MICROFILM DIVIDER

OMB/RECORDS MANAGEMENT DIVISION
SFN 2053 (2/85) 5M

ROLL NUMBER

DESCRIPTION

2343

2005 SENATE JUDICIARY

SB 2343

2005 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2343

Senate Judiciary Committee

☐ Conference Committee

Hearing Date February 8 , 2005

Tape Number	Side A	Side B	Meter #
1	X		1950 - End
		X	0.0 - 1550
Committee Clerk Signature	Mona L Solberg		

Minutes: Relating to health care decisions and directions; treatment declarations.

Senator John (Jack) T. Traynor, Chairman called the Judiciary committee to order. All Senators were present. The hearing opened with the following testimony:

Testimony In Support of the Bill:

Sen. Judy Lee, Dist. #13 Introduce the bill (meter 1950) Gave Testimony - Att. #1a and also introduced Mr. Levi.

Sen. Traynor asked if on page 26, line 20 (meter 2450) is the person explaining document to the patient have any training in explaining the information? Yes discussed the designated person.

Mr. Bruce Levi, ND Medical Assoc. (NDMA) Gave Testimony - Att. #1b Proposed and Amendment Att. #2 and submitted two publications - Att. #3a and #3b.

Mr. Levi discussed with the committee the education process with a physician on "EPEC" using a curriculum and a video. Mr. Levi also handed out a news paper article from last November - Att. #4a and #4b.

Sen. Trenbeath asked (meter 4732) if there was a discrepancy on page 5, line 7 and line 2. Discussion if I do not sign the document myself (meter 4909) my power of attorney may sign it. can a power of Attorney change my directive? Sen. Traynor asked were format came from? It is based on MN law due to ease of use and the "valley" included so many MN in there hospitals that it works well to have a very similar document. Discussion of MN's law originating in 1998.

Christopher Dobson, Ex. Dir. catholic Services Diocese. (meter 5995) We are neutral to this document but we are called to use it often.

- No statute will be perfect.
- Early discussion is better.
- Primary benefit is to the person ability of what is going to happen and communicating it to family and friends; i.e.; assisted suicides)
- Change in the culture about death and our wishes and a change in the law.
- This document is better then a "living will'.
- We need to get rid of having 2 documents, people feel they have to offer both and one uniform one is best, less confusing.

Rodger Wetzel, Dir. Eldercare Program, St. Alexis Bismarck (meter 500) Gave Testimony - Att. #5

Clyde Leimberer, Chaplain-The Baptist Home in Bismarck (meter 916) Gave Testimony - Att. #6

Additional Testimony:

Susan Bosak, Public Affairs Officer at MeritCare Health Systems, Fargo - Att. #7

Testimony in Opposition of the Bill:

Malcolm Brown, Attorney in Bismarck. I visit approx. one time a week with a client on this issue the following are some of my problems with this bill. Under "Health Care Agent" and part 2 Lawyers vs. Health Care. The form can be confusing they must complete "some or all" for example. A living will is very simple and easy to fill out. Some clients do not want to get as involved as this document is.

Sen. Trenbeath discussed if we divide Part II into Sub A and Sub B. separating out what must and optionally needed to complete would he be satisfied? Yes.

Senator John (Jack) T. Traynor, Chairman closed the Hearing

2005 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2343

Senate Judiciary Committee

☐ Conference Committee

Hearing Date February 9, 2005

Tape Number	Side A	Side B	Meter #
1	X		0.0 -2335
Committee Clerk Signature	Maria L Solberg		

Minutes: Relating to health care decisions and directions.

Senator John (Jack) T. Traynor, Chairman called the Judiciary committee to order. All Senators were present. The hearing opened with the following:

Discussion of amendment proposed by the ND Medical Association.- Att. #1

Senator Triplett stated an error on the amendment page 12 line 21 not 9.

Senator Triplett made the motion to Do Pass corrected amendment and **Sen. Nelson** seconded the motion. All were in favor and motion passes

The committee discussed breaking out the minimum requirement section and the Power of Attorney to ND directive. Discussed Mental Health concerns (meter 350) and using the word "competent adult" and incapacitated.

Sen. Trenbeath made the motion to change line 3 to A and line 26 to B "minimum" requirements. **Senator Triplett** seconded the amendment. All were in favor and motion passes

Senator Triplett made the motion to reconsider amend #2 and **Sen. Nelson** seconded the motion. All were in favor motion passes

Senator Triplett made the motion to do pass new amendment #1 and **Sen. Nelson** seconded the motion. All were in favor and motion passes.

Sen. Trenbeath made the motion to Do Pass as amended and **Senator Triplett** seconded the motion. All were in favor and the motion passes.

Carrier: **Senator Triplett**

Senator John (Jack) T. Traynor, Chairman closed the Hearing

ND Medical Association
February ~~8, 2005~~ 2/9 #A

PROPOSED AMENDMENTS TO SB 2343

Page 4, line 24, after "provider" insert "unless specific reasons why the principal wants a health care provider to act as agent are provided in the health care directive"
Page 4, line 25, after "provider" insert "unless specific reasons why the principal wants a health care provider to act as agent are provided in the health care directive"

Page 5, line 13, replace the first underscored comma with "or" and remove "durable"
Page 5, line 29, overstrike "power of"
Page 5, line 30, overstrike "attorney for health care" and insert immediately thereafter "directive"

Page 6, line 20, replace "to" with "regarding"

Page 7, line 11, overstrike "power" and insert immediately thereafter "directive"

Page 10, line 28, overstrike "durable power of attorney for" and after "care" insert "directive"

Page 11, line 19, replace "Permit the agent to arrange" with "Arranges"
Page 11, line 25, overstrike "a durable power of"
Page 11, line 26, overstrike "attorney for health care" and insert immediately thereafter "the appointment of an agent in a health care directive"

Page 12, line 21, replace "withdrawl" with "withdrawal"
Page 12, line 28, replace "withdrawl" with "withdrawal"
Page 12, line 29, replace "qualified patient" with "principal"

Page 13, line 4, replace "withdrawl" with "withdrawal"
Page 13, line 10, after "**attorney**" insert "**or other directives**"

Page 18, line 23, replace "know" with "known", after "or" insert "my agent", and replace "may" with "my"

Renumber accordingly

Date: 2/9/05
Roll Call Vote #: 1

2005 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. SB2343

Senate Judiciary Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken Do Pass as Corrected (pg #)

Motion Made By Sen. Triplett Seconded By Sen. Nelson

Senators	Yes	No	SenatorsSen. Nelson	Yes	No
Sen. Traynor	✓		Sen. Nelson	✓	
Senator Syverson	✓		Senator Triplett	✓	
Senator Hacker	✓			✓	
Sen. Trenbeath	✓				

Total (Yes) 6 No 0

Absent 0

Floor Assignment _____

If the vote is on an amendment, briefly indicate intent:

Date: 2/9/05
Roll Call Vote #: 2

2005 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. SB 2343

Senate Judiciary Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken Line 3 "A" Line 26 "B" Minimum of Part B

Motion Made By Sen Trenbeath Seconded By Sen. Triplett

Senators	Yes	No	SenatorsSen. Nelson	Yes	No
Sen. Traynor	✓		Sen. Nelson	✓	
Senator Syverson	✓		Senator Triplett		
Senator Hacker	✓			✓	
Sen. Trenbeath	✓				

Total (Yes) 6 No 0

Absent 0

Floor Assignment _____

If the vote is on an amendment, briefly indicate intent:

Date: 2/9/05
Roll Call Vote #: 3

2005 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. SB 2343

Senate Judiciary Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken Move To Reconsider Amend Att #1

Motion Made By Sen. Triplett Seconded By Sen Nelson

Senators	Yes	No	SenatorsSen. Nelson	Yes	No
Sen. Traynor	✓		Sen. Nelson	✓	
Senator Syverson	✓		Senator Triplett	✓	
Senator Hacker	✓				
Sen. Trenbeath	✓				

Total (Yes) 6 No 0

Absent 0

Floor Assignment _____

If the vote is on an amendment, briefly indicate intent:

Date: 2/9/05
Roll Call Vote #: 4

2005 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. SB 2343

Senate Judiciary Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken Move to do pass New Amend #1

Motion Made By _____ Seconded By _____

Senators	Yes	No	SenatorsSen. Nelson	Yes	No
Sen. Traynor	✓		Sen. Nelson	✓	
Senator Syverson	✓		Senator Triplett	✓	
Senator Hacker	✓				
Sen. Trenbeath	✓				

Total (Yes) 6 No 0

Absent 0

Floor Assignment _____

If the vote is on an amendment, briefly indicate intent:

Date: 2/9/05
Roll Call Vote #: 5

2005 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. SB 2343

Senate Judiciary Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken Do Pass As Amended

Motion Made By Sen. Trenbeath Seconded By Sen. Triplett

Senators	Yes	No	SenatorsSen. Nelson	Yes	No
Sen. Traynor	✓		Sen. Nelson	✓	
Senator Syverson	✓		Senator Triplett	✓	
Senator Hacker	✓				
Sen. Trenbeath	✓				

Total (Yes) 6 No 0

Absent 0

Floor Assignment Sen. Triplett

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

SB 2343: Judiciary Committee (Sen. Traynor, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2343 was placed on the Sixth order on the calendar.

Page 4, line 24, after "provider" insert "unless a specific reason why the principal desires a health care provider to act as an agent is provided in the health care directive"

Page 4, line 26, after "provider" insert "unless a specific reason why the principal desires an employee of the health care provider to act as an agent is provided in the health care directive"

Page 5, line 13, replace the first underscored comma with "or" and remove "durable"

Page 5, line 29, overstrike "power of"

Page 5, line 30, overstrike "attorney for health care" and insert immediately thereafter "directive"

Page 6, line 20, replace "to" with "regarding"

Page 7, line 11, overstrike "power" and insert immediately thereafter "directive"

Page 10, line 28, overstrike "durable power of attorney for" and after "care" insert "directive"

Page 11, line 19, replace "Permit the agent to arrange" with "Arrange"

Page 11, line 25, overstrike "a durable power of"

Page 11, line 26, overstrike "attorney for health care" and insert immediately thereafter "the appointment of an agent in a health care directive"

Page 12, line 21, replace "withdrawl" with "withdrawal"

Page 12, line 28, replace "withdrawl" with "withdrawal"

Page 12, line 29, replace "qualified patient" with "principal"

Page 13, line 4, replace "withdrawl" with "withdrawal"

Page 13, line 10, after "**attorney**" insert "or other directives"

Page 18, line 23, replace "know" with "known", after the second "or" insert "my agent", and replace "may" with "my"

Page 20, line 29, replace "some or all" with ", at a minimum,"

Page 20, line 30, remove "of this" and after "II" insert "(B)"

Page 21, line 2, after the second underscored period insert:

"(A)"

Page 21, after line 25, insert:

"(B)"

Renumber accordingly

2005 HOUSE HUMAN SERVICES

SB 2343

2005 HOUSE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2343

House Human Services Committee

❑ Conference Committee

Hearing Date 3-9-05

Tape Number	Side A	Side B	Meter #
1	x		0-end
Committee Clerk Signature			

Minutes:

Chairman Price: Opened the hearing on SB 2343.

Senator J Lee: Appeared in support of SB 2343. This bill will establish health care directives, that is providing a current living will in one factor and durable power of attorney for health care in another factor and the bill will also provide statutory health directive form based on statutory form currently used in Minnesota.

Chairman Price: Can current living wills still stand?

Senator Lee: I am not an attorney, but I would say that the one that people already have would be fine, this would just make it a little more cleaner process and user friendly.

Chairman Price: If my parents said, I just want you to decide based on circumstances at the time, would this let you do that?

Senator Lee: I believe it is possible to do that, but I would also ask you to confirm that with Mr. Levi.

Bruce Levi, Executive Director, North Dakota Medical Association: Appeared in support of the bill and provided a written statement **(SEE ATTACHED TESTIMONY).**

Representative Kaldor: As I look at the duties of providers, the duty of a health care provider they may declined to comply with the health care decision of a principle, designated agent, or health care instruction, for reasons of conscious, and then it goes on to say that a provider that declines to comply with this directives, shall take all reasonable steps to transfer and that is old language, I m curious about institutions health care, institutions in situations like this, if an institution refuses to comply with a directive, is there any possibility that they would even refuse to transfer the patient?

Senator J. Lee: That certainly is not the intent, that they would refuse to do that, what we were tying to do is to make sure that medical ethics are followed.

Chris Dodson, Executive Director, North Dakota Catholic Council: If you do not have and Advanced directive, someone is still going to make a decision, and under our current statute, that person is going to make that decision, based on what their knowledge is, of what you would have wanted, and if they can't determine that, then what is in the best interest. So what an advanced directive does, is simply provides the mechanism that the state prefers to put into that myth, that if there is advanced directives, that is something that have weight and recognized by the state as indicating what you want because it was signed and notarized and so on. And if you have some body that is appointed an agent, that person takes priority over others on that list. I think through the years we have learned, that it is more then just a mechanism, because it is also part of the process and we have learned that people that have advanced directives, are much more comfortable with the dying process, and more importantly the family is more comfortable.

This bill is only about simplifying the process. so what you have is basically nothing that changes the law.

Representative Kreidt: What we have developed here is a guide, a person could still use an attorney?

Chris Dodson: Basically that is correct, yes, the form needs to be witnessed, if not signed, substituted judgment law.

Representative Kriedt: Any preexisting forms will still stand?

Chairman Price: This really combines what we had before in 2 separate documents.

Chris Dodson: Over all this will make is easier. The living will statute is only operative under certain conditions, you had to be incompacitated and they could intercept, and terminal condition would have a specific definition on its own and then it was only presumptive evidence of what you wanted.

Representative Kriedt: I know we are combing the two but in essence couldn't we just eliminate the chapter on the living will and just have the durable power of attorney, and making that more effective increments.

Chris Dodson: That is one suggestion we threw around, there are separate sections within the living will chapter, that list some of the duties of the health care provider.

Susan Bosak, Public Affairs Officer, MeritCare Health System, Fargo, ND: Appeared in support of the bill and provided a written statement **(SEE ATTACHED TESTIMONY)**

Representative Sitte: Appeared in opposition of SB 2343 **(SEE ATTACHED TESTIMONY)** I'm coming before you today because of a personal experience, my mother was 95 and living alone in her own home when she finally had a stroke and died, but at about the age of 92 she

decided we should go to a seminar together one summer afternoon on living wills, so we did, at the end of the entire thing, she took a look at me and said I don't think I can sign this, and I said I wouldn't allow you to sign it, instead we signed the medical power of attorney, it gave me an enormous responsibility but it also provided me with peace of mind.

Hearing closed.

2005 HOUSE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2343

House Human Services Committee

❑ Conference Committee

Hearing Date March 21, 2005

Tape Number	Side A	Side B	Meter #
1		x	Tape is hard to hear.
			641-1315
Committee Clerk Signature			

Minutes:

Chairman Price opened discussion on SB 2343.

(These are being done from written minutes as the tape is very hard to hear)

Bruce Levi: 23-06-54, Take section out, retain statutory language. Amendment did 3 things. Amend line 7, capacity - effective date when principal. Line 13-16, go to the form that is used in Minn. "Decide/or Speak". Assistant AG, need to change form, inserted, make and communicate decision. Amendment proposed.

Rep. Kaldor: What language are you removing?

B. Levi: 23-06-54, regarding who can be an agent, current law will provide necessary, provider cannot act as agent.

Chairman Price: What if someone doesn't want all the choices? Part 1 (durable power of attorney)

B. Levi: Living will - can choose a living will and an agent under Section 1.

Chairman Price: Does anyone have any more questions of Mr. Levi?

Rep. Kaldor: Under the current code appointing an agent, when can I?

B. Levi: Language in the bill explains who can be appointed.

Rep. Damschen: If a temporary situation, if what a patient has written, conflicts with the doctor and or agent. Which takes precedent? Or if the agent goes against that person's wishes.

B. Levi: The directives have to be followed.

Chairman Price: Let's say I made the decision for life, my agent said no, is there a penalty?

B. Levi: No penalty per say, cannot alter the document, you can indirectly be advised from the Dr. but the document provides immunity. The agent is required to act in good faith.

(MR# 5855)

Rep. Kaldor: In regards to the best interest of the party, when does that come into play?

B. Levi: The initial determination, understanding the value's of the individual and what they really wanted. (RE: Health care provider)

V. Chairman Kreidt: You have follow the document directives.

Rep. Devlin: Who determines that?

B. Levi: Agent is appointed, decisions are based on statements. The person appointing the agent needs to direct agent as to their wishes.

Rep. Pietsch: If we have a durable power of attorney now, do we need to do a new one?

B. Levi: No, you don't have to.

Rep. Uglem: **I move the amendment. Rep. Pietsch: I second. Voice Vote: Unanimous.**

Rep. Devlin: I move a Do Pass, Rep. Nelson: Second.

Vote: 11-1-0 Carrier: Rep. Weisz

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2343

Page 1, line 3, remove "23-06.5-04"

Page 4, remove lines 19 through 30

Page 5, remove lines 1 and 2

Page 6, remove lines 25 and 26
Page 6, line 27, remove "agent"

Page 7, line 3, overstrike "a duty" and insert immediately thereafter "authority"

Page 18, line 26, replace "decide or speak" with "make and communicate health care decisions"

Page 19, line 4, after "make" insert "and communicate"
Page 19, line 10, replace "DECIDE OR SPEAK" with "MAKE AND COMMUNICATE HEALTH CARE DECISIONS"
Page 19, line 15, after the underscored period insert "None of the following may be designated as your agent: your treating health care provider, a nonrelative employee of your treating health care provider, an operator of a long term care facility, or a nonrelative employee of a long term care facility."
Page 19, line 16, replace "decide or speak" with "make and communicate health care decisions".
Page 19, line 30, replace "DECIDE OR SPEAK" with "MAKE AND COMMUNICATE HEALTH CARE DECISIONS"

Page 20, line 5, replace "decide or speak" with "make and communicate health care decisions"

Page 21, line 6, replace "decide or speak" with "make and communicate health care decisions"

Page 22, line 12, replace "decide or" with "make and communicate health care decisions"
Page 22, line 13, remove "speak"
Page 22, line 17, replace "decide or speak" with "make and communicate health care decisions"
Page 22, line 21, replace "decide or speak" with "make and communicate health care decisions"
Page 22, line 26, replace "decide or speak" with "make and communicate health care decisions"

Page 26, after line 21, insert:

"PRINCIPAL'S STATEMENT

I have read a written explanation of the nature and effect of an appointment of a health care agent that is attached to my health care directive.
Dated this _____ day of _____, 20____.

_____
(Signature of Principal)"

Page 26, line 24, after the underscored period insert "This statement does not need to be completed if the resident has read a written explanation of the nature and effect of an appointment of a health care agent and completed the Principal's Statement above."

Page 27, line 5, after the underscored period insert "This statement does not need to be completed if the patient or person being admitted has read a written explanation of the nature and effect of an appointment of a health care agent and completed the Principal's Statement above."

Renumber accordingly

Explanation of Amendments

Agent's Responsibility – Clarification in Existing Law
Under the existing law (section 23-06.5-06) on page 7, line 1, of the engrossed bill, the acceptance by the agent to being an agent "creates a duty for the agent to make health care decisions on behalf of the principal" once the principal becomes incapacitated. What is ambiguous is that in the current optional form, the existing law states that the agent's acceptance "gives me authority over health care decisions for the principal" when the principal becomes incapacitated" (page 6, lines 9-10). Again in existing law in section 23-06.5-03 (page 3, line 25), it states the agent "has the authority" to make health care decisions. The ambiguity is in the existing DPAHC law. Minnesota's statute clearly addresses the matter as "authority," stating there is no "legal duty to act" imposed (Mn Stat 145C.07). The amendment would clarify existing law that the agent's acceptance gives the agent "authority" to make health care decisions.

Statutory Form – Capacity
As proposed, the new health care directive would become effective when the principal lacks capacity to make health care decisions, which is defined in the engrossed bill on page 2, lines 13-16, as "the ability to understand and appreciate the nature and consequences of a health care decision, including the significant benefits and harms of and reasonable alternatives to any proposed health care, and the ability to communicate a health care decision." The proposed new statutory form, in using layperson language to describe "capacity" uses the phrase "if I am unable to decide or speak for myself." This phrase is not technically accurate, based on the definition of "capacity" as the ability to understand and communicate. The proposed amendment would clarify the language in the optional statutory form to use the phrase: "If I am unable to make and communicate health care decisions for myself."

Principal's Statement
Under current law in section 23-06.5-10 for appointment of a health care agent, a resident of a long term care facility or hospital patient or person being admitted to a hospital must have the nature and effect of an agent appointment explained to them. The proposed statutory form includes new language incorporating an acknowledgment of this process, as used currently in a form used by the ND Long Term Care Ombudsman (page 26, line 22 through page 27, line 13). Section 23-06.5-10 also provides in current law that the verbal explanation is not necessary if the resident or patient reads a written explanation of the appointment of an agent. A "Principal's Statement" acknowledging that the resident or patient read a written explanation should also be included. The proposed amendment would include such a statement.

Provider as Agent
The amendment would retain the current restriction on who can, and cannot, be an agent as provided in section 23-06.5-04.

1. Amd: uglem - Pietsch
unam - 12-0-0

Date: 3/21/05

Roll Call Vote #: 2 - Devlin - Weisz
11-1-0

2005 HOUSE STANDING COMMITTEE ROLL CALL
BILL/RESOLUTION NO. SB 2343

House Human Services **Committee**

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken Do Pass As Amd

Motion Made By **Rep.** Devlin Seconded By **Rep** Weisz

Representatives	Yes	No	Representatives	Yes	No
Chairman C.S. **Price**	✓		Rep.L. **Kaldor**	↘	
V Chrm.G. **Kreidt**	✓		Rep.L. **Potter**		✓
Rep. V. **Pietsch**	✓		Rep.S. **Sandvig**	↘	
Rep.J.O. **Nelson**	✓				
Rep.W.R. **Devlin**	✓				
Rep.T. **Porter**	✓				
Rep.G. **Uglem**	✓				
Rep C. **Damschen**	✓				
Rep.R. **Weisz**	✓				

Total **Yes** 11 **No** 1

Absent 0

Floor Assignment **Rep.** Weisz

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

SB 2343, as engrossed: Human Services Committee (Rep. Price, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (11 YEAS, 1 NAY, 0 ABSENT AND NOT VOTING). Engrossed SB 2343 was placed on the Sixth order on the calendar.

Page 1, line 3, remove "23-06.5-04,"

Page 4, remove lines 19 through 30

Page 5, remove lines 1 and 2

Page 6, line 24, after the underscored semicolon insert "and"

Page 6, remove lines 25 through 27

Page 6, line 28, replace "8." with "7."

Page 7, line 3, overstrike "a duty" and insert immediately thereafter "authority"

Page 18, line 26, replace "decide or speak" with "make and communicate health care decisions"

Page 19, line 4, after "make" insert "and communicate"

Page 19, line 10, replace "DECIDE OR SPEAK" with "MAKE AND COMMUNICATE HEALTH CARE DECISIONS"

Page 19, line 15, after the underscored period insert "None of the following may be designated as your agent: your treating health care provider, a nonrelative employee of your treating health care provider, an operator of a long-term care facility, or a nonrelative employee of a long-term care facility."

Page 19, line 16, replace "decide or speak" with "make and communicate health care decisions"

Page 19, line 30, replace "DECIDE OR SPEAK" with "MAKE AND COMMUNICATE HEALTH CARE DECISIONS"

Page 20, line 5, replace "decide or speak" with "make and communicate health care decisions"

Page 21, line 6, replace "decide or speak" with "make and communicate health care decisions"

Page 22, line 12, replace "decide or" with "make and communicate health care decisions"

Page 22, line 13, remove "speak"

Page 22, line 17, replace "decide or speak" with "make and communicate health care decisions"

Page 22, line 21, replace "decide or speak" with "make and communicate health care decisions"

Page 22, line 26, replace "decide or speak" with "make and communicate health care decisions"

Page 26, after line 21, insert:

"PRINCIPAL'S STATEMENT

I have read a written explanation of the nature and effect of an appointment of a health care agent that is attached to my health care directive.

Dated this day of , 20 .

_____

(Signature of Principal)"

Page 26, line 24, after the underscored period insert "This statement does not need to be completed if the resident has read a written explanation of the nature and effect of an appointment of a health care agent and completed the Principal's Statement above."

Page 27, line 5, after the underscored period insert "This statement does not need to be completed if the patient or person being admitted has read a written explanation of the nature and effect of an appointment of a health care agent and completed the Principal's Statement above."

Renumber accordingly

2005 TESTIMONY

SB 2343

Sen. Judy Lee
Att 1a.

Senate Bill No. 2343

Advance Directives

SB 2343 would establish a single advance directive document, called the "health care directive," by combining the current "living will" in chapter 23-06.4 and the "durable power of attorney for health care" in chapter 23-06.5. The bill would also provide for a new, combined statutory health directive form, based on the statutory form currently in use in Minnesota.

From 1998 through 2003, I participated as a representative of the Legislative Assembly in a coalition of state organizations and individuals committed to improving end-of-life care in North Dakota. The coalition project, known as *Matters of Life and Death*, initiated efforts to educate professionals and the public on advance care planning. A telephone survey conducted early in the project found that there is a lack of public understanding and knowledge in North Dakota about advance care planning. We engaged in a comprehensive public education effort at that time, which included the publication of a guide to advance care planning and an effort to develop an advance directive form that incorporates both the living will and durable power of attorney for health care. Other barriers to planning were also identified, including the complex and often confusing nature of advance directive legal forms; that advance directives do not always adequately inform physicians of the patient's wishes or communicate important values; and that advance care planning often occurs as crisis decision making or is focused on the act of completing a legal form rather than engaging in a process of conversation and listening with family members, friends and health professionals..

SB 2343 responds to the need to address confusion with our advance directive laws, which conflict in various ways. In 2001, I sponsored legislation that conformed the witnessing requirements between chapters 23-06.4 (living will) and 23-06.5 (durable power of attorney for health care) and addressed other issues in the spirit of making our advance directives more user friendly and encouraging North Dakotans to plan in advance for their health care needs. After our legislative effort in 2001, I encouraged representatives of the *Matters of Life & Death* Project to continue efforts to improve our advance directive laws. SB 2343 is the product of that continued effort. SB 2343 would take the next step in combining both advance directive

chapters and creating a single advance directive that incorporates the features of both the living will and the durable power of attorney for health care.

I encourage the committee to consider this proposal as a good, forward step in improving the opportunity for people in North Dakota to plan for their future health care needs. I understand there are proposed amendments that will be offered by Bruce Levi of the North Dakota Medical Association. I urge you to work further on this bill if necessary, and recommend a "DO PASS" as amended.

Att #1b.

ND Medical Association

Testimony in Support of Senate Bill No. 2343
Senate Judiciary Committee
February 8, 2005

Mr. Chairman, Members of the Senate Judiciary Committee, my name is Bruce Levi and I represent the North Dakota Medical Association. NDMA is the professional membership organization for North Dakota physicians, residents and medical students.

The North Dakota Medical Association supports Senate Bill No. 2343.

SB 2343 would establish a single advance directive document, called the "health care directive," by combining the current "living will (ch. 23-06.4)" and the "durable power of attorney for health care (ch. 23-06.5)." The bill would also provide for a new, combined statutory health directive form, based on the statutory form currently in use in Minnesota.

My written testimony includes proposed amendments, which are attached. The amendments provide additional changes which were missed in the drafting and some additional clarification, as well as correcting several typographical errors.

I've also attached an article from the American Bar Association's *Probate & Property* publication which discusses how a state's advance care planning laws impact advance planning and drafting by attorneys, as well as care provided by medical professionals. That article describes well the notion that effective health care advance planning is more than simply signing a legal form. The goal is meaningful communication that defines and communicates an individual's values and wishes about treatment to physicians and other health professionals, or to an appointed agent or surrogate decisionmaker, in anticipation of the individual losing the capacity to make or communicate health care decisions. The article also describes some of the shortcomings of advance directives which are the impetus for SB 2343.

Advance directive statutes provide a pathway for expressing wishes and preferences for end-of-life care. From 1998 through 2003, the North Dakota Medical Association participated in a coalition of state organizations and individuals committed to improving end-of-life care in North Dakota. The coalition project, known as *Matters of Life and Death*, initiated efforts to educate professionals and the public on advance care planning.

As part of the *Matters of Life and Death* project, barriers to advance care planning were identified. Surveys found that there is a lack of public understanding and knowledge in North Dakota about advance care planning. Other barriers include the complex and often confusing nature of advance directive legal forms; that advance directives do not always adequately inform physicians of the patient's wishes or communicate important values; and that advance care planning often occurs as crisis decision making or is focused on the act of completing a legal form rather than engaging in a process of conversation, listening, and reflective decision making.

Development of North Dakota's Advance Directive Laws

Our laws in North Dakota on advance directives were developed much like other states – in a piece-meal manner starting with the adoption in 1989 of the "Uniform Rights of Terminally Ill Act (1985)" in chapter 23-06.4, which is better known as the "living will" advance directive law [1989 HB 1481, Rep. DeMers]. The living will law is narrowly construed to allow an adult to execute a directive governing the withholding or withdrawal of life-sustaining treatment. The law provides both civil and criminal immunity for physicians and other health care providers for their actions in accordance with declarations made under chapter 23-06.4, as long as the actions are not done in a grossly negligent manner. In 1991, chapter 23-06.5 authorizing the use of the durable power of attorney for health care was adopted [1991 HB 1384, Rep. DeMers]. That law provides the parameters for appointing an agent to make health care decisions if the individual executing the power of attorney, known as the "principal," later lacks capacity to make decisions.

Further revisions to chapter 23-06.4 relating to the administration, withholding or withdrawal of nutrition and hydration and the statutory living will form were added in 1993, based on recommendations developed by a forum initiated by Chief Justice Ralph Erickstad and comprised of a number of diverse stakeholders [1993 SB 2394 / Sen. DeMers, Rep. Price]. Later, in 1994, the Legislative Council's interim Judiciary Committee considered the new Uniform Health Care Decisions Act approved by the National Conference of Commissioners on Uniform State Laws in 1993 (1993 Uniform Act). That Act would have replaced North Dakota's laws relating to living wills and powers of attorney for health care with a single statute. At that time testimony in opposition to the 1993 Uniform Act indicated that the basic premise of the Act

was good because it would have consolidated and coordinated legislation from 1989 through 1993 concerning living wills, durable powers of attorney for health care and our substituted judgment law in section 23-12-13. However, the conclusion by the interim committee in 1994 was that "the existing laws had not been in effect long enough to sufficiently evaluate their effectiveness," and consideration of the 1993 Uniform Act was "postponed."

In 2001, various organizations involved in the *Matters of Life and Death* project worked to enact a measure sponsored by Sen. Judy Lee which conformed witnessing requirements between the living will and the durable power of attorney for health care, allowed for verifying signatures by notary, and clarified that the statutory forms for both the living will and durable power of attorney for health care were "preferred" forms, but not required forms. One of the primary purposes for the 2001 legislation was to change our advance directives statutes to allow for the use of other advance directive forms, forms that are more conducive to the process of advance care planning.

Moving Toward Simplification and More Flexibility in Use of Directives

During the 1990's, states began moving towards simplification and greater flexibility in the use of advance directives, primarily as a result of the 1993 Uniform Act. Many states have combined their laws on advance directives into comprehensive advance directive Acts, which cover living wills and the durable power of attorney for healthcare in the same law. Minnesota is one such state that now has a comprehensive advance directive law.

As recognized in the ABA literature, multiple advance directive laws within a single state increase the likelihood of inconsistency and confusion within the state's own laws. North Dakota law on advance directives evolved much like other state laws with the incremental passage of multiple statutes. At least 16 states have now accomplished the goal of merging all or most of their separate laws into one comprehensive statute.

SB 2343 represents an effort to address the fragmentation and conflict among the statutes relating to living wills and durable power of attorney for health care. The bill would take a step forward in addressing the increasing demand for simplicity and flexibility in the legal tools that were created for healthcare advance planning, and clarify some issues resulting from different

language and standards used for the existing "living will" and durable power of attorney for health care (DPAHC). The bill was drafted in an effort which included participation by NDMA's Commission on Ethics, attorneys Paul Richard and Jane Voglewede of Meritcare, and Christopher Dodson of the North Dakota Catholic Conference. The bill is an effort to combine chapters 23-06.4 and 23-06.5, by moving much of the language in chapter 23-06.4 with respect to living wills into the DPAHC law, chapter 23-06.5. The result is the recognition of a combined statutory framework which recognizes a new advance directive called the "health care directive."

SB 2343 Summary

•*Cross References*

Section 1 would amend a cross reference to chapter 23-06.4, which would be repealed under section 20 of the bill, in the criminal statute relating to endangering a vulnerable adult.

•*Statement of Purpose* (23-06.5-01)

Section 2 would incorporate the legislative intent language from section 23-06.4-01 (living will) into the existing statement of purpose provision in section 23-06.5-01 (DPAHC). The living will language in section 23-06.4-01 currently states that "every competent adult has the right and responsibility to control the decisions relating the adult's own medical care, including the decision to have medical or surgical means or procedures calculated to prolong the adult's life provided, withheld, or withdrawn." The legislative intent provision in chapter 23-06.4 would be repealed in section 20 of the bill.

•*Definitions* (23-06.5-02)

Section 3 would provide new terminology in the definitions provision in chapter 23-06.5 to incorporate the concept of a combined advance directive or "health care directive." The definitions provision in chapter 23-06.4 would be repealed by section 20 of the bill.

Subsections 1 and 4 would remove references to the durable power of attorney for health care.

Subsection 3 would clarify the definition of "capacity" as it is used in this context to include the ability of an individual to communicate a health care decision. This is language used in the 1993 Uniform Act and Minnesota. This definition is important in determining when the

authority of an agent becomes operative or when instructions include in a health care directive become operative under subsection 3 of section 23-06.5-03 (section 4).

Subsection 4 would expand the definition of the term "health care decision" to include the selection and discharge of health care providers and institutions, the approval or disapproval of diagnostic tests, surgical procedures, programs of medication and orders not to resuscitate, and directions to provide, withhold, or withdraw artificial nutrition and hydration in subdivisions (a) through (c). This language is derived from the 1993 Uniform Act. The additional language in subdivision (d) would extend the term to health care related issues regarding an individual's personal security and residence, and is derived from Minnesota law (MN Stat. 145C.01(4)).

Subsection 5 introduces the term "health care directive," which would be the operative language describing the new combined advance directive and is derived from Minnesota law. A health care directive would include one or more health care instructions (defined in subsection 6), a power of attorney for health care, or both.

Subsection 6 would define the term "health care instruction," a term used to describe the various means by which an individual might provide direction regarding future health care decisions as derived from Minnesota law (MN Stat. 145C.01(7a)).

Subsection 9 would remove the DPAHC reference in the definition of "principal," which is an adult who executes a health care directive.

•*Execution of a Health Care Directive* (23-06.5-03)

Section 4 would amend subsection 1 of section 23-06.5-03 to provide the operative language authorizing an adult to execute a health care directive. This language, derived from Minnesota law, provides that the directive may include one or more health care instructions to health care providers, others assisting with health care, family members, or the individual's appointed agent. The directive could also include a power of attorney appointing an agent to make health care decisions for the principal when the principal lacks the capacity to make health care decisions.

Subsection 2 of section 23-06.5-03 would be amended to clarify the standards used by an agent in making decisions on behalf of the principal, after consultation with the attending physician and other health care providers. The new language in subdivision (b) requiring the agent to consider the principal's personal values to the extent known when the principal's

wishes are unknown and the "best interests" of the principal are being assessed, is derived from the 1993 Uniform Act. As indicated in comments to the 1993 Uniform Act, this language "does not prescribe a detailed list of factors for determining the principal's best interests but instead grants the agent discretion to ascertain and weigh the factors likely to be of importance to the principal."

Subsection 3 of section 23-06.5-03 would be amended to clarify that the agent's authority ceases whenever a determination is made that the principal has recovered capacity, which is also language derived from the 1993 Uniform Act.

•*Agent Restrictions* (23-06.5-04)

Section 5 would amend section 23-06.5-04, which restricts who can act as an agent, by allowing a health care or long-term care provider who is a relative of the principal to act as an agent, but not nonrelatives. This is the approach used in Minnesota (MN Stat. 145C.03(2)).

•*Health Care Directive Requirements* (23-06.5-05)

Section 6 would amend section 23-06.5-05 by incorporating language from Minnesota law in setting forth requirements for health care directives (MN Stat. 145C.03(1)). Subsection 1 of section 23-06.5-04 would require that a health care directive be in writing, be dated, state the principal's name, be executed by a principal who has the capacity to do so by signature, and contain verification of that signature by notary or through witnesses. A healthcare directive would be required to include a health care instruction, a power of attorney for health care, or both.

•*Suggested Health Care Directive Form*

Section 7 would create a new section to chapter 23-06.5 that provides a list of other provisions that might be included in a health care directive, but not limit what provisions might be included. This language is incorporated from Minnesota law (MN Stat. 145C.05). It suggests that the following items may also be part of a healthcare directive:

1. The designation of alternate agents that could act if the named agent is not reasonably available;

2. Specific directions and authority to appoint joint agents and the process or standards by which joint agents would reach a healthcare decision;

3. Limitations on the right of an agent or alternate agents to review, obtain copies of, or consent to the disclosure of the principal's medical records (see section 10 on inspection and disclosure of medical information);

4. Any limitations on the nomination of the agent as a guardian;

5. An anatomical gift provision;

6. Any limitations to the effect of a divorce or annulment on the appointment of an agent;

7. Any specific reasons why a principal would want a health care provider or an employee of a health care provider to be eligible to act as the principal's agent; and

8. Any health care instructions regarding artificially administered nutrition or hydration.

•*Agent Acceptance and Withdrawal* (23-06.5-06)

Section 8 would amend section 23-06.5-06 in using the term "incapacitated," rather than "incapable," in addressing when the agent's authority to make health care decisions begins. The language is more consistent with the "capacity" definition used in section 23-06.5-02.

•*Revocation of a Health Care Directive* (23-06.5-07)

Section 9 would amend section 23-06.5-07, applying the current revocation provision relating to a durable power of attorney for health care to a health care directive.

Subsection 1 would provide that an individual may revoke a directive by notification orally or in writing or by any other act evidencing a specific intent to revoke the directive.

Subsection 2 would make minor changes in the provision requiring the provider to record the revocation in the principal's medical record and notify any agent, the attending physician, and staff responsible for the principal's care of the revocation.

Subsection 3 would clarify the current requirement that if the spouse is the principal's agent, the divorce of the principal and spouse revokes the appointment of the divorced spouse as the principal's agent. The clarification specifies that the appointment revocation in such a case could be addressed in the health care directive. A similar provision is allowed in subsection 6 of the new section to chapter 23-06.5 provided in section 7.

•*Inspection and Disclosure of Medical Information* (23-06.5-08)

Section 10 would amend section 23-06.5-08 in addressing the inspection and disclosure of medical information. Only minor changes would be made in referencing the health care directive rather than the durable power of attorney for health care. An agent stands in the shoes of the patient when making health care decisions. To assure fully informed decision making, this section provides that an agent who is then authorized to make healthcare decisions for a patient has the same right of access to healthcare information as does the patient. However, that right could be limited by the specifying otherwise in the health care directive, as also provided under subsection 3 of section 7.

•*Duties of Provider* (23-06.5-09)

Section 11 would amend section 23-06.5-09 in identifying the obligations of the health care or long term care provider.

Subsection 1 would provide minor changes incorporating the new health care directive language. That section requires providers to follow the healthcare decisions of the principal's agent or a healthcare instruction to the extent they are consistent with chapter. 23-06.5 and the health care directive.

Subsection 2 incorporates language from the 1993 Uniform Act in recognizing that a health care or long term care services provider may decline to comply with a health care decision of an agent or health care instruction for reasons of conscience or other conflict. The provision would require a provider that declines to comply with a health care decision or instruction to take all reasonable steps to transfer care of the principal to another health care provider who is willing to honor the agent's health care decision or instruction or directive. In such a case, the provider is required to provide continuing care to the principal until a transfer can be effected. Subsections 3, 5, and 6 are current provisions of chapter 23-06.4, which are incorporated in the revised chapter 23-06.5.

Subsection 3 takes the current subsection 6 of section 23-06.4-11 in providing that the health care directive law does not require any physician or other health care provider to take any action contrary to reasonable medical standards.

Subsection 4 states that the chapter would not affect the responsibility of the attending physician or other health care provider to provide treatment for a patient's comfort, care, or alleviation of pain, as derived from Minnesota law.

Subsection 5 incorporates current language from section 23-06.4-07, requiring that care be provided to a pregnant principal except under specific circumstances provided under current law.

Subsection 6 incorporates current language in section 23-06.4-06.1 relating to the withdrawal, withholding, or administering of nutrition or hydration, which was enacted in 1993.

• *Undue Influence* (23-06.5-10)

Section 12 would make minor changes to section 23-06.5-10. These provisions provide assurance that the principal's actions in executing a health care directive or appointing an agent are free from undue influence. The bill would remove what is essentially a statement of legislative intent in subsection 2 (page 10, lines 6 through 10).

• *Reciprocity With Other States* (23-06.5-11)

Section 13 would revise the current reciprocity provision in section 23-06.5-11 by providing the technical reference to a health care directive rather than to a durable power of attorney for healthcare. That section states that the chapter does not limit the enforceability of a health care directive or similar instrument executed in another state or jurisdiction in compliance with the law of that state or jurisdiction.

• *Immunity* (23-06.5-12)

Section 14 would amend section 23-06.5-12 to expand the current immunity provisions provided in that section for actions taken in good faith by an agent or health care or long term care provider.

Subsection 1 would expand that immunity to persons authorized to provide informed consent under section 23-12-13, consistent with the approach of the 1993 Uniform Act.

Subsection 3 would incorporate language derived from Minnesota law (MN Stat. 145C.11) providing immunity to a provider who administers health care necessary to keep the principal alive, despite a health care decision of the agent to withhold or withdraw that health care, or a provider who withholds health care that the provider has determined to be contrary to

reasonable medical standards, despite a health care decision of the agent so long as the provider takes all reasonable steps to promptly notify the agent of the health care provider's unwillingness to comply, document the notification in the principal's medical record, and permit the agent to arrange to transfer care of the principal to another health care provider willing to comply with the decision of the agent.

•*Presumptions and Applications* (23-06.5-13)

Section 15 would amend section 23-06.5-13 to provide a variety of presumptions and application statements that would apply to the execution of a health care directive. Subsections 1 and 2 provide technical changes in language regarding which documents take precedence over others. Subsections 3 through 8 are derived from Minnesota law (145C.10). Subsection 9 incorporates current language from section 23-06.4-11(1). Subsection 10 incorporates language from section 23-06.4-11(2). Subsection 11 incorporates language from section 23-06.4-11(3). Subsection 12 incorporates language from section 23-06.4-11(5). Subsection 13 incorporates current language from section 23-06.4-11(7).

•*Previously Executed Directives* (23-06.5-15)

Section 16 would revise section 23-06.5-15 in continuing to provide legal recognition to previously executed health care directives, including durable powers of attorney executed under chapter 23-06.5 and "living wills" executed under chapter 23-06.4 before the effective date of SB 2343.

•*Statutory Form* (23-06.5-16)

Section 17 would revise section 23-06.5-16 with language derived from the 1993 Uniform Act that would clarify that the statutory form provided in section 18 would be an optional form and not a required form by which a person may execute a health care directive. Any other form may be used if it complies with chapter 23-06.5.

•*Optional Health Care Directive Form* (23-06.5-17)

Section 18 would provide an optional form that incorporates requirements applicable to health care directives, amending the current durable power of attorney for health care form in section 23-06.5-17. Statutory forms provide a number of benefits. Because the form is standard and widely available, individuals who would otherwise be reluctant to pay to have a form prepared

are more likely to execute an advance directive. The availability of an officially sanctioned form would reduce the reluctance of health care providers to honor a directive. Through continued use of the form, health care professionals can also become more familiar with its provisions and make more informed decisions.

The optional form in SB 2343 is derived from Minnesota law (MN Stat. 145C.16). There are four parts to the form. An individual may, or may not decide to complete part one of the form which would provide for the appointment of an agent. An individual may, or may not, decide to complete part two of the form which provides an opportunity to give health care instructions to guide others, including the agent, in making health care decisions. An individual may also, but need not, complete part three which would allow an individual to make an anatomical gift upon their death. Part four of the form would incorporate current North Dakota provisions relating to the signing or notarizing of the optional form.

•*Penalties* (23-06.5-18)

Section 19 would make minor changes in the language in section 23-06.5-18 in imposing penalties upon individuals who willfully conceal or destroy revocation or willfully alter, forge, conceal or destroy a health care directive.

•*Repealer*

Section 20 would repeal the current "living will" chapter, chapter 23-06.4.

On behalf of the North Dakota medical Association, I urge you to recommend a "DO PASS" on SB 2343 with the proposed amendments. Thank you Mr. Chairman.

Att #2

ND Medical Association
February 8, 2005

PROPOSED AMENDMENTS TO SB 2343

Page 4, line 24, after "provider" insert "unless specific reasons why the principal wants a health care provider to act as agent are provided in the health care directive"
Page 4, line 25, after "provider" insert "unless specific reasons why the principal wants a health care provider to act as agent are provided in the health care directive"

Page 5, line 13, replace the first underscored comma with "or" and remove "durable"

Page 6, line 20, replace "to" with "regarding"

Page 7, line 11, overstrike "power" and insert immediately thereafter "directive"

Page 10, line 28, overstrike "durable power of attorney for" and after "care" insert "directive"

Page 11, line 19, replace "Permit the agent to arrange" with "Arranges"

Page 11, line 25, overstrike "a durable power of"
Page 11, line 26, overstrike "attorney for health care" and insert immediately thereafter "the appointment of an agent in a health care directive"

Page 12, line 21, replace "withdrawl" with "withdrawal"
Page 12, line 28, replace "withdrawl" with "withdrawal"
Page 12, line 29, replace "qualified patient" with "principal"

Page 13, line 4, replace "withdrawl" with "withdrawal"
Page 13, line 10, after "**attorney**" insert "**or other directives**"

Page 18, line 23, replace "know" with "known", after "or" insert "my agent", and replace "may" with "my"

Renumber accordingly

3a

American Bar Association

Publications

Section of Real Property, Probate, and Trust Law

PROBATE & PROPERTY

July/August 2001

Advance Planning and Drafting for Health Care Decisions

By Rebecca C. Morgan and Charles P. Sabatino

Effective health care advance planning requires two things: meaningful conversation and more meaningful conversation. Having a written and executed health care advance directive is *not* the goal of legal planning for health care. Instead, the goal is to define and communicate the client's values and wishes about treatment to caregivers and surrogate decision makers in anticipation of the client's losing the capacity to make health care decisions personally.

Many people neither sign advance directives nor discuss with loved ones their wishes about health care decisions if they become incapacitated. Signing an advance directive cannot by itself accomplish the goals of health care planning, but it can provide a good starting point for the decision making process.

Research indicates that it is difficult to get people to engage in advance planning, despite a variety of educational initiatives. Although public education certainly helps, most people will never meaningfully engage in health care advance planning. There is a cultural aversion to the subject matter, but there is also a dissatisfaction with the legal tools. This article discusses some of the problems with the state advance directive laws and standardized forms, explains what advance directives can and cannot do, and suggests six steps for effective client counseling on this important but difficult-to-discuss topic.

Shortcomings of Advance Directives

Every state has one or more advance directive laws. Over the past 25 years, many layers of these laws have contributed to a great deal of confusion and complexity. A state may have separate statutory provisions for health care directives (i.e., living wills), durable powers of attorney for health care, default surrogate decision making, out-of-hospital do-not-resuscitate orders and even special mental health powers of attorney. States lack uniformity. In the last few years, states have begun to simplify and combine these separate laws, but much more needs to be done.

Generally, advance directive statutes limit the liability of health care providers. These

statutes confer protection from liability or professional discipline for those who honor a directive in good faith. Mostly the statutes provide a process for making a directive but do not provide any true penalties for failing to enforce or honor such a directive. Rather, they mandate only a good faith effort to transfer the patient to a doctor or facility that will comply with the patient's directive. Enforcement is left to the courts in "wrongful life" suits, which have met with varying results.

Many states provide sample or suggested form directives within the statute. Some statutes make these forms mandatory and discourage the use of writings that are not substantially similar. There are other forms developed by organizations—such as the Five Wishes document available from Aging with Dignity—that have been drafted to comply with the majority of state statutes.

Rigid requirements for validity make a national model advance directive virtually impossible. Many states require precise witnessing and execution formalities. Others mandate multiple medical preconditions before the directive becomes effective. These medical preconditions, such as "terminal condition" and "permanent unconsciousness," are neither defined consistently among the states nor understood clearly. Moreover, patients may want certain treatments withheld under conditions not authorized by the statute.

Research has shown that advance directives simply do not provide much guidance to medical professionals. One study concluded that the standardized and general language of most advance directives does not address the complicated situations encountered by medical professionals. As a result, the directives fail to inform medical decision making beyond the naming of a health care proxy or surrogate. Joan Teno, et al., *Do Advance Directives Provide Instructions That Direct Care?*, 45 J. Am. Geriatric Soc. 508 (1997).

A study of the Maryland statutory advance directive form highlights another problem with statutory forms. Researchers interviewed more than 80 seniors who had completed the Maryland statutory form and then reviewed the completed forms. They found that 41% of the group gave internally inconsistent instructions within the form. When asked their wishes in different scenarios, in face-to-face interviews, up to 45% of the respondents gave answers inconsistent with their written instructions. Gender, education, occupation and race made little difference in the results. Dianne E. Hoffman, et al., *The Dangers of Directives or the False Security of Forms*, 24 J. Law, Medicine & Ethics 5 (1996). These results raise serious questions about the validity and reliability of standardized statutory forms.

Instead of focusing on an instructional directive, the appointment of an agent deserves priority in advance planning if the client has a trusted advocate on whom to rely. A health care agent can weigh all the facts and circumstances at the time an actual decision must be made and, presumably, make the decision the patient would have made. Naming an agent will succeed only if the agent knows the principal's wishes. Most lawyers who prepare advance directives for clients recommend that the client discuss the directive with the named agent and the client's physician. In practice, clients rarely follow through. Thus it is not surprising that individuals may prefer to spell out their wishes in writing.

As a practical matter, health care professionals cannot implement advance directives about which they have not been told. For the most part, the burden of notifying the health care professionals of the existence of a directive falls squarely with the client. The Patient Self-Determination Act, passed in 1990, requires certain health care professionals to ask a patient about the existence of an advance directive at the time of

admission to a health care facility and to document it in the patient's record. See §§ 4206 and 4751, Omnibus Reconciliation Act of 1990, P.L. 101-508. In most instances, documentation merely re-quires a notation that a directive exists. The patient, agent or family members must provide a copy of the directive and ask that it be included in the patient's medical record. Even at that point, documentation guarantees nothing. If the patient moves to another hospital or nursing home, there is likewise no guarantee that the document will travel with the patient. The process starts again.

Proponents of advance directives suggest a variety of additional strategies, such as carrying a wallet card or filing directives with a private living will registry. Although these may help, the honoring of an incapacitated patient's wishes depends on a health care professional's immediate awareness of the directive and the initiative of the appointed agent.

What Advance Directives Cannot Do

Advance directives were designed to help clients accomplish end-of-life medical planning. Paradoxically, advance directives may help clients avoid the real task of end-of-life planning. Executing an advance directive may create a safe, legal fiction that the directive will accomplish the client's wishes regarding end-of-life care while the reality is far different.

There are at least four things advance directives **cannot** do. A directive cannot provide "cookbook" directions. Dying is just too complicated. It is individualized, personalized, sacred, profane and endlessly nuanced. A directive cannot eliminate an individual's personal ambivalence. Most clients have some level of am-bivalence for themselves and for loved ones when faced with balancing the length of life versus quality of life. Goals and wishes can and do change with passage of time and with changes in a client's medical condition, level of functioning, treatment options and quality of life.

An advance directive is a poor substitute for discussions among the client, the family and the health care professional. Effective advance planning must be a continuing conversation. The relationship between principal and proxy is a covenant, not a contract. If the client perceives the execution of an advance directive as the end point, the conversation ends. There is simply no substitute for continued communication among all the parties concerned.

Finally, an advance directive can-not control health care professionals. Whether because of a disagreement with the client's wishes, professional objection or an ambiguity in the document, a health care professional may simply overrule or ignore the client's directive or object based on conscience, an option provided in almost every state's law.

What Advance Directives Can Do

Advance planning is a process of reflection and communication, and advance directives play a threefold role in the process. A directive should serve as a catalyst for thinking, discussing and clarifying values and wishes. In addition, directives can enable the client to choose a substitute decision maker. Finally, they can provide guideposts for the course of treatment to the extent the client desires, as long as the directive is a true reflection of the client's wishes and not a generic, one-size-fits-all directive.

Public Policy Implications

Public policy directly affects the options available, the choices made and the documents drafted. Legislatures must determine what the basic elements of advance planning public policy should look like. Four principles that merit explicit incorporation into advance planning legislation are as follows:

- Good health care decision making requires a meaningful, ongoing process of communication among patient, family and health care provider about present and future health care decisions, shaped primarily by the patient's needs, values and goals.
- Advance directive statutes provide a nonexclusive pathway for expressing wishes and preferences for end-of-life care. Constitutional, common law, medical and ethical principles require respect for any other authentic expression of one's wishes about care and treatment.
- Public policy and education initiatives should provide a variety of advance planning tools and forms, since no two people approach the task in exactly the same way and no one form or planning tool is ideal for everyone.
- Statutory advance directive rules require simple, flexible, user-friendly and meaningful interpretation and implementation, so that the process is tailored to meet the individual's needs as well as personal and cultural preferences.
  To realize these principles, advance directive laws should be amended where necessary to:
- Avoid standardized statutory forms, since they tend to elevate form over substance.
- Permit wide latitude in both proxy instructions and authority.
- Avoid mandatory medical preconditions.
- Give priority to naming a proxy.
- Honor rather than preempt authentic instructions, regardless of the manner in which instructions are expressed.
- Address continuity across care settings by ensuring that patients' wishes follow them.
- Recognize default surrogates in the absence of a directive.

Most state advance directive laws do not contain these characteristics. The Uniform Health-Care Decisions Act comes closest to these attributes, although it, too, insists on including a suggested form and does not ad-dress the issue of continuity across care settings.

The Six Steps to Effective Counseling

Lawyers should offer clients advance planning services, not just advance directives. This does not mean spending hours discussing a client's deepest personal values and beliefs and facilitating maximum communication among client, family and providers. It does mean more than simply printing out the standard advance directive form. The "print and sign" routine is the essence of fast food advance planning. There are six steps a lawyer should take to serve clients well:

1. Incorporate advance planning as routine. Health care advance planning should be incorporated into the practice as a routine and essential part of estate planning. If the clients do not bring it up, the lawyer must.

2. Give clients homework. Do not provide form advance directives to clients. Clients can be given homework that informs them and stimulates thinking and discussion before they sign an advance directive. There are good workbooks, values histories and similar tools available to help lawyers do this. For example, the ABA recently published *The*

Lawyer's Tool Kit for Health Care Advance Planning, which includes 10 worksheets that can be provided to clients to help them understand, think about and discuss advance planning, preferably before signing an advance directive. See **http://www.abanet.org/elderly**.

3. Discuss a power of attorney for health care. If the client has someone who can and will fulfill the job, give priority to creating a durable power of attorney for health care. The job of health care agent or proxy is not one with which most people are familiar. It is not an easy job, so a lawyer should counsel both the client and the health care agent. With the client's consent, the agent could attend an orientation by trained staff designed to make sure that the agent knows the job description and is willing to fulfill it. Clients should share the results of their homework with the agent. Completed worksheets or similar tools can add depth to the agent's understanding of the client's values and wishes.

Clients need to understand the importance of having open and direct discussions with the agent so the agent clearly understands his or her duties and obligations as well as the client's wishes and preferences. If the agent does not intend to carry out the client's decisions or will not be capable, emotionally or otherwise, of making the necessary decisions, then the client needs to select another to serve as the agent.

Lawyers must especially be sure that the client understands the factors to consider in selecting a proxy, such as the proxy's willingness to make decisions, to implement the client's wishes and not override the client's wishes with the proxy's personal views and to be available to health care providers when and where decisions need to be made. The attorney also needs to counsel the client about the pitfalls of naming joint agents. A client may request this because the client has more than one child and does not want to appear to be playing favorites. All co-agents must agree to a course of action unless the directive contains some provision for decision making in the event of a disagreement.

Clients need to understand that the desire to avoid the appearance of favoritism among their children might actually become an impediment to effectively implementing the client's wishes. Instead, the client could appoint one agent and singular successors but provide that the proxy consult with the other children in the decision making process. In drafting such precatory language, a lawyer should be careful to stipulate that the agent is not bound by the opinions of the others. In one way or another, clients must resolve this issue and explain their decision to the children as part of the advance planning discussion.

4. Develop good counseling skills. Lawyers must develop good interviewing and counseling skills in discussing end-of-life planning with the client. End-of-life planning is a sensitive and emotional topic and, in some cases, painful for the client to consider, much less discuss. Legal staff should be sensitive to the issues involved in assisting clients with the matters and have appropriate training and decorum to effectively assist the clients in this planning process.

5. Customize language. Lawyers should customize the language of a directive to fit the client's needs. A potential limitation exists in states with a requirement that the form be "substantially" in the language contained in the statute. Although the form "substantially" can be quite liberally construed, the lawyer must make a professional judgment as to what will best serve the client. Even when state and local law does not require substantial conformity, practitioners have related stories of health care providers that refuse to honor customized advance directives merely because they do not look like the standard advance directive. The presumption of the health care providers is that

only the suggested statutory form will provide the health care provider the immunity from liability provided in the statute. Such anecdotes should not be a deterrent to the customization of an advance directive. Unless the statutory form is truly mandatory, there is no reason for immunity to be lost in honoring a customized advance directive.

The task of customizing the directive can be approached in more than one way. Giving the client two or three significantly different types of advance directive helps bring this point home. If a client chooses to include otherwise optional instructions in a directive, the client will have a greater sense of what he or she wants to say, compared to the alternative of merely checking off a box to select a standard instruction drafted by state legislators.

The lawyer should always focus on a client's priorities. Not all information necessary to the drafting of the directive is of equal importance to the client. The lawyer may be concerned about such matters as who will serve as the agent and what limitations or conditions are to be placed on the exercise of the agent's power. The client may have other concerns, such as privacy and pain control. In gathering the information and drafting the directive, lawyers must keep sight of the client's values and vision.

6. Encourage periodic review. The lawyer should encourage periodic review and discussion of the advance directive and the client's goals for end-of-life care. Priorities change with age, experience and physical and mental condition. The need for review becomes even more important as one ages and the future is not what it used to be. Lawyers can incorporate this function in their practices by scheduling periodic advance planning reviews with their clients or by simply counseling their clients to do so periodically. The client must understand that a signed advance directive should not be thrown in a drawer and forgotten. Advising a client to provide copies of the directive to the client's physician and agent is necessary advice, but it is not enough. Talking about the directive and the thinking behind it with all of the parties who may be involved in future decision making is far more important than papering the landscape with copies. Talking is the only way to ensure that no surprises will befall the client in the form of resistance to the client's wishes. The only practical way to ensure the enforcement of an advance directive is to stress the importance of communication that occurred before the presenting health decision. Effective end-of-life planning must be an ongoing, reflective communication process.

Conclusion

Lawyers must remember that the document is just one part of the process of end-of-life planning. The lawyer's most important role is to stimulate conversation and give guidance to the process. Naming and educating a health care agent or proxy deserves priority. Instructions, if included in an advance directive, should be tailored to the individual client's goals and wishes and drafted with clarity, so that the agent and health care professionals can implement them appropriately. Planning for end-of-life health care requires, above all, meaningful conversation.

Rebecca C. Morgan is a professor at Stetson University School of Law in St. Petersburg, Florida. Charles P. Sabatino is the Assistant Director of the ABA Commission on Legal Problems of the Elderly.

'Kitchen table' the place for end-of-life debate

End-of-life group urges everyone to make living wills

By KAREN HERZOG
Bismarck Tribune

Is Terri Schiavo in what is called a "persistent vegetative condition?" Could she ever recover? Should her feeding tube be removed? What would she have wanted?

The parents and siblings of the disabled Florida woman, who want to keep her alive, are bitterly divided from her husband, who is her guardian. For several years, the courts have seesawed between allowing the removal, then ordering the replacement of her feeding tube. Now the Florida Legislature and Gov. Jeb Bush have passed what is called Terri's Law — her feeding has been resumed until the next court challenge.

Florida Catholic Bishop Robert Lynch issued a statement in which he calls the situation "sad," and urging caution in denying food and water in a case with so much evidence in dispute.

If North Dakotans can learn anything from this Florida case, it's that those decisions aren't to be made at the hospital or the lawyer's office, but "around the kitchen table," said Christopher Dodson, of Jamestown, executive director of the North Dakota Catholic Conference and a member of the Matters of Life and Death project in North Dakota.

Matters of Life and Death is a coalition of 50 organizations in North Dakota committed to improving end-of-life care, said Rodger Wetzel, of Bismarck, the coalition chairman, who is director of community health, eldercare and development at St. Alexius Medical Center in Bismarck.

Wetzel listed some issues around the Schiavo situation:

"Number one, the importance of writing out advance directives, durable power of attorney for health care and living wills."

Second, "how important it is for people to communicate their wishes to their whole family."

Third, he said, it's important to learn the difference between a terminal illness and persistent vegetative state.

"We may have strong feelings about our wishes in a case of terminal cancer," he said. "But what about a permanent vegetative state (which is not a terminal illness)?"

Lastly, "these are very personal and sensitive issues that need to be addressed by family members." With the government, Legislature and courts involved in Florida, any decision from here on will be difficult, he said.

The federal Patient Self-determination Act says that competent adults have the right to make their own medical decisions, which can be expressed in writing, Wetzel said. With a durable power of attorney for health care, you can create directives and your chosen agent makes the decisions.

The form for durable power of attorney for health care has a space for a person to list specific wishes in cases, for example, of persistent vegetative state, he said.

In the end, advance directives are really about preparing someone and their family, Dodson said.

This helps ease what doctors have told Dodson is a classic, common situation — an estranged family member appears and wants to keep the ill person alive because they have issues that were never resolved.

Sometimes these difficult decisions resurrect already-existing family conflicts, Wetzel said.

"(Families) need to set other conflicts aside and ask, what is in the best interest of the patient?" he said.

Matters of Life and Death formally opposes euthanasia, Wetzel said, adding many hospitals would provide nutrition and hydration if the patient's situation was questionable.

There is no moral obligation to keep someone alive at all costs, Dodson said. If someone is near death, one doesn't need to prolong the dying process, he said.

But nutrition and hydration — feeding and liquids — is presumed to be "ordinary care" and not medical treatment, Dodson said, "until the burden outweighs the benefit. For example, if feeding is painful; if the person can no long assimilate the nutrition."

Catholic health care facilities are to use "ordinary and proportionate means with a reasonable hope of benefit and not an excessive burden," Dodson said. "But that differs for each person.

"What's not allowed is any action or omission to relieve suffering which causes death. However, you can relieve suffering (even) if it has the effect of shortening life," he said.

Bishops have differed on this, Dodson said. Dodson wouldn't characterize North Dakota's bishops' positions, "but neither bishop has a position on the persistent vegetative question, which would be binding on the faithful or Catholic facilities," he said.

"We are not in a position to comment on the Schiavo case," he said. But from appearances, death is not imminent; she is not dying, he said.

"If she is not in a persistent vegetative state, it's very clear she should be receiving nutrition and hydration. She may have a medical right to refuse, but she should have made that clear."

As a further complication, some medical experts consider persistent vegetative state a pathology; others consider it just a condition, "not an end of life, just a state.

"That's the struggle," Dodson said.

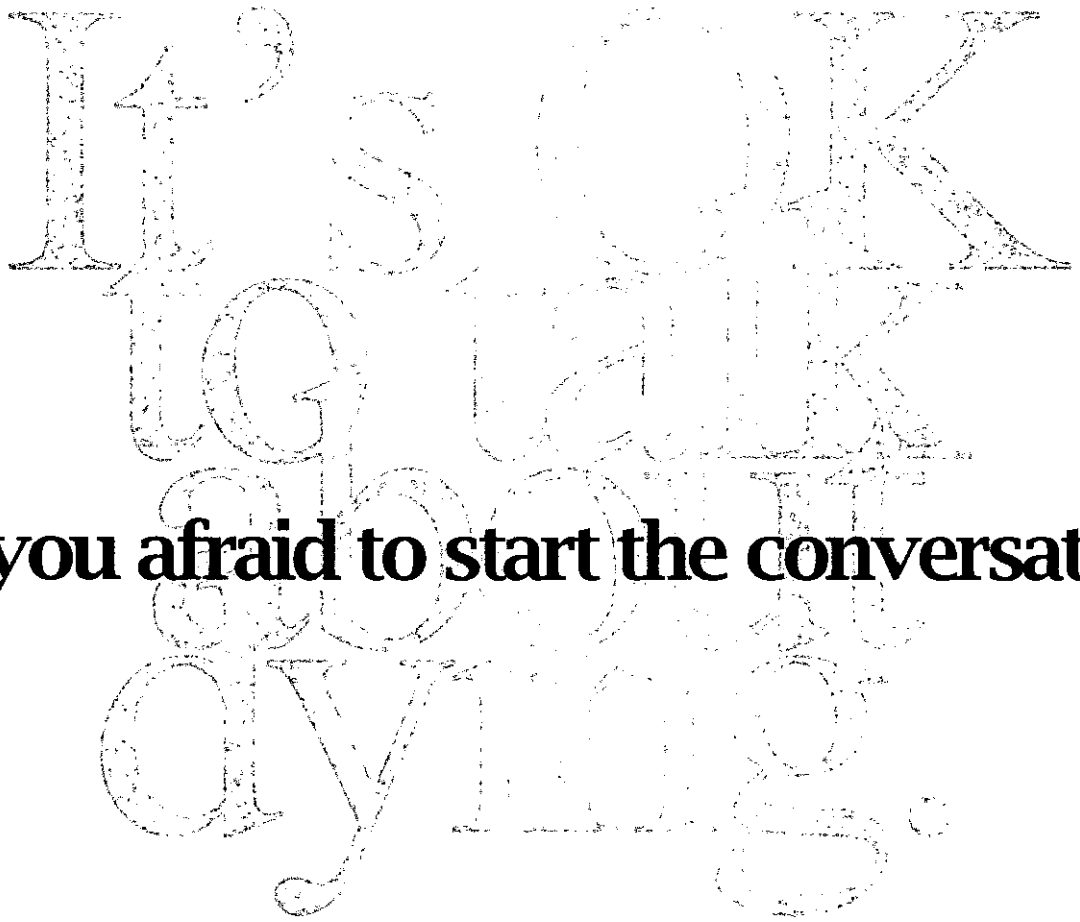
Some state law specifically addresses persistent vegetative state; North Dakota's does not, Wetzel said.

This whole case just underscores the importance of people looking at advance directives, said Bruce Levi, executive director of the North Dakota Medical Association and a member of Matters of Life and Death.

Advance directive forms are available from attorneys and from hospital and nursing home social work and pastoral care departments, Wetzel said. His office also can supply them; call 530-7389.

3b

AH 4a



Are you afraid to start the conversation?

Advance Care Planning Resource Guide for North Dakotans

In This Guide

Dear Fellow Citizens of North Dakota,

Caring for a family member or client at the end of life can be one of the most difficult experiences any of us will face. We all want life's end to be peaceful and pain free. We also want to maintain the dignity of people who are dying, and to follow their choices and wishes. Improving care at the end of life is the goal of North Dakota's Matters of Life and Death project. It is also a national goal that is being addressed in many other states.

Funded by The Robert Wood Johnson Foundation and Dakota Medical Foundation, our Matters of Life and Death project is supported by more than 50 statewide organizations, led by the North Dakota Medical Association.

We have found that many of our state's citizens do not know where to get the information necessary to help loved ones receive the care they want and need at end of life. We also have found that many of our state's citizens are unaware of the option to complete advance directives, such as a living will or durable power of attorney for health care.

There is much that professionals can do to improve care at the end of life. But there are also many things you and your family can do. You can start important conversations about your wishes for your own end-of-life care. You can communicate these wishes to your doctor and pastor. You can make plans and complete documents to make sure your wishes are followed.

As participants in the Matters of Life and Death project, it is our hope that this guide will help you and your loved ones attain a peaceful and comfortable experience at the end of life.

Sincerely,

Rodger Wetzel
Steering Committee Chair

Bruce Levi
Project Director

Susan Fuglie
Steering Committee Vice Chair

Clayton Jensen
Project Investigator

The Most Important Conversation

ONE FAMILY'S STORY ...

For reasons unknown—maybe because her mother was a former nurse—care at the end of life was an issue Anne had talked about with her parents for a long time.

"It just came up really naturally," recalls Anne, "especially as they had friends who were aging or ill. And my parents must have visited about it between them. They were very unified about what they wanted."

After Anne's mother was hospitalized with a brain hemmorhage, Anne realized that not only had her parents "talked the talk," but that the right paperwork had been done, too. Says Anne: "We had the legal papers—the advance directives—and I knew where they were."

Anne's mother had also spoken with her physician about the kind of care she wanted at the end of life.

"Nobody has ever been clearer with me about her wishes than your mother," the doctor told Anne.

The most important conversation you hold while you're living ... may be about dying. Most of us know we *should* talk to a variety of people about our end-of-life wishes. It's just that, often, we *don't*.

Yet, if we can document and discuss in advance our end-of-life wishes, a conversation that once seemed scary can actually become comforting.

It really *is* OK to talk about dying. It *has* to be. Use this guide to help you start to ...

- Hold conversations about your end-of-life wishes with family, health care providers and others who may be involved in your care.
- Document those wishes, in writing, by preparing an advance directive.

If in the future you are unable to communicate or make decisions, your family, physician and others will know your wishes.

Who needs to talk about it?

You need to start this important conversation if you ...

- Are an elderly person, or have loved ones who are aging.
- Want to make sure your wishes for end-of-life care, at any age, are understood and followed.
- Don't want to burden family members or others with decisions or misunderstandings when you are dying.
- Want to achieve peace of mind for you and your loved ones.

Making Sure Your Wishes

Are Followed

How do you *know* that your wishes for end-of-life care will be followed? How can you be certain, for example, that you won't receive unwanted medical treatments that will sustain your life, even if your quality of life is poor? Or, how do you know your life will be prolonged, if you wish, as long as possible?

There is only one way to be as certain as you can that your family, health care providers and others will understand and follow your end-of-life wishes: *You must put them in writing,* using a special form called an "advance directive." (More information about and an example of these forms are found on pages 7 - 12 of this resource guide.)

Keep in mind that ...

- If you do not have an advance directive in place and you become seriously ill or injured, your doctors, hospital staff and loved ones will do the best they can.
- **However, without clear direction from you, your loved ones may have to guess what you would want.**
- If there is any uncertainty about your wishes, care *could* be delivered that may *not* be consistent with your wishes.
- **Remember, if you want people to know—and follow—your wishes, you should talk with them about your preferences *and* have a written and signed advance directive in place.**

Let this guide help you start the conversations to get that done.

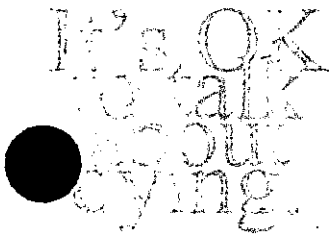
A GIFT YOU CAN GIVE

Talking with other people about your wishes for the end of life is a true gift you give to those you love!

When you start the conversation about dying—and when you document and discuss your wishes through an advance directive—you can help family, friends, clergy and others who might otherwise be uncertain about what you would want done at the end of your life.

This vital conversation is also a great opportunity to talk about very meaningful issues:

- Your past
- Love and forgiveness
- Relationships
- Hopes and fears
- Spiritual beliefs



How to start the Conversation

You need to talk with your loved ones and health care provider about your wishes, so that they understand how you want to be treated at the end of life.

Sometimes it is difficult to begin a conversation about dying. But it really *is* OK to do so. How can you start?

- Use this guide and the sample form as a starting point for writing down notes and questions you may have about your options and wishes for care at the end of life.
- Talk with those closest to you about your values and preferences for end-of-life care. This may be an ongoing discussion for a while, and that's OK, too.
- Talk to your health care provider about medical options and the kind of treatment you want or do not want for end-of-life care.
- Think of other people—including your pastor or attorney—to whom you may also want to talk about dying.
- Document your wishes by completing and signing an "advance directive" form. (More information and a sample form are found on pages 7 -12 of this guide.)

Conversation starters ...

- Encourage family members to discuss their plans by talking about your own: "Mom, did you know that I have filled out a living will?"
- Open conversation by relating to a personal event: "When I was a girl, people never talked about dying, but I think it's important."
- "(Doctor, Pastor, etc.), I would like to talk about my options for the end of life and make sure you understand what I want when that time comes."
- Tell a story about someone else's experience with an end-of-life situation and relate that to what you would like your own experience to be.

ONE FAMILY'S STORY ...

While telling family about your wishes may not make all decisions easy, it does provide a "roadmap" to guide them, Anne says.

Following a brain hemmorhage, Anne's mother underwent surgery and a variety of treatments. Gradually, though, her condition worsened. Knowing her mother expressly did *not* want to be permanently sustained by artificial means—particularly after she became unable to speak or take care of herself—Anne and her father were finally able to "let go," allowing Anne's mother to die naturally once there was no hope of recovery.

"The gift she gave us was immeasurable," says Anne. "She made it easier for us to make the decision to withdraw futile treatment. Knowing we honored her wishes has made it easier to accept what's happened."

Questions to

re you getting ready to talk about dying? This Conversation Checklist offers some questions about different aspects of dying to help you get started. Make sure your specific wishes related to these questions are indicated when you create your advance directive.

Conversation Checklist

Who will you talk to about dying?

- ❑ Who will be involved in your care and needs to understand your wishes?
- ❑ Think about opening a conversation, or setting up an appointment to do so, with ...
  - ❑ Family members or loved ones closest to you (list them)

    _____

    _____
  - ❑ Your doctor or caregiver

    _____
  - ❑ Your pastor or spiritual advisor

    _____
  - ❑ Other people such as your attorney, hospice care provider or funeral home director

    _____

    _____

Where do you want to be when you die? Who do you want around you?

Most North Dakotans want to die at home.

- ❑ Are there services, such as hospice care, that could help you do that?
- ❑ Who do you want near you when you die? What do you want your loved ones to know?

Who do you want to make decisions for you when you can't?

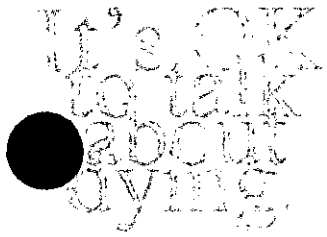
You should name a "representative," someone you fully trust, who will help to see that your wishes are carried out.

- ❑ Who will be involved in your care?
- ❑ Have you talked to this person about being your representative if you are unable to make decisions?
- ❑ Does your representative understand your wishes for the end of life?
- ❑ Does your representative have a copy of your advance directive?

What kinds of medical treatment do you want or not want? What services will you need to be as comfortable as you want to be?

Discuss specific medical options with your health care provider.

- ❑ How do you feel about relying on machines to stay alive?
- ❑ Do you want everything possible to be done to prolong your life?
- ❑ What kind of "quality of life" measures, such as pain management, do you want at the end of life?
- ❑ How could hospice care help you and your family at the end of life? How can you access those services when that time comes?



... and Issues to Talk About

ONE FAMILY'S STORY ...

Dr. Hanson already knew Bill's wishes. Suffering from terminal cancer, 80-year-old Bill had told his physician he wanted no "heroic measures."

"When the time comes, just let me go," Bill said.

Near the end of Bill's life, though, his children—concerned about dehydration and nutrition—insisted on continuing IVs and oxygen.

"He was unconscious, and there was no hope he would recover," Dr. Hanson recalls. "I felt we were prolonging his suffering."

Unfortunately, the scenario is familiar to people in medicine.

"People really should talk over their wishes with their family as well as their physician," states Dr. Hanson. "If they have a document on hand, they should show that to their family, too. When people have talked to their family members, it really helps family make decisions that are what the loved one would have wished."

Hospice Care and Pain Management

Hospice care is a form of end-of-life care that focuses on enhancing the quality of life of a person's last days. Hospice care services, including medical, emotional, spiritual and grief care, help you stay as comfortable as possible and allow many people to stay in the familiar surroundings of home.

You will want to consider choosing hospice care ...

- When you want the focus to be on your comfort and the needs of you *and* your family.
- For expert help in pain and symptom management.
- When you want your loved ones to have help caring for you while you are dying.

Hospice care can have a positive impact on you and your loved ones.

When you talk about dying ...

Tell your loved ones, health care provider, spiritual advisor and others ...

- Where do you want to die? Do you want to die at home, if possible?
- Are there hospice services that will help your family care for you? How can they access them?
- What kind of help might your loved ones need if you are dying at home?
- Do you have questions about pain and symptom management?

What Forms Do You Need?

North Dakota has legal forms that you can use to help start conversations and clearly set forth your wishes, in writing, for the end of life.

These forms are called "advance directives." By using an advance directive, such as a living will or durable power of attorney for health care, you can ...

- Give instructions about any aspect of your health care.
- Choose a person to make health care decisions for you.
- Give instructions about specific medical treatments you do or do not want, including life-sustaining measures.

If in the future you are unable to communicate or make decisions, your family, physician and others will know your wishes.

Make sure you ...

- Talk beforehand to any person you wish to appoint as your representative.
- Discuss your advance directive with your representative, family, health care providers and others.
- Give each of them a copy of your signed advance directive form.

On the following pages, you will find a sample advance directive.

This form combines a living will and a durable power of attorney for health care.

TERMS TO KNOW

Advance Care Planning: Making decisions, in advance, about the care you would want to receive if you are unable to communicate or make decisions for yourself. Advance planning should be based on an understanding of your own values, personal reflections, and discussions you hold with loved ones, health care providers and others.

Advance Directive: A legal document, including a durable power of attorney for health care and/or a living will, that provides directions for your health care if you are unable to communicate or make decisions.

Living Will: Your directions to health care providers for the kinds of end-of-life treatment you do and do not want if you are terminally ill and cannot communicate or make decisions for yourself.

Durable Power of Attorney for Health Care: A document choosing someone to make health care decisions for you if you are unable to communicate or make your own decisions.

North Dakota
ADVANCE DIRECTIVE FOR MY HEALTH CARE

Print your full name _____ **Date of birth** _____

PART 1 Allows you to appoint another person (called a health care representative or "agent") to make health care decisions if you lack the capacity to do so, consistent with your representative's knowledge of your wishes and religious or moral beliefs. If you wish, you may also express your desires about your health care in this directive. If your wishes are unknown, your representative will make health care decisions that are deemed to be in your best interest.

PART 2 Allows you to complete a "living will" by expressing your wishes for the kind of medical treatment you want or do not want if you become terminally ill and your death is imminent.

PART 3 Allows you to make an organ and tissue donation upon your death, by signing a document of anatomical gift.

PART 4 Requires you and others to sign or notarize this advance directive.

This is an important legal document for completion by individuals eighteen years or older. It substantially incorporates the Durable Power of Attorney for Health Care form (Part 1) and the Living Will form (Part 2), which are two kinds of advance directives authorized in North Dakota law. Not all parts of this combined form need to be completed. You may designate a health care representative in Part 1, and not complete a living will in Part 2. You may also complete a living will in Part 2, and not designate a representative in Part 1. Or you may complete both Parts 1 and 2. The document also incorporates a document of anatomical gift (Part 3), which is optional and need not be completed if you do not wish to make an anatomical gift.

Even if you sign an advance directive, you have the right to make medical and other health care decisions for yourself so long as you can give informed consent with respect to the particular decision. If there is anything in this document that you do not understand, you should ask a lawyer to explain it to you. *You may want to consult with a lawyer regarding the legal sufficiency of your advance directive. You are also encouraged to talk with other professionals, including your physician or other health care provider, about your options.*

PART 1. MY HEALTH CARE REPRESENTATIVE

Part 1, the Durable Power of Attorney for Health Care, would authorize your representative to make health care decisions on your behalf if you lack the capacity to make health care decisions as certified in writing by your attending physician. This authority applies to all health care decisions — that is, your representative would have authority to request, consent to, refuse to consent to, or to withdraw consent for any care, treatment, service, or procedure to maintain, diagnose, or treat a physical or mental condition if you are unable to do so yourself. This power is subject to any statement of your desires and any limitation that you include in this document or otherwise make known. You may state in this document any types of treatment that you do not desire. In addition, a court can take away the power of your representative to make health care decisions for you if your representative authorizes anything that is illegal; acts contrary to your known desires; or, where your desires are not known, does anything that is clearly contrary to your best interest.

My health care representative may make **ALL** health care decisions for me as authorized in this document and shall be given access to all my medical records. This appointment, in accordance with North Dakota's Durable Power of Attorney for Health Care law (NDCC 23-06.5), applies if I lack the capacity to make health care decisions.

1. **DESIGNATION OF HEALTH CARE REPRESENTATIVE.**
   I,_____
   (Insert your name and address.)
   appoint: _____
   (Insert name, address, and telephone number of one individual only.)
   as my attorney in fact ("representative") to make health care decisions for me as authorized in this document. My representative's authority is effective when I cannot understand and appreciate the nature and consequences of a health care decision, including the significant benefits and harms of, and reasonable alternatives to, any proposed health care. I revoke any prior appointments. *None of the following may be designated as your health care representative: your treating health care provider, a nonrelative employee of your treating health care provider, an operator of a long-term care facility, or a non-relative employee of an operator of a long-term care facility.*

2. **DESIGNATION OF ALTERNATE REPRESENTATIVES.**
   If the person designated as my representative in paragraph 1 is not available or becomes ineligible to act as my representative to make health care decisions for me or loses the mental capacity to make health care decisions for me, or if I revoke that person's appointment or authority to act as my representative to make health care decisions for me, then I designate and appoint the following persons to serve as my representative to make health care decisions for me as authorized in this document, such persons to serve in the order listed below:

   a. First Alternate: _____
   (Insert name, address and telephone number of first alternate representative.)
   b. Second Alternate: _____
   (Insert name, address and telephone number of second alternate representative.)

3. **GENERAL STATEMENT OF AUTHORITY GRANTED.** Subject to any limitations in this document, I hereby grant to my representative full power and authority to make health care decisions for me to the same extent that I could make such decisions for myself if I had the capacity to do so. In exercising this authority, my representative shall make health care decisions that are consistent with my desires as stated in this document or otherwise made

known to my representative, including my desires concerning obtaining, refusing or withdrawing life-prolonging care, treatment, services, and procedures.

4. **STATEMENT OF DESIRES, SPECIAL PROVISIONS, AND LIMITATIONS.** In exercising the authority under this advance directive, my representative must make health care decisions that are consistent with my known desires. I have decided to make the following written statement concerning my desires (a written statement is not required).

_____

_____

You may attach additional pages if you need more space to complete your statement. If you attach additional pages, you must date and sign EACH of the additional pages at the same time you date and sign this document.

5. **INSPECTION AND DISCLOSURE OF INFORMATION RELATING TO MY PHYSICAL OR MENTAL HEALTH.** Subject to any limitations in this document, my representative has the power and authority to do all of the following:
   a. Request, review, and receive any information, verbal or written, regarding my physical or mental health, including medical and hospital records.
   b. Execute on my behalf any releases or other documents that may be required in order to obtain this information.
   c. Consent to the disclosure of this information.

If you want to limit the authority of your representative to receive and disclose information relating to your health, you must state the limitations in paragraph 4 above.

6. **SIGNING DOCUMENTS, WAIVERS, AND RELEASES.** Where necessary to implement the health care decisions that my agent is authorized by this document to make, my representative has the power and authority to execute on my behalf all of the following:
   a. Documents titled or purporting to be a "Refusal to Permit Treatment" and "Leaving the Hospital Against Medical Advice."
   b. Any necessary waiver or release from liability required by a hospital or physician.

PART 2. LIVING WILL DECLARING MY WISHES IF I AM TERMINALLY ILL

I provide these directions in accordance with the North Dakota Rights of the Terminally Ill Act (NDCC 23-06.4). These directions concern life-prolonging treatment, and nutrition and hydration. *Life-prolonging treatment is any medical procedure, treatment or intervention that will only serve to prolong the process of dying and where, in the judgment of the attending physician, death will occur whether or not treatment is provided. Life-prolonging treatment does not include nutrition or hydration, or medical procedures necessary to provide comfort care or alleviate pain.* These directions in Part 2 apply only if **BOTH** of the following two conditions exist. If my attending physician and another physician determine that:

(1) I have a terminal condition (an incurable or irreversible condition that, without the administration of life-prolonging treatment, will result in my imminent death); **AND**

(2) I am no longer able to make decisions regarding administration of life-prolonging treatment.

If I have been diagnosed as pregnant and that diagnosis is known to my physician, these directions are not effective during the course of my pregnancy. I may revoke these directions at any time.

4b

1. **LIFE-PROLONGING TREATMENT.** I have made the following decision concerning life-prolonging treatment *(initial only one statement):*

[ ] I provide no directions at this time.

[ ] I direct my attending physician to provide life-prolonging treatment, which could extend my life ~~and that I be permitted to die naturally~~. It is my intention that this declaration be honored by my family and physicians as the final expression of my legal right to direct that medical or surgical treatment be provided.

[ ] I direct my attending physician to withdraw or withhold life-prolonging treatment that would serve only to prolong the process of my dying, and that I be permitted to die naturally. It is my intention that this declaration be honored by my family and physicians as the final expression of my legal right to refuse medical or surgical treatment and that they accept the consequences of that refusal, which is death.

2. **HYDRATION / FLUIDS.** I have made the following decision concerning the administration of fluids when my death is imminent *(initial only one statement):*

[ ] I provide no directions at this time.

[ ] If I cannot drink, I want to receive fluids.

[ ] If I cannot drink, I want to receive fluids, unless I cannot physically assimilate fluids, fluids would be physically harmful or would cause unreasonable physical pain, or fluids would only prolong the process of my dying.

[ ] If I cannot drink, I do not want to receive fluids.

3. **NUTRITION / FOOD.** I have made the following decision concerning the administration of food when my death is imminent *(initial only one statement):*

[ ] I provide no directions at this time.

[ ] If I cannot eat, I want to receive food.

[ ] If I cannot eat, I want to receive food, unless I cannot physically assimilate food, food would be physically harmful or would cause unreasonable physical pain, or food would only prolong the process of my dying.

[ ] If I cannot eat, I do not want to receive food.

Concerning the administration of food and fluids, I understand that if I make no statement about food or fluids, my attending physician may withhold or withdraw food or fluids if the physician determines that I cannot physically assimilate food or fluids or that food or fluids would be physically harmful or would cause unreasonable physical pain.

4. **STATEMENT OF ADDITIONAL DESIRES AND LIMITATIONS.**

[ ] I have these additional directions:

_____

_____

You may attach additional pages if you need more space to complete your statement. If you attach additional pages, you must date and sign EACH of the additional pages at the same time you date and sign this document.

PART 3. DOCUMENT OF ANATOMICAL GIFT

I, _____, would like to be an organ donor at the time of my death. I have told my family my decision and ask my family to honor my wishes. I wish to donate the following *(initial one statement):*

[ ] any needed organs, tissue or other body parts.

[ ] only the following organs, tissue or other body parts: _____

_____

PART 4. SIGNATURES

1. YOUR SIGNATURE

I sign my name to this document on _____(Date) at _____(City), _____ (State).

_____
You sign here

THIS DIRECTIVE WILL NOT BE VALID UNLESS IT IS NOTARIZED OR SIGNED BY TWO QUALIFIED WITNESSES WHO ARE PRESENT WHEN YOU SIGN OR ACKNOWLEDGE YOUR SIGNATURE. IF YOU HAVE ATTACHED ANY ADDITIONAL PAGES TO THIS FORM, YOU MUST DATE AND SIGN EACH OF THE ADDITIONAL PAGES AT THE SAME TIME YOU DATE AND SIGN THIS DIRECTIVE.

IF YOU ARE A RESIDENT OF A LONG-TERM CARE FACILITY, OR IF YOU ARE A PATIENT IN A HOSPITAL OR BEING ADMITTED TO A HOSPITAL, YOU SHOULD CONSULT WITH A FACILITY OR HOSPITAL REPRESENTATIVE REGARDING THE NEED FOR ANY ADDITIONAL STATEMENTS OR SIGNATURES.

2. THE SIGNATURE OF YOUR HEALTH CARE REPRESENTATIVE TO ACCEPT APPOINTMENT (if appointed under Part 1)

I accept this appointment and agree to serve as representative for health care decisions. I understand I have a duty to act consistently with the desires of the principal as expressed in this appointment. I understand that this document gives me authority over health care decisions for the principal only if the principal becomes incapable. I understand that I must act in good faith in exercising my authority under this power of attorney. I understand that the principal may revoke this power of attorney at any time in any manner. If I choose to withdraw during the time the principal is competent, I must notify the principal of my decision. If I choose to withdraw when the principal is incapable of making the principal's health care decisions, I must notify the principal's physician.

_____
Signature of representative/date

_____
Signature of alternate representative/date

3. SIGNATURES OF WITNESSES OR NOTARY (required)

This document must be notarized **OR** witnessed by two qualified adult witnesses. The person notarizing this document may be an employee of a health care or long-term care provider providing your care. At least one witness must not be a health care or long-term care provider providing you with direct care or an employee of the health care or long-term care provider providing you with direct care. None of the following may be used as a notary or witness: (1) A person you designate as your agent or alternate agent; (2) Your spouse; (3) A person related to you by blood, marriage, or adoption; (4) A person entitled to inherit any part of your estate upon your death; (5) A person who has, at the time of executing this document, any claim against your estate; (6) Your attending physician; or (7) A person directly financially responsible for your medical care.

Choose either option 1 ***OR*** *option 2 below:*

Option 1: Notary Public

In my presence on _____ (date), _____ (name) acknowledged his/her signature on this document or acknowledged that he/she directed the person signing this document to sign on his/her behalf.

_____

(Signature of Notary Public) My commission expires_____, 20__.

Option 2: Two Witnesses

Witness One:

(1) In my presence on _____ (date), _____ (name) acknowledged his/her signature on this document or acknowledged that he/she directed the person signing this document to sign on his/her behalf.
(2) I am at least eighteen years of age.
(3) If I am a health care provider or an employee of a health care provider giving direct care to the principal, I must initial this box: [ ].

I certify that the information in (1) through (3) is true and correct.

_____ _____

(Signature of Witness One) (Address)

Witness Two:

(1) In my presence on _____ (date), _____ (name) acknowledged his/her signature on this document or acknowledged that he/she directed the person signing this document to sign on his/her behalf.
(2) I am at least eighteen years of age.
(3) If I am a health care provider or an employee of a health care provider giving direct care to the principal, I must initial this box: [ ].

I certify that the information in (1) through (3) is true and correct.

_____ _____

(Signature of Witness Two) (Address)

It's OK to talk about dying.

Resources

NORTH DAKOTA RESOURCES

General Information

N.D. Senior INFO-LINE
(Resource Directory)
800-451-8693
Email: *dhssrinf@state.nd.us*
www.ndseniorinfoline.com

Matters of Life and Death
N.D. Medical Association
P.O. Box 1198
Bismarck, ND 58501
701-223-9475 Fax: 223-9476
www.ndmed.com/mld

N.D. Long Term Care Association
1900 North 11th Street
Bismarck, ND 58501
701-222-0660 Fax: 223-0977
http://www.ndltca.org/

N.D. Healthcare Association
P.O. Box 7340
Bismarck, ND 58507
701-224-9732 Fax 224-9529
http://www.ndha.org/

BlueCross BlueShield of N.D.
4510 13th Ave SW
Fargo, ND 58103
701-282-1100
www.bcbsnd.com/index.html

N.D. Association of Home Care
P.O. Box 2175
Bismarck, ND 58507
701-224-1815 Fax: 224-9824
http://www.aptnd.com/ndahc/

State Bar Association of N.D.
Lawyer Referral Program/
Volunteer Lawyer
701-255-1406
800-932-8880 (in-state only)
www.sband.org

Legal Assistance of N.D.
800-634-5263
www.legalassist.org

Hospice Programs

Ashley Medical Center Hospice
Ashley - **701-288-3433**

MedCenter HMR/The Hospice
Bismarck - **701-323-8400**

St Alexius Hospice
Bismarck - **701-530-4500**

Presentation Hospice
Carrington - **701-652-3141**

Mercy Hospice
Devils Lake - **701-662-2131**

Heartland Hospice
Dickinson - **701-264-4378**

Hospice of the Red River Valley
Fargo - **701-237-4629**
Lisbon - **701-683-4649**
Mayville - **701-786-4432**
Valley City - **701-845-1781**

Altru Home Services
Grand Forks - **701-780-5258**
Grafton - **701-352-1620**
Langdon - **701-256-6126**
McVille - **701-322-4328**
Park River - **701-284-4548**

Sakakawea Hospice
Hazen - **701-748-2041**

Jamestown Hospital Hospice
Jamestown - **701-253-4484**

Trinity Hospice Agency
Minot - **701-857-5000**

Heart of America Hospice
Rugby - **701-776-5261**

Mercy Hospice
Williston - **701-774-7430**

Dakota Prairie Hospice
Hettinger - **701-567-4975**

Riveredge Hospice
Breckenridge - **218-643-7513**

NATIONAL RESOURCES

Aging With Dignity
"Five Wishes"
1-888-5-WISHES
www.agingwithdignity.org

Midwest Bioethics Center
"Caring Conversations"
800-344-3829
Email: bioethic@midbio.org
www.midbio.org

National Hospice and Palliative Care Organization
800-658-8898
www.nhpco.org

Funeral Consumers Alliance
http://www.funerals.org/

Last Acts
http://www.lastacts.org/

AARP
Legal counsel for the elderly
800-424-3410
http://www.aarp.org/endoflife

Pain and Policy Study Group
608-263-7662
www.medsch.wisc.edu/painpolicy

Growth House, Inc.
415-255-9045
E-mail:
info@growthhouse.org
http://www.growthhouse.org

American Pain Society
847-375-4715
www.painfoundation.org

Indian Health Service
http://www.ihs.gov/

Missoula Demonstration Project
www.dyingwell.com

AH # 5

SB 2343 - Re: Health care decisions & treatment; advance directives

-by Rodger Wetzel, Director, Eldercare Program, St. Alexius

-Past Chair of N.D. "Matters of Life and Death Project" to improve end of life care

Chairman Traynor and members of the Committee:

My name is Rodger Wetzel. I am the director of the Eldercare Program at St. Alexius. I formerly served as the Assistant Director of the Aging Services Division of the NDDHS, and have been working in aging-related programs for 35 years. (I am getting pretty close myself.)

I served as Chair of the state Steering Committee for the N.D. "Matters of Life and Death Project", which for 3 years worked with a coalition of more than 50 organizations to improve end of life care in North Dakota. Some of the other people here today were active participants in that project, and we have often discussed potential improvements in our advance directive legislation.

I personally have assisted hundreds of people with completing advance directives. I also do regular community presentations on advance directives and related issues.

I have been involved in assisting to develop advance directive legislation in N.D. since the beginning. I recall the living will law being passed, and I recall the durable power of attorney for healthcare law being passed the following session. Unfortunately, they were developed and passed at different legislative session, and there are inconsistencies between the two laws and the resulting sample forms.

Our "Matters of Life and Death" Project developed a wonderful booklet entitled, "It's O.K. to Talk About Dying," copies of which are available today. We worked to supplement the existing laws, processes and sample forms. We combined the two sample forms into one sample form, and provided additional educational information and resources.

This proposed law, SB 2343, in many ways is a continuation of our Project efforts. It combines the two laws and sample forms into one law and one sample form. It allows additional decision options, such as organ/tissue donations, resuscitation, dialysis decisions, surgeries, use of antibiotics, and blood transfusions. It also provides some additional informational content. Hopefully the language will be more easily understood by most adults.

At St. Alexius our policy is to ask each adult being admitted to the medical center if they have an advance directive. If they do, we place a copy in the medical record. If they do not, we offer to: provide them with information, provide sample forms if requested, assist them with completing forms, and answer any questions that they may have. Our social work department staff and pastoral care department staff are the designated contact departments, and generally are available 7 days/week to assist patient/families. Therefore, St. Alexius staff, through their efforts, have assisted hundreds, perhaps thousands, of patients with advance directive issues.

Their two department directors have reviewed this draft legislation. They are reviewing this proposed legislation and sample forms with their other staff, and with a sampling of adults/patients, to get their input on the proposed law, sample forms and process.

They soon may have some additional recommendations on this draft legislation after this process. They may also contact staff at Altru Hospital in Grand Forks and Meritcare Hospital in Fargo, who have more often seen/used the Minnesota law/sample form, after which this proposed law/format has been modeled.

Thank you. I would be happy to answer any questions.

AH #6

Testimony on SB 2343
Senate Judiciary Committee
February 8, 2005

Chairman Traynor and members of the Senate Judiciary Committee, my name is Clyde Leimberer, and I would like to speak to you regarding Senate Bill 2343. I am the Chaplain at The Baptist Home here in Bismarck where we give skilled nursing care to 150 persons at a time and last year had 62 deaths and 28 persons were discharged, often to a lower level of care. I am a member of the North Dakota Chaplain's Association, the North Dakota Long Term Care Association and was a member of the Community Education Committee of the Matters of Life and Death Coalition a couple of years ago. As these groups have not taken a position on this bill, I am speaking on my own behalf.

Along with working with individuals and families to support them as they are making end of life decisions, I have a continuing role to train our staff in their supportive role and I cover Advance Directives in a training series on Pastoral Care at the End of Life I have presented to pastors, hospice workers and other persons. Thus, I have contact with a number of persons who directly and indirectly are working with these issues daily.

I have read the bill in its entirety twice and appreciate how it combines the concepts of the Living Will, Durable Power of Attorney for Health Care and Organ and Tissue Donation Statement in one easy to understand document.

Thank you again for the opportunity to testify on this bill. I would be happy to answer any questions.

Rev. Clyde Leimberer
The Baptist Home
1100 E. Boulevard Ave.
Bismarck, ND 58501

#7

North Dakota 2005 Legislative Session

Senate -- ~~Human Services~~ Judiciary Committee

Senate Bill 2343

February 8, 2005

Same given to House

Madam Chair and Members of the Committee:

My name is Susan Bosak. I am the Public Affairs Officer at MeritCare Health System in Fargo, North Dakota. I strongly urge the Senate Human Services Committee to bring Senate Bill 2343 to the Senate floor with a DO PASS recommendation.

The current law on advance directives serves a worthwhile purpose, but we have discovered some problems in its implementation. We believe this bill would improve the process that patients follow for giving advance directives about their care, and make it easier for health care providers to implement patients' wishes.

We've seen a number of different concerns and questions from patients and families about the current advance directives law. They include:

- Many people think of a healthcare directive as something only for the elderly or terminally ill. Living wills do become effective only for the terminally ill. But other healthcare directives can be used whenever patients cannot speak for themselves or are incapacitated, at any age and in a variety of circumstances.

- As a border provider, MeritCare has forms available for both Minnesota and North Dakota. Minnesota uses only one form for all advance directives while North Dakota has two. Many North Dakotans see how much simpler it is to fill out one form with the options outlined in that form, rather than filling out two or more different forms. We have had North Dakota residents ask us if they can use the Minnesota form even though they are not residents of Minnesota.
- Some patients are confused by the existence of two forms, one for a Durable Power of Attorney for Health Care, and the other for a Living Will. They wonder whether to fill out both forms or just one, and if one, which one? Does a "living will" mean they need an attorney to help them complete it? The forms are not "user friendly" for people of any age.
- When patients or families do have legal questions about the forms or the process, MeritCare staff cannot dispense legal advice to them. We must refer them to their personal attorneys if they have legal concerns or questions.
- We deal with many situations where patients are incapacitated but are not terminally ill. Many people do not have a living will or a durable power of attorney for health care, but still wish to put some of their wishes for health care into writing. They are uncertain about how to accomplish that.

We think that patients and their families should be able to state their wishes and have them followed in an understandable way, on their own, with minimal confusion and complexity. We think this bill will help achieve that. The single health care directive in this bill also gives patients more flexibility, so that they can make their instructions as

general or as detailed as they wish. Our primary goal is to honor patients' wishes, and we think Senate Bill 2343 will make it easier to accomplish that.

Madam Chair and Members of the Committee, thank you for allowing me the opportunity to address you this morning. I would be willing to answer any questions you would have at this time.

NORTH DAKOTA
MEDICAL
ASSOCIATION

1622 East Interstate Avenue
Post Office Box 1198
Bismarck, North Dakota
58502-1198

(701) 223-9475
Fax (701) 223-9476

Robert W. Beattie, MD
Hettinger
President

Shari L. Orser, MD
Bismarck
Vice President
Council Chair

John H. Windsor, DO
Bismarck
Secretary-Treasurer

Robert A. Thompson, MD
Grand Forks
Speaker of the House

Jack Kerbeshian, MD
Grand Forks
AMA Delegate

Bruce Levi
Executive Director

David Peske
Director of
Governmental Relations

Leann Tschider
Director of Membership
Office Manager

Testimony in Support of Engrossed Senate Bill No. 2343
House Human Services Committee
March 9, 2005

Madam Chairman, Members of the House Human Services Committee, my name is Bruce Levi and I represent the North Dakota Medical Association. NDMA is the professional membership organization for North Dakota physicians, residents and medical students.

The North Dakota Medical Association supports Engrossed Senate Bill No. 2343.

SB 2343 would establish a single advance directive document, called the "health care directive," by combining the current "living will (ch. 23-06.4)" and the "durable power of attorney for health care (ch. 23-06.5)." The bill would also provide for a new, combined statutory health directive form, based on the statutory form currently in use in Minnesota. The bill passed the Senate by a vote of 45-0.

My written testimony includes a proposed amendment, which is attached. One of the proposed changes was brought to my attention by Senator Trenbeath after the Senate Judiciary Committee recommended the bill for passage. The amendment would correct a discrepancy in existing law relating to the obligation of an agent under a durable power of attorney for healthcare. Another amendment would clarify language in the proposed optional advance directive form relating to when an advance directive becomes effective, which is when the individual executing an advance directive lacks capacity to make and communicate health care decisions. Another amendment would include a "Principal's Statement" in the proposed optional form that would acknowledge the explanation of the appointment of an agent for a resident of a long term care facility or hospital patient. These amendments are more fully explained in the attached amendment.

From a physician standpoint, what is important in an advance directive? Research has shown that advance directives sometimes do not provide enough information to give appropriate guidance to medical professionals. In 1997, the American Medical Association's Council on Ethical and Judicial Affairs identified advance care planning as an essential component of standard medical care. It called for physicians to conduct advance care planning discussions on a routine basis using advisory documents or worksheets as an adjunct to the statutory documents, the living will and the durable power of attorney for healthcare.

The legal tools are critical in this process, and that's where SB 2343 comes in. Are the tools as effective as they can be to facilitate the process of advance care planning? When you compare the statutory framework for the living will and durable power of attorney for healthcare in North Dakota, there are conflicts. The mere existence of two documents causes public confusion. SB 2343 would resolve the conflicts and clear up the confusion.

Effective health care advance planning is more than simply signing a legal form. The goal is meaningful communication that defines and communicates an individual's values and wishes about treatment to physicians and other health professionals, or to an appointed agent or surrogate decisionmaker, in anticipation of the individual losing the capacity to make or communicate health care decisions. Advance directive statutes provide a pathway for expressing wishes and preferences for end-of-life care. From 1998 through 2003, the North Dakota Medical Association participated in a coalition of state organizations and individuals committed to improving end-of-life care in North Dakota. The coalition project, known as *Matters of Life and Death*, initiated efforts to educate professionals and the public on advance care planning.

As part of the *Matters of Life and Death* project, barriers to advance care planning were identified. Surveys found that there is a lack of public understanding and knowledge in North Dakota about advance care planning. Other barriers include the complex and often confusing nature of advance directive legal forms; that advance directives do not always adequately inform physicians of the patient's wishes or communicate important values; and that advance care planning often occurs as crisis decision making or is focused on the act of completing a legal form rather than engaging in a process of conversation, listening, and reflective decision making.

Development of North Dakota's Advance Directive Laws

Our laws in North Dakota on advance directives were developed much like other states – in a piece-meal manner starting with the adoption in 1989 of the "Uniform Rights of Terminally Ill Act (1985)" in chapter 23-06.4, which is better known as the "living will" advance directive law [1989 HB 1481, Rep. DeMers]. The living will law is narrowly construed to allow an adult to execute a directive governing the withholding or withdrawal of life-sustaining treatment. The law provides both civil and criminal immunity for physicians and other health care providers for their actions in accordance with declarations made under chapter 23-06.4, as long as the actions are not done in a grossly negligent manner. In 1991, chapter 23-06.5 authorizing the use of the durable power of attorney for health care was adopted [1991 HB 1384, Rep. DeMers]. That law provides the parameters for appointing an agent to make health care decisions if the individual executing the power of attorney, known as the "principal," later lacks capacity to make decisions.

Further revisions to chapter 23-06.4 relating to the administration, withholding or withdrawal of nutrition and hydration and the statutory living will form were added in 1993, based on recommendations developed by a forum initiated by Chief Justice Ralph Erickstad and comprised of a number of diverse stakeholders [1993 SB 2394 / Sen. DeMers, Rep. Price]. Later, in 1994, the Legislative Council's interim Judiciary Committee considered the new Uniform Health Care Decisions Act approved by the National Conference of Commissioners on Uniform State Laws in 1993 (1993 Uniform Act). That Act would have replaced North Dakota's laws relating to living wills and powers of attorney for health care with a single statute. At that time testimony in opposition to the 1993 Uniform Act indicated that the basic premise of the Act was good because it would have consolidated and coordinated legislation from 1989 through 1993 concerning living wills, durable powers of attorney for health care and our substituted judgment law in section 23-12-13. However, the conclusion by the interim committee in 1994 was that "the existing laws had not been in effect long enough to sufficiently evaluate their effectiveness," and consideration of the 1993 Uniform Act was "postponed."

In 2001, various organizations involved in the *Matters of Life and Death* project worked to enact a measure sponsored by Sen. Judy Lee which conformed witnessing requirements between the living will and the durable power of attorney for health care, allowed for verifying signatures by

notary, and clarified that the statutory forms for both the living will and durable power of attorney for health care were "preferred" forms, but not required forms. One of the primary purposes for the 2001 legislation was to change our advance directives statutes to allow for the use of other advance directive forms, forms that are more conducive to the process of advance care planning.

Moving Toward Simplification and More Flexibility in Use of Directives

During the 1990's, states began moving towards simplification and greater flexibility in the use of advance directives, primarily as a result of the 1993 Uniform Act. Many states have combined their laws on advance directives into comprehensive advance directive Acts, which cover living wills and the durable power of attorney for healthcare in the same law. Minnesota is one such state that now has a comprehensive advance directive law.

As recognized in literature of the American Bar Association, multiple advance directive laws within a single state increase the likelihood of inconsistency and confusion within the state's own laws. North Dakota law on advance directives evolved much like other state laws with the incremental passage of multiple statutes. At least 16 states have now accomplished the goal of merging all or most of their separate laws into one comprehensive statute.

SB 2343 represents an effort to address the fragmentation and conflict among the statutes relating to living wills and durable power of attorney for health care. The bill would take a step forward in addressing the increasing demand for simplicity and flexibility in the legal tools that were created for healthcare advance planning, and clarify some issues resulting from different language and standards used for the existing "living will" and durable power of attorney for health care (DPAHC). The bill was drafted in an effort which included participation by NDMA's Commission on Ethics, attorneys Paul Richard and Jane Voglewede of Meritcare, and Christopher Dodson of the North Dakota Catholic Conference. The bill is an effort to combine chapters 23-06.4 and 23-06.5, by moving much of the language in chapter 23-06.4 with respect to living wills into the DPAHC law, chapter 23-06.5. The result is the recognition of a combined statutory framework which recognizes a new advance directive called the "health care directive."

Engrossed SB 2343 Summary

- *Cross References*

Section 1 would amend a cross reference to chapter 23-06.4, which would be repealed under section 20 of the bill, in the criminal statute relating to endangering a vulnerable adult.

•*Statement of Purpose* (23-06.5-01)

Section 2 would incorporate the legislative intent language from section 23-06.4-01 (living will) into the existing statement of purpose provision in section 23-06.5-01 (DPAHC). The living will language in section 23-06.4-01 currently states that "every competent adult has the right and responsibility to control the decisions relating the adult's own medical care, including the decision to have medical or surgical means or procedures calculated to prolong the adult's life provided, withheld, or withdrawn." The legislative intent provision in chapter 23-06.4 would be repealed in section 20 of the bill.

•*Definitions* (23-06.5-02)

Section 3 would provide new terminology in the definitions provision in chapter 23-06.5 to incorporate the concept of a combined advance directive or "health care directive." The definitions provision in chapter 23-06.4 would be repealed by section 20 of the bill.

Subsections 1 and 4 would remove references to the durable power of attorney for health care.

Subsection 3 would clarify the definition of "capacity" as it is used in this context to include the ability of an individual to communicate a health care decision. This is language used in the 1993 Uniform Act and Minnesota. This definition is important in determining when the authority of an agent becomes operative or when instructions include in a health care directive become operative under subsection 3 of section 23-06.5-03 (section 4).

Subsection 4 would expand the definition of the term "health care decision" to include the selection and discharge of health care providers and institutions, the approval or disapproval of diagnostic tests, surgical procedures, programs of medication and orders not to resuscitate, and directions to provide, withhold, or withdraw artificial nutrition and hydration in subdivisions (a) through (c). This language is derived from the 1993 Uniform Act. The additional language in subdivision (d) would extend the term to health care related issues regarding an individual's personal security and residence, and is derived from Minnesota law (MN Stat. 145C.01(4)).

Subsection 5 introduces the term "health care directive," which would be the operative language describing the new combined advance directive and is derived from Minnesota law. A health care directive would include one or more health care instructions (defined in subsection 6), a power of attorney for health care, or both.

Subsection 6 would define the term "health care instruction," a term used to describe the various means by which an individual might provide direction regarding future health care decisions as derived from Minnesota law (MN Stat. 145C.01(7a)).

Subsection 9 would remove the DPAHC reference in the definition of "principal," which is an adult who executes a health care directive.

•*Execution of a Health Care Directive* (23-06.5-03)

Section 4 would amend subsection 1 of section 23-06.5-03 to provide the operative language authorizing an adult to execute a health care directive. This language, derived from Minnesota law, provides that the directive may include one or more health care instructions to health care providers, others assisting with health care, family members, or the individual's appointed agent. The directive could also include a power of attorney appointing an agent to make health care decisions for the principal when the principal lacks the capacity to make health care decisions.

Subsection 2 of section 23-06.5-03 would be amended to clarify the standards used by an agent in making decisions on behalf of the principal, after consultation with the attending physician and other health care providers. The new language in subdivision (b) requiring the agent to consider the principal's personal values to the extent known when the principal's wishes are unknown and the "best interests" of the principal are being assessed, is derived from the 1993 Uniform Act. As indicated in comments to the 1993 Uniform Act, this language "does not prescribe a detailed list of factors for determining the principal's best interests but instead grants the agent discretion to ascertain and weigh the factors likely to be of importance to the principal."

Subsection 3 of section 23-06.5-03 would be amended to clarify that the agent's authority ceases whenever a determination is made that the principal has recovered capacity, which is also language derived from the 1993 Uniform Act.

•*Agent Restrictions* (23-06.5-04)

Section 5 would amend section 23-06.5-04, which restricts who can act as an agent, by allowing a health care or long-term care provider who is a relative of the principal to act as an agent, but not nonrelatives. This is the approach used in Minnesota (MN Stat. 145C.03(2)).

•*Health Care Directive Requirements* (23-06.5-05)

Section 6 would amend section 23-06.5-05 by incorporating language from Minnesota law in setting forth requirements for health care directives (MN Stat. 145C.03(1)). Subsection 1 of section 23-06.5-04 would require that a health care directive be in writing, be dated, state the principal's name, be executed by a principal who has the capacity to do so by signature, and contain verification of that signature by notary or through witnesses. A healthcare directive would be required to include a health care instruction, a power of attorney for health care, or both.

•*Suggested Health Care Directive Form*

Section 7 would create a new section to chapter 23-06.5 that provides a list of other provisions that might be included in a health care directive, but not limit what provisions might be included. This language is incorporated from Minnesota law (MN Stat. 145C.05). It suggests that the following items may also be part of a healthcare directive:

1. The designation of alternate agents that could act if the named agent is not reasonably available;
2. Specific directions and authority to appoint joint agents and the process or standards by which joint agents would reach a healthcare decision;
3. Limitations on the right of an agent or alternate agents to review, obtain copies of, or consent to the disclosure of the principal's medical records (see section 10 on inspection and disclosure of medical information);
4. Any limitations on the nomination of the agent as a guardian;
5. An anatomical gift provision;
6. Any limitations to the effect of a divorce or annulment on the appointment of an agent;
7. Any specific reasons why a principal would want a health care provider or an employee of a health care provider to be eligible to act as the principal's agent; and

8. Any health care instructions regarding artificially administered nutrition or hydration.

•*Agent Acceptance and Withdrawal* (23-06.5-06)

Section 8 would amend section 23-06.5-06 in using the term "incapacitated," rather than "incapable," in addressing when the agent's authority to make health care decisions begins. The language is more consistent with the "capacity" definition used in section 23-06.5-02.

•*Revocation of a Health Care Directive* (23-06.5-07)

Section 9 would amend section 23-06.5-07, applying the current revocation provision relating to a durable power of attorney for health care to a health care directive.

Subsection 1 would provide that an individual may revoke a directive by notification orally or in writing or by any other act evidencing a specific intent to revoke the directive.

Subsection 2 would make minor changes in the provision requiring the provider to record the revocation in the principal's medical record and notify any agent, the attending physician, and staff responsible for the principal's care of the revocation.

Subsection 3 would clarify the current requirement that if the spouse is the principal's agent, the divorce of the principal and spouse revokes the appointment of the divorced spouse as the principal's agent. The clarification specifies that the appointment revocation in such a case could be addressed in the health care directive. A similar provision is allowed in subsection 6 of the new section to chapter 23-06.5 provided in section 7.

•*Inspection and Disclosure of Medical Information* (23-06.5-08)

Section 10 would amend section 23-06.5-08 in addressing the inspection and disclosure of medical information. Only minor changes would be made in referencing the health care directive rather than the durable power of attorney for health care. An agent stands in the shoes of the patient when making health care decisions. To assure fully informed decision making, this section provides that an agent who is then authorized to make healthcare decisions for a patient has the same right of access to healthcare information as does the patient. However, that right could be limited by the specifying otherwise in the health care directive, as also provided under subsection 3 of section 7.

•*Duties of Provider* (23-06.5-09)

Section 11 would amend section 23-06.5-09 in identifying the obligations of the health care or long term care provider.

Subsection 1 would provide minor changes incorporating the new health care directive language. That section requires providers to follow the healthcare decisions of the principal's agent or a healthcare instruction to the extent they are consistent with chapter. 23-06.5 and the health care directive.

Subsection 2 incorporates language from the 1993 Uniform Act in recognizing that a health care or long term care services provider may decline to comply with a health care decision of an agent or health care instruction for reasons of conscience or other conflict. The provision would require a provider that declines to comply with a health care decision or instruction to take all reasonable steps to transfer care of the principal to another health care provider who is willing to honor the agent's health care decision or instruction or directive. In such a case, the provider is required to provide continuing care to the principal until a transfer can be effected. Subsections 3, 5, and 6 are current provisions of chapter 23-06.4, which are incorporated in the revised chapter 23-06.5.

Subsection 3 takes the current subsection 6 of section 23-06.4-11 in providing that the health care directive law does not require any physician or other health care provider to take any action contrary to reasonable medical standards.

Subsection 4 states that the chapter would not affect the responsibility of the attending physician or other health care provider to provide treatment for a patient's comfort, care, or alleviation of pain, as derived from Minnesota law.

Subsection 5 incorporates current language from section 23-06.4-07, requiring that care be provided to a pregnant principal except under specific circumstances provided under current law.

Subsection 6 incorporates current language in section 23-06.4-06.1 relating to the withdrawal, withholding, or administering of nutrition or hydration, which was enacted in 1993.

• *Undue Influence* (23-06.5-10)

Section 12 would make minor changes to section 23-06.5-10. These provisions provide assurance that the principal's actions in executing a health care directive or appointing an agent are free from undue influence. The bill would remove what is essentially a statement of legislative intent in subsection 2 (page 10, lines 6 through 10).

• *Reciprocity With Other States* (23-06.5-11)

Section 13 would revise the current reciprocity provision in section 23-06.5-11 by providing the technical reference to a health care directive rather than to a durable power of attorney for healthcare. That section states that the chapter does not limit the enforceability of a health care directive or similar instrument executed in another state or jurisdiction in compliance with the law of that state or jurisdiction.

• *Immunity* (23-06.5-12)

Section 14 would amend section 23-06.5-12 to expand the current immunity provisions provided in that section for actions taken in good faith by an agent or health care or long term care provider.

Subsection 1 would expand that immunity to persons authorized to provide informed consent under section 23-12-13, consistent with the approach of the 1993 Uniform Act.

Subsection 3 would incorporate language derived from Minnesota law (MN Stat. 145C.11) providing immunity to a provider who administers health care necessary to keep the principal alive, despite a health care decision of the agent to withhold or withdraw that health care, or a provider who withholds health care that the provider has determined to be contrary to reasonable medical standards, despite a health care decision of the agent so long as the provider takes all reasonable steps to promptly notify the agent of the health care provider's unwillingness to comply, document the notification in the principal's medical record, and permit the agent to arrange to transfer care of the principal to another health care provider willing to comply with the decision of the agent.

• *Presumptions and Applications* (23-06.5-13)

Section 15 would amend section 23-06.5-13 to provide a variety of presumptions and application statements that would apply to the execution of a health care directive. Subsections 1 and 2 provide technical changes in language regarding which documents take precedence over others.

Subsections 3 through 8 are derived from Minnesota law (145C.10). Subsection 9 incorporates current language from section 23-06.4-11(1). Subsection 10 incorporates language from section 23-06.4-11(2). Subsection 11 incorporates language from section 23-06.4-11(3). Subsection 12 incorporates language from section 23-06.4-11(5). Subsection 13 incorporates current language from section 23-06.4-11(7).

•*Previously Executed Directives* (23-06.5-15)

Section 16 would revise section 23-06.5-15 in continuing to provide legal recognition to previously executed health care directives, including durable powers of attorney executed under chapter 23-06.5 and "living wills" executed under chapter 23-06.4 before the effective date of SB 2343.

•*Statutory Form* (23-06.5-16)

Section 17 would revise section 23-06.5-16 with language derived from the 1993 Uniform Act that would clarify that the statutory form provided in section 18 would be an optional form and not a required form by which a person may execute a health care directive. Any other form may be used if it complies with chapter 23-06.5.

•*Optional Health Care Directive Form* (23-06.5-17)

Section 18 would provide an optional form that incorporates requirements applicable to health care directives, amending the current durable power of attorney for health care form in section 23-06.5-17. Statutory forms provide a number of benefits. Because the form is standard and widely available, individuals who would otherwise be reluctant to pay to have a form prepared are more likely to execute an advance directive. The availability of an officially sanctioned form would reduce the reluctance of health care providers to honor a directive. Through continued use of the form, health care professionals can also become more familiar with its provisions and make more informed decisions.

The optional form in SB 2343 is derived from Minnesota law (MN Stat. 145C.16). There are four parts to the form. An individual may, or may not decide to complete part one of the form which would provide for the appointment of an agent. An individual may, or may not, decide to complete part two of the form which provides an opportunity to give health care instructions to guide others, including the agent, in making health care decisions. An individual may also, but

need not, complete part three which would allow an individual to make an anatomical gift upon their death. Part four of the form would incorporate current North Dakota provisions relating to the signing or notarizing of the optional form.

•*Penalties* (23-06.5-18)

Section 19 would make minor changes in the language in section 23-06.5-18 in imposing penalties upon individuals who willfully conceal or destroy revocation or willfully alter, forge, conceal or destroy a health care directive.

•*Repealer*

Section 20 would repeal the current "living will" chapter, chapter 23-06.4.

On behalf of the North Dakota Medical Association, I urge you to recommend a "DO PASS" on Engrossed SB 2343 with the proposed amendment. Thank you Madam Chairman and Committee Members.

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2343

Page 7, line 3, overstrike "a duty" and insert immediately thereafter "authority"

Page 18, line 26, replace "decide or speak" with "make and communicate health care decisions"

Page 19, line 4, after "make" insert "and communicate"
Page 19, line 10, replace "DECIDE OR SPEAK" with "MAKE AND COMMUNICATE HEALTH CARE DECISIONS"
Page 19, line 16, replace "decide or speak" with "make and communicate health care decisions"
Page 19, line 30, replace "DECIDE OR SPEAK" with "MAKE AND COMMUNICATE HEALTH CARE DECISIONS"

Page 20, line 5, replace "decide or speak" with "make and communicate health care decisions"

Page 21, line 6, replace "decide or speak" with "make and communicate health care decisions"

Page 22, line 12, replace "decide or" with "make and communicate health care decisions"
Page 22, line 13, remove "speak"
Page 22, line 17, replace "decide or speak" with "make and communicate health care decisions"
Page 22, line 21, replace "decide or speak" with "make and communicate health care decisions"
Page 22, line 26, replace "decide or speak" with "make and communicate health care decisions"

Page 26, after line 21, insert:

"PRINCIPAL'S STATEMENT

I have read a written explanation of the nature and effect of an appointment of a health care agent that is attached to my health care directive.

Dated this _____ day of _____, 20____.

_____

(Signature of Principal)"

Page 26, line 24, after the underscored period insert "This statement does not need to be completed if the resident has read a written explanation of the nature and effect of an appointment of a health care agent and completed the Principal's Statement above."

Page 27, line 5, after the underscored period insert "This statement does not need to be completed if the patient or person being admitted has read a written explanation of the nature and effect of an appointment of a health care agent and completed the Principal's Statement above."

Renumber accordingly

Explanation of Amendments

Agent's Responsibility – Clarification in Existing Law
Under the existing law (section 23-06.5-06) on page 7, line 1, of the engrossed bill, the acceptance by the agent to being an agent "creates a duty for the agent to make health care decisions on behalf of the principal" once the principal becomes incapacitated. What is ambiguous is that in the current optional form, the existing law states that the agent's acceptance "gives me authority over health care decisions for the principal" when the principal becomes incapacitated" (page 6, lines 9-10). Again in existing law in section 23-06.5-03 (page 3, line 25), it states the agent "has the authority" to make health care decisions. The ambiguity is in the existing DPAHC law. Minnesota's statute clearly addresses the matter as "authority," stating there is no "legal duty to act" imposed (Mn Stat 145C.07). The amendment would clarify existing law that the agent's acceptance gives the agent "authority" to make health care decisions.

Statutory Form – Capacity
As proposed, the new health care directive would become effective when the principal lacks capacity to make health care decisions, which is defined in the engrossed bill on page 2, lines 13-16, as "the ability to understand and appreciate the nature and consequences of a health care decision, including the significant benefits and harms of and reasonable alternatives to any proposed health care, and the ability to communicate a health care decision." The proposed new statutory form, in using layperson language to describe "capacity" uses the phrase "if I am unable to decide or speak for myself." This phrase is not technically accurate, based on the definition of "capacity" as the ability to understand and communicate. The proposed amendment would clarify the language in the optional statutory form to use the phrase: "If I am unable to make and communicate health care decisions for myself."

Principal's Statement
Under current law in section 23-06.5-10 for appointment of a health care agent, a resident of a long term care facility or hospital patient or person being admitted to a hospital must have the nature and effect of an agent appointment explained to them. The proposed statutory form includes new language incorporating an acknowledgment of this process, as used currently in a form used by the ND Long Term Care Ombudsman (page 26, line 22 through page 27, line 13). Section 23-06.5-10 also provides in current law that the verbal explanation is not necessary if the resident or patient reads a written explanation of the appointment of an agent. A "Principal's Statement" acknowledging that the resident or patient read a written explanation should also be included. The proposed amendment would include such a statement.

(#4) SB 2343 Sitte

Wesley J. Smith, attorney, works with the International Anti-Euthanasia Task Force, and has contributed a number of articles on the subject of assisted suicide and euthanasia to *National Review.* Some of you might not know that the living will was developed in 1967 by the Euthanasia Society of America, now called Choice in Dying. The article below was printed in the *Wall Street Journal* about a year ago. It is sent to you with Mr. Smith's permission. Questions and comments are welcome.

THE LIVING WILL'S FATAL FLAW

by Wesley J. Smith

The recent death of Richard Nixon, who in his final illness was not put on a ventilator because he had signed a living will, has once again put the spotlight on the document and the power it allegedly bestows on people to control their own future medical care. For example, an April 24, 1994, New York Times story extolled Mr. Nixon's decision, stating that living wills permit patients to retain control even while incapacitated since the document requires "doctors and families" to "execute" a patient's pre-stated desires regarding his or her own care.

That sounds good. There's only one problem: it isn't true. Living wills do permit doctors to decide issues of life and death for their patients. However, they do not permit families to exercise any power at all.

A LOSS OF POWER

That is an important distinction. In our health care delivery system patients make health care decisions, not doctors. This is known as the law of informed consent. Under the law of informed consent, the doctor is charged with fully advising their patient of the pros and cons of treatment or nontreatment, testing and the like and giving opinions. The patient is then free to accept or refuse a doctor's recommendation, get a second opinion or even a different doctor if that is what the patient desires. That provides a valuable fail-safe system since doctors sometimes make mistakes.

The living will changes this balance of power. Once a living will is signed, the patient gives up the protections of informed consent, leaving all health care decisions in the hands of the medical profession. The power to decide whether a patient shall be given the chance to live belongs to the doctor. The decision whether the time has come for the living will to go into effect belongs to the doctor. The type and extent of medical intervention that is to be withheld belongs to the doctor. And this power isn't restricted to extraordinary care" such as ventilators to assist with breathing, but to any medical intervention - from not treating a curable bacterial infection to withdrawing food and fluids so that the patient starves and dehydrates to death.

A BUM'S RUSH TO DEATH

There is an increasing body of evidence that living wills are being misapplied so as to deny care to people with treatable medical conditions. For example, there is the tragic case of the seventy-three year old woman who was given a living will to sign along with the other admission forms upon entering a hospital for hip replacement surgery.

She tolerated the surgery well and was on the road to recovery. Then, she suffered a cardiac arrest. Rather than attempt to save her (remember, the woman was not otherwise terminally ill), it was assumed that because she had signed a living will, she wanted to die if faced with a grave medical condition. Thus, the woman was given no medical assistance whatsoever and died - a process that took some twenty minutes. The woman's daughter was not even notified of the problem or asked for permission to "do nothing." The first the daughter found out about her mother's crisis was when she was informed of her mother's passing.

Then there is the case of the nursing home resident from Washington state who was accidentally given the wrong medication by a staff nurse. The mistake was quickly discovered. However, the patient was not advised of the mishap even though mentally competent. Why? She had signed a living will which instructed that she not be resuscitated if she suffered a cardiac arrest. It was thus assumed she would not want to be treated for a condition that could (and did) lead to her death, even though she was capable of making that decision herself.

A BETTER ADVANCED DIRECTIVE

Happily, there is an advanced medical directive that receives far less publicity than the living will, that allows patients to decide ahead of time on the level of care they want while retaining the important protection of informed consent. It is the Durable Power of Attorney for Health Care.

In a Durable Power of Attorney for Health Care, the patient appoints a designated agent as his or her health care decision maker. The agent will generally be a family member or close friend - someone who knows the patient intimately and who will have a true understanding of the patient's attitudes having discussed the matter at length with the person granting the power. The Durable Power also permits people to opt in favor of life prolonging care, an option often unavailable to the signer's of living wills.

In such circumstances, the doctor will have to justify his or her recommendation to either provide or withhold care. Second opinions can be sought. The chance of a tragic misapplication of the advanced directive that can occur with a living will is greatly reduced. For example, in the case of the woman allowed to die when she suffered a cardiac arrest, a call to her agent (presumably her daughter) might have brought instructions to intervene and the woman could well be with us today, enjoying the mobility accorded by her new hip. At least it would have been worth the try.

Living wills are analogous to the used car advertised as a reampuff that is really a lemon. In a world of assembly line medicine where, unlike that the former president, many patients have little interaction with their doctors, would it not be better to eschew doctor-empowering living wills in favor of the "real people" empowering Durable Power of Attorney? It's not as catchy a name but it is a much better document that may make the difference between a premature death and receiving the personal level of health care decision making that every one deserves.

CHAPTER 111 — THE LIVING WILL: PASSPORT TO FATAL ABUSE

American Life League

We have 'Baby Does' now. It won't be long before we have 'Granny Does.'

Former Surgeon General C. Everett Koop.

Anti-Life Philosophy.

It is every person's right to control his or her own body. A natural and logical extension of this "right to choose" is the right to determine how one will be treated if one is incapable of voicing an opinion regarding one's own medical care.

Most people do not want to go on living as hopeless vegetables after they lose the capacity to make decisions. This prospect fills us with dread and is an unconscionable invasion of privacy. The "Living Will" fills the vital need of allowing individuals to specify what medical care is and is not desired after he or she is rendered incompetent.

What is a "Living Will?"

"Living Will" legislation goes by many names. It may be called "Death With Dignity," "Rights of the Terminally Ill," or "Patient's Rights" legislation. All of these names emphasize understanding and compassion.

The "Living Will" is defined by pro-euthanasia groups as a document by which a person can assert, in writing, a desire not to be kept alive by life-sustaining medical equipment and procedures when his or her condition has been diagnosed as terminal, or under certain other well-defined conditions.

Most "Living Wills" signed in this country today are form-type wills, but, as with any legal document, they can be custom-tailored to meet any actual or perceived need or wish, including;

- requesting or refusing artificial feeding tubes, antibiotics, dialysis, respirators, cardiopulmonary resuscitation, and other specified treatments;
- requesting pain medication;
- stating the desired place of death, including at home;
- designating a proxy to make health care decisions when the individual is incapable of doing so; and
- requesting designation as an organ donor.

Is A "Living Will" Necessary?

Some persons believe that the "Living Will" is necessary in order to clarify a patient's legitimate right to refuse extraordinary medical treatment. However, this is a right that all patients *already* possess. Public support for such pro-"Living Will" legislation is primarily due to the fact that a very small minority of doctors resist even morally appropriate requests for the withdrawal of treatment.

"Living Wills" are generally unnecessary under present law, because there is nothing to prevent doctors from withholding or withdrawing life-sustaining medical treatment when all reasonable hope for recovery is gone. Patients already have the right to give their doctors and family instructions on how they want to be treated in the event of a terminal illness or grave injury, particularly when they are in no condition to decide for themselves.

Who Backs the "Living Wills?"

Most "Living Will" proposals have been written and promoted by the following organizations. The membership of this list alone should sound alarm bells for those dedicated to protecting human life;

- The Society for the Right to Die, which shed its non-progressive title "Euthanasia Society of America" in 1975;
- Americans Against Human Suffering (AAHS);
- Concern for Dying (formerly the Euthanasia Educational Council), which split from the Society for the Right to Die in 1979;
- the National Hemlock Society, which lobbies for direct euthanasia, and which publishes a "cookbook," or "how-to" manual on suicide; and, not surprisingly,
- the American Civil Liberties Union (ACLU).

In fact, the original concept of the "Living Will" originated with these pro-euthanasia groups. The "Living Will" is seen as a publicly-acceptable way to introduce the agenda of legalized active euthanasia, suicide, and assisted suicide.

Notice that none of these organizations uses the term "euthanasia" in their titles (they prefer the euphemisms "right to die," "death with dignity," and "mercy killing"). Note also that all of these groups operate primarily in California, Arizona, and Florida, all states with large elderly and retired populations.

JUST THE FIRST STEP ...

The Three-Step Strategy.

Pro-euthanasia activists consider the "Living Will" just the first step on the road to active, *involuntary* euthanasia of those considered to be useless to society. They know full well that if they can get society to make this first critical step, all of the

other steps no matter how many there are will be much easier.

Subsequent steps are always easier. The first step down the slippery slope is the hardest, but, once a society's downward plunge gathers momentum, it will find itself moving so quickly that it is difficult to stop or turn back.

As Derek Humphry, the Director of the Hemlock Society, said in a December 18, 1986 interview; "We have to go stage by stage, with the living will, with the power of attorney, with the withdrawal of this; we have to go stage by stage. Your side would call that the 'slippery slope'... We would say, proceed with caution; learning as we go along how to handle this very sensitive situation."[1] The headline of an August 16, 1985 *USA Today* article which was a compendium of interviews with pro-euthanasiasts said it all: "Living Wills 1st Step, Euthanasia Group Says."

The "Living Will" is only the first of three major steps in the pro-euthanasia strategy. The second is passive euthanasia (assisted suicide). In such an action, the doctor prescribes a lethal dose of medication at the request of the patient, or he discusses how a hypothetical patient, using hypothetical means (of course) can kill himself.

Dr. Jack ("The Dripper") Kevorkian is now making this second step a reality. As of March 1993, the retired Michigan pathologist had assisted in the suicides of fifteen people, and had made it perfectly clear that he wanted to set up a chain of euthanasia clinics across the country, as described in Chapter 109, "History of Euthanasia."

The third and final step in the strategy is direct euthanasia, where the patient or his "attorney-in-fact" requests that the patient be injected with a combination of barbiturates and paralyzing drugs. This type of direct killing was proposed in the "Oregon Death With Dignity Act" and Washington State's Initiative 119, which failed by popular vote in November of 1990.

Example Expansion.

This three-step strategy for direct euthanasia was demonstrated vividly after California passed its "Natural Death Act" in 1983. *Within just the first year after its passage*, seven amendments were made to this Act, each of which substantially expanded its original intent. The Hemlock Society supported a proposed bill that would have allowed doctors to give their patients lethal injections in other words, direct euthanasia.

The Future of the "Living Will."

As with the other aspects of euthanasia, we need only to look to Holland for a vivid picture of the future of the "Living Will" and its natural successors.

Dutch cardiologist Dr. Richard Fenigsen recently described the ultimate evolution of

the "Living Will" in Holland.

More than 40 percent of all Dutch physicians have admitted to killing one or more of their patients *against their wills*. In light of this fact, most Dutch, especially the elderly, are extremely afraid of doctors and, even more so, of hospitals.[2]

The number of nursing homes in Holland has decreased by more than 80 percent in the last 20 years, and the life expectancy of the few elderly who remain in such homes is becoming shorter all the time. In some cases, the life span of healthy elderly who enter Dutch nursing homes can be measures in *hours*.

Many Dutch citizens, therefore, are now carrying a defensive document entitled the "Declaration of a Will To Live," which states that they *do not* want to be euthanized without their knowledge. This document was originated by the appropriately-named Sanctuary Society.

Predictably, these Declarations carry very little weight with the same doctors who introduced the equivalent of the so-called "Living Wills" in Holland. As always, what matters is not what the patient desires, but what the physicians see as beneficial to the medical profession and to society at large.

As Dr. Fenigsen noted, "The burden of justifying his existence is now placed upon the patient."[2]

WHAT ARE THE DANGERS OF THE "LIVING WILL?"

No Reliable Oracles.

The primary danger of the "Living Will" lies in the fact that it is usually signed long before the person knows when he or she will be incapacitated or what the circumstances of that incapacitation will be. This means that the specific treatment (or lack thereof) for the future condition cannot be specified.

Presumably, one can revoke a "Living Will" at any time by making a verbal or written statement to a physician, nurse, or other health care worker. This, of course, is contingent upon the individual's condition at the time he wishes to change his mind. If he should experience a change of heart after he is incapable of communicating, he is out of luck. Also, if the presiding health care professional feels that the patient's wishes are the result of trauma or some other cause, they can be totally disregarded.

If a "Living Will" has been signed, it is probably legally binding under the current conditions in the American judicial system. It would therefore be difficult or impossible for a family doctor to make the decisions which could be in the patient's best interests.

This set of conditions makes it virtually impossible for the signer of a "Living Will" to define precisely that treatment that he wants or does *not* want.

Specific Problems.

An example "Living Will" is shown below in bold type. The [*bracketed and italicized sections*] highly the extreme vagueness of the so-called "Model Living Will" that is being proposed for general usage in every state by pro-euthanasia groups.

INTRODUCTORY TEXT OF A TYPICAL 'LIVING WILL'

If I should have an incurable or irreversible condition [*does this include asthma, diabetes, cerebral palsy, heart conditions, AIDS?*] that will cause my death within a relatively short time, [*this could be hours or weeks or even months*] and if I am no longer able to make decisions [*what if the person is affected by medication or allergies? What if he is temporarily disoriented or depressed? Or senile?*] regarding any medical treatment, I direct my attending physician [*family doctor? Friend? Attorney-in-fact? What about a doctor in a strange city who knows nothing about you?*] to withhold or withdraw treatment [*what about respirators or chemotherapy? How about insulin, nitroglycerin, blood pressure medicine, oxygen, antibiotics, even food and water?*] that only prolongs the dying process and is not necessary to my comfort or to alleviate pain [*if you are transitorily comatose or drugged, what degree of pain is being specified here?*].

Reference. "Living Wills." Pamphlet by Mary C. Senander, Human Life Alliance of Minnesota, Inc., Post Office Box 293, Minneapolis, Minnesota 55440. 1986.

A person may feel justified and secure in signing a "Living Will," but, even if the document were medically and legally secure in every way *at the time of its signing*, there is no way of knowing how the definitions and rules will change as the pro-euthanasia groups lobby and push for more favorable (for them) conditions.

Take as an example the most common "form" "Living Will," which has been signed by millions; "If I am permanently unconscious or there is no reasonable expectation of my recovery from a seriously incapacitating or lethal illness or condition, I do not wish to be kept alive by artificial means."

Ten years ago, "artificial means" would have meant truly extraordinary or "heroic" medical or surgical procedures. Now, in some states, respirators, codes, kidney dialysis, and even *food and water* are defined as "artificial!" In other words, a person might sign a 'Living Will' in a state where food and water are standard treatment, and then travel to a state where they are defined as "extraordinary treatment," and become incapacitated. Or else, the courts or legislator in his home state may quietly

define food and water as "extraordinary treatment," and he will not be aware of the fact.

What happens then?

Terms whose definitions are constantly shifting or are difficult to define are the heart of the "Living Will's" problems. Figure 111-1 lists the ten primary objections to current "Living Wills."

FIGURE 111-1
THE TEN BASIC LOGICAL OBJECTIONS TO THE "LIVING WILL"

(1) The "Living Will" is unnecessary because everyone *already has* the right to make informed consent decisions about their own medical treatment.

(2) The "Living Will" is unnecessary because doctors are *already free* to withhold or withdraw useless procedures that provide no comfort or profit to terminal patients.

(3) The "Living Will" is unworkable because it is *theoretically impossible* to make well-informed and logical decisions regarding health care before illness or accidents happen. Nobody even knows how they will react if they are incapacitated.

(4) "Living Will" language appears to be precise, but in reality it is extremely vague, and can be interpreted in an almost unlimited number of ways, many contrary to the actual intent of the signer.

(5) The "Living Will" is counterproductive because doctors are currently protected from malpractice suits to a certain degree when dealing with terminal cases. However, the addition of a relatively random legal element such as the "Living Will" greatly increases the possibility of malpractice claims by surviving relatives due to the extremely vague language of the "Living Will." Physicians are in the midst of an acute malpractice crisis. A doctor may take the safest course of action for himself and withhold treatment that would preserve the life of the patient in cases where there is some question brought on by the vagueness of the "Living Will" language. In other words dead patients don't sue!

(6) The "Living Will" is counterproductive because it may restrict physicians and relatives from making health care decisions that are truly in the best interests of the incapacitated signer.

(7) The definitions contained in a "Living Will" are constantly changing. For example, the term "heroic treatment" may soon evolve to include food and water. Therefore, a person signing a "Living Will" now may have unintentionally signed his own death warrant by starvation and thirst if he does not carefully keep up with legislation in the area of health care decisions. And it is a safe bet to say that 99

percent of "Living Will" signers *do not* do this.

(8) Legally binding fill-in-the-blank "Living Wills" do not make age distinctions. A person who might refuse a certain life-sustaining measure if he were dying of brain cancer at age 85 may not refuse the same treatment if he were the victim of a car accident at age 25. The "Living Will" makes no distinctions in this matter.

(9) The "Living Will" is dangerous because it does not completely define the complex term "competency." Therefore, a person who decides to contradict one or more of the specifications in his own "Living Will" might be refused because he is ruled technically "incompetent."

(10) The "Living Will" is dangerous because there is a heavy push on for cost containment and socialized or nationalized health care. The widespread use of "Living Wills" will insure that the balance tips towards *undertreating* patients, which has killed a thousand times as many people as *overtreating* them.

Emergency Room Intruder.

If "Living Wills" become popular, their existence will vastly complicate hospital decisionmaking. How would a doctor treat a patient who has *not* signed a "Living Will?" Would he expend every effort possible to save the patient? Or no effort at all, in the belief that the person wanted no treatment whatever? If a significant percentage of the population had signed "Living Wills," would it be assumed that every possible effort should be expended to save all emergency room patients? How can the physician be certain that a person has or has not signed a "Living Will?"

Perhaps uppermost in the physician's mind is the fact that failure to comply with a legally binding "Living Will" would make him liable for damages. What would he do if confronted with an emergency situation where the status of the patient's "Living Will" were unknown? Would he proceed with treatment that might be against the patient's wishes? What would he do if the "Living Will" specified some action or lack of action that conflicted with his religious beliefs, or with hospital regulations? What if a custom-written "Living Will" featured particularly bizarre or dangerous specifications based on personal beliefs?

The personal beliefs of doctors, of course, carry little weight in the legal system. This will inevitably lead to physicians being forced to choose between their consciences and their jobs and security. Doctors will be forced to choose death over life.

In fact, some states now require that a doctor not only try, but actually *find* another physician willing to kill the patient, under pain of severe penalties in some cases, even jail terms.

"imminent death," "terminal condition," and "life-sustaining procedures."

[4] In 1986, Alaska passed legislation which includes nutrition and hydration in its definition of life-sustaining treatment that may be withdrawn. This is the most liberal and frightening "Living Will" statute on the books. Significantly, it is considered the most ideal existing "Living Will" by "Right to Die" groups.

[5] In accordance with the Supreme Court abortion decision *Roe v. Wade*, these states allow "Living Wills" for pregnant women. This means that a woman may be euthanized even if her baby is full-term. Even those states that do not allow the killing of a pregnant woman have endured strong challenges from those who believe that she should be allowed to not only commit suicide, but murder-suicide.

References. "Living Wills." *Human Life News* (publication of the Washington State National Right to Life affiliate), November/December 1988, page 2. Also see "Guide to the Living Will." *Hippocrates* Magazine, May/June 1988, page 60. Also see Society for the Right to Die. *Handbook of Living Will Laws, 1981-1984*, *Handbook of 1985 Living Will Laws*, and annual updates.

References: The "Living Will."

[1] Derek Humphry, quoted in Leslie Bond. "Hemlock Society Forms New Organization to Push Assisted Suicide Initiative." *National Right to Life News*, December 18, 1986, pages 1 and 10.

[2] Presentation by Dutch cardiologist Richard Fenigsen, M.D., Ph.D., at Seattle University on November 2, 1990. Described in "Holland Euthanasia Experience Described." *Human Life News* (Washington State). November/December 1990, page 6.

Further Reading: The "Living Will."

Paul A. Bryne, M.D. ***Understanding Brain Death.***
Order from American Life League, Post Office Box 2250, Stafford, Virginia 22554. Is "brain death" really the death of the person? This booklet examines this critical question.

Father Robert Barry, O.P. ***Protecting the Medically Dependent: Social Challenge***

and Ethical imperatives.
Order from American Life League, Post Office Box 2250, Stafford, Virginia 22554. How to construct, ethically and legislatively, a proper plan of protection for the seriously ill.

A.R. Saqueton, M.D. ***In Defense of Life.***
ARS Publishing Company, Post Office Box 6444, Stockton, California 95206. 232 pages, 1981. Reviewed by Felicia Goeken on page 9 of the May 10, 1982 issue of *National Right to Life News* and page 11 of the July 8, 1982 issue of the same publication. Also reviewed by Robert L. Sassone on page 20 of the May 1982 issue of *ALL About Issues.* One of the most valuable references available on "right to die" legislation. The 'Right to Die,' Living Wills, terminal conditions, and many other aspects of euthanasia are covered in this primer-type work.

Society for the Right to Die. ***Refusal of Treatment Legislation: A State By State Compilation of Enacted and Model Statutes.***
Society for the Right to Die, 250 West 57th Street, New York, New York 10107, telephone: (212) 246-6973. This ring binder includes the full text of every living will and durable power of attorney statute in the United States, the model statute entitled the Uniform Rights of the Terminally Ill Act, and summaries and highlights of the significant features of all of these documents.

This is a chapter of the *Pro-Life Activist's Encyclopedia* published by American Life League.

Provided Courtesy of:
Eternal Word Television Network
5817 Old Leeds Road
Irondale, AL 35210