compliance with the requirements of state law
- Maintain written policies and procedures with respect to advance directives

Call 1-800-989-WILL for more information

- Document in the individual's medical record whether or not the individual has executed an advance directive

- Provide educational opportunities for facility staff and the community on issues concerning advance directives

Compliance/Effectiveness

While the PSDA continues to be hailed as breakthrough legislation on end-of-life care, early returns indicate that providers are either confused by or reticent to comply with the requirements of this statute. A January 12, 1993 article in The Los Angeles Times reported, "in the 13 months since the PSDA took effect, proponents say enforcement has not been easy or uniform." The article also reported that one-third of the nursing homes in Los Angeles County were cited for violations ranging from failure to notify patients of their rights under the law to failure to provide community education.

Recent anecdotal information observed by Governor Cuomo's New York Task Force on Life and the Law noted a gap in patients who filled out their advance directives. Only 15 percent of incoming emergency room patients filled out their advance directives after being educated about the documents by admission staff. This contrasts to approximately 80 percent of patients who completed advance directives that they received a few days prior to admission as part of the pre-admission materials.

The current malpractice climate and general discomfort among health care providers about the subject of death and dying, makes physicians more reluctant to rely on traditional methods of decisionmaking. This makes having an advance directive more important than ever.

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KAREN ORLOFF KAPLAN, MPH, ScD

EXECUTIVE DIRECTOR

CHOICE IN DYING

November 9, 1993

Good Morning. I am Karen Kaplan, Executive Director of Choice In Dying and I welcome you all here today. This morning CID is launching a 50 state grassroots campaign to educate the public and health care professionals about advance directives and we appreciate the opportunity to talk with you about the need for this campaign and what it will involve.

Choice In Dying is the oldest and largest organization in the United States dedicated to ensuring patients rights at the end of life. For more than 50 years, we have gone to bat for Americans and their families who need assistance in making decisions and in getting them honored. Choice In Dying also is the organization which pioneered living wills 26 years ago.

- We have distributed 18 million advance directives since 1967--all of them free. (CALL 1-800-989-WILL)
- We've helped enact advance directive legislation in all 50 states and the District of Columbia and served as a resource to the legislators drafting federal law-- the Patient Self Determination Act (PSDA).
- And since the state laws differ, we provide 51 different sets of documents. Each set is designed for the state in which it will be used.
- We answer between 50 and 1,000 calls a day offering free counseling, legal assistance, crisis intervention, and information to Americans from coast to coast.
- We have a Living Will Registry...and much more.

The country is in the midst of a major national debate about health care reform. Regardless of who is doing the proposing, or what they are proposing, <u>patient choice is one of the fundamentals.</u> However, there are critical choices that-- unfortunately-- aren't discussed much, they aren't a practical

part of the health reform proposals, and they aren't made by most Americans. These choices--choices about end-of-life treatment-- are ours to make. Every American has the right to request or refuse treatment. But most Americans don't know that they have that right (or if they do know it) they don't know how to exercise it. That lack of knowledge can lead to truly heartbreaking problems-- and you will hear about some of those problems today. That lack of knowledge is what we are about today.

We are mounting a national campaign--"CHOOSE....or someone else WILL"... to raise awareness of advance directives and end-of-life decisionmaking. Every adult--be he or she 18 or 80--should know what an advance directive is, where to get one, how to complete it, and why it is so important to do so. But the sad reality is that most Americans don't have advance directives-- a living will or a durable power of attorney for health care. Alot of Americans know about living wills--In fact a recent (1991) Gallup Poll found that 75% of those questioned approved of living wills. But that same poll found that only 20% of those people actually had a living will.

That gap--between theory and practice is very wide. The goal of our campaign is to bridge that gap. It is an excellent time to start the campaign. Health care reform is on the table. The Clintons have been talking about signing their own living wills and Americans are primed to think and talk about all of their health care choices.

A state-specific set of advance directives should be part of every American's planning and a part of everyone's important papers. Life insurance, health insurance, fire insurance, a property will...We have those. We should also have a living will.

This morning, it is my privilege to introduce you to the people who are with me on the podium. Each of them will be speaking briefly and I will follow with a description of the campaign and of some health care reform enhancements we are recommending to Mrs. Clinton. Then we'll have plenty of time for questions.

Before I introduce our first speaker, I would like to introduce Christopher Bates who is sitting in the front row...Mr. Bates is the Executive Director of the D.C. Care Consortium, serving people with HIV diseases. Mr. Bates is working with us to educate groups with special needs about advance directives.

Statement of Pete Busalacchi
Choice In Dying
Press Conference, National Press Club
November 9, 1993

Good Morning. Eight months ago my daughter's heart stopped beating. A car accident in 1987 was the cause of her death. And, really, her life ended that night. Medical technology gave her a chance to recover. The best doctors, the best therapists, all tried to help her to regain some semblance of life. Her condition was listed as "persistent vegetative."

Almost three years following the accident I made a decision for her that she would have wanted. She was only 17 at the time of the accident so there was no plan to formalize her wishes. For all of her 17 years I chose the doctors who treated my daughter.

Because Missouri's political leaders, the governor and his attorney general, had just intruded into the Cruzan's family decision I attempted to move Chris to Minnesota.

On the day that I arrived at the state hospital to take her there I was met by state patrolmen and the hospital's director who were armed with a temporary restraining order. The state was beginning their battle to take over as her father. This "was" ended more than two years later, after several sessions in court.

And, it wasn't the court's decision that finalized our tragic situation. Chris died on March 6 of this year because there was an election on November 3 last year. The newly elected attorney general, Jay Nixon, announced that his first action would be to remove the state from our plight. Even then Missouri's supreme court, all appointed by John Ashcroft, would not recognize this fact and waited more than two months to dismiss the case.

The intruders, former governor John Ashcroft and his staff, maybe were well intentioned, but misguided. More than twenty doctors examined my daughter and found her not to be aware of her environment. They, almost to a man, said she had no hope for recovery and that it was appropriate to end her treatment. The former governor, an ordained minister of the Assembly of God, injected his religious beliefs into my daughter's care.

The state spent hundreds of thousands of dollars of taxpayers money to intrude where they had no business. For example, a doctor at the state facility where Chris was treated and called in a specialist from Wisconsin. They were unsure of their diagnosis, after three years there, so they wanted more input.

The specialist told them what they didn't want to hear. that Chris was truly in a vegetative condition. This state facility is

located just thirty-eight miles west of Springfield, Missouri, where the Assembly of God has its national headquarters.

The governor let his untrained nursing staff help him make a decision based on their religious beliefs rather than on medical guidance.

To this date, in Missouri, you must have "clear and convincing" evidence to have treatment stopped. In the case of minors, whether their age be 7 or 17, I believe that families, guided by doctors and their religiouis beliefs, should make decisions for those they love. Whether you live in Missouri or anywhere in the U.S. there is no room, no place at the bedside for strangers, and that includes governors.

Comments of Christy Cruzan White
at
Choice In Dying Press Conference
National Press Club
November 9, 1993

Good Morning. You have been provided with a summary and a chronology of Nancy's case, and most of you are very aware of what hapened in her situation. I would like to use my time this morning to share a few of the things we learned during those eight years.

First, I truly believe that one of the greatest gifts you can give yourself and your loved ones is to take responsibility for your own end-of-life decisionmaking by preparing an advance directive. Whether you should choose to have treatment discontinued at some point, it is important to complete an advance directive. It is equally important to discuss your choices with your loved ones and your health providers to ensure that your wishes are known, understood and will be respected.

Another thing we learned was the importance of communication between health care providers and patients and their families. There is a great need to be willing to re-evaluate the situations and the treatments that are being provided. In our case, it was more than three years before we were given the diagnosis of persistent vegetative state. I think one of the reasons that it tooks so long for us to receive the diagnosis was because we didn't know the "right" questions to ask.

And finally, I believe that all competent adults should complete an advance directive. We talk about these being end-of-life issues and assume that only seniors or individuals with chronic illness need to address the subject of medical decision-making, but Nancy was only 25 years old at the time of her accident. To me, young people are perhaps the most vulnerable to being held hostage to medical technology simply because their wishes are not known.

I would like to offer my gratitude to Choice In Dying for inviting me to participate at this conference. I look forward to the question and answer session that will follow our remarks. And I would like to thank all of you for being here this morning.