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Taking Control of Life and Death Health Care Decisions





Taking Control of Life and Death Health Care Decisions

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TAKING CONTROL OF LIFE AND DEATH HEALTH CARE DECISIONS

This packet contains master copies of the following pages and forms from Minnesota Extension Service Publication HE-MI-5614-S, in this order:

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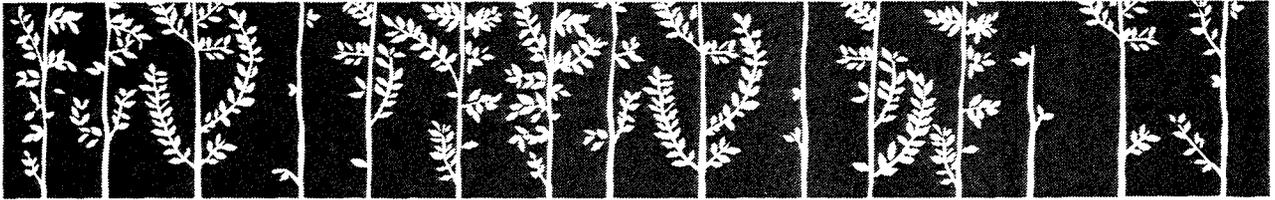
Worksheet 4-3

Talking With Professionals (Health Care Providers,
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Glossary

Self-Evaluation Form

Taking Control of Life and Death Health Care Decisions



User's Guide

Purpose And Organization Of Self-Study

"Taking Control of Life and Death Health Care Decisions" is a self-study packet designed to help people make informed decisions and plan ahead regarding an important issue facing individuals, families, and society. Working through the self-study will help people ask the right questions and think through the implications of planning options. Participants will begin to develop their own "answers" or decisions based upon personal preferences; there will be no grading or right or wrong answers. The self-study format allows individuals to work on their own or with others and allows people to set their own pace in working with the materials.

Overall Objectives

Participants completing the self-study will be able to:

- gain an understanding of the complex ethical, legal, medical, economic, and policy issues involved in life and death health care decision making;
- develop personal perspectives regarding life and death health care dilemmas and decisions;
- identify the myths and facts about health care decision-making planning options, both formal and informal; and
- increase skills in communicating with family, friends, and professionals about the issue.

Basic Content

The self-study consists of the following four major sections:

- Understanding The Issue
- Sorting Out Preferences
- Myths And Facts About Planning Options
- Communicating With Others

Each of the sections contains reading material, worksheets, and discussion questions for participants. Worksheets may be copied so that all participants have their own copies. While the sections are in a suggested order, individuals may change the order to meet their own needs. A glossary of terms is included and can be referred to throughout the self-study. A self-evaluation for use after working through the four sections completes the self-study.

Suggestions On How To Use The Self-Study

The materials in the self-study can be used in a variety of situations. Some of these include the following:

Discussion with family members and/or friends. Life and death health care decision making often involves an individual's close family and/or friends. It is logical then that family members and close friends work through the decision-making process together--thinking, sharing, and discussing. Many of the worksheets in the self-study are designed to encourage sharing and communication among a group of adults who have chosen to participate. The self-study has successfully been used by groups of individuals made up of many different ages and types of relationships--parents, adult children, older teenagers, spouses, and close friends. The materials can be shared through the mail with family and friends who do not live nearby. Reading material in each section can be shared with others; additional copies of worksheets can be made for each participant.

Individual study sessions. Some individuals may not have close family members or friends who are interested in participating, able to, or who live nearby. In these cases, individuals are encouraged to work through the self-study alone and may find sharing or discussing with health care providers, clergy, or attorneys helpful as they work through the materials.

Group study sessions with facilitator(s). Each of the sections in the self-study could provide the structure for a four-week group study on the subject. While it is important that individuals take the time to work through the worksheets on their own, weekly meetings with other individuals also working through the materials could be helpful. Facilitators can help guide weekly discussion of the reading material, answer questions, and direct further group discussion.

Adapting For Use Outside Of Minnesota

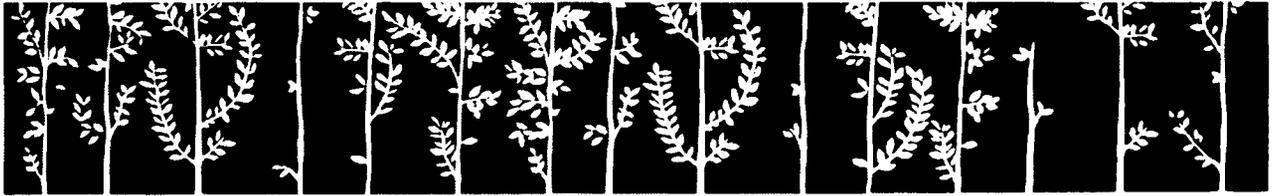
All information in the self-study applies to residents of states outside of Minnesota except for the state-specific policies on formal planning options in section 3, "Myths And Facts About Planning Options." The section labeled "Minnesota Myths And Facts" can be replaced with similar content on living wills and Durable Power of Attorney policies in other states. A state-specific quiz on myths and facts could also be developed using the Minnesota quiz as a guide. Some states have existing materials summarizing related policies and these materials could simply be added. Check with your State Board on Aging, as well as any other senior organizations or coalitions for further information in a particular state.

Developed by Marlene S. Stum, Family Social Science, State Extension Faculty, University of Minnesota, St. Paul.
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MINNESOTA EXTENSION SERVICE

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Taking Control of Life and Death Health Care Decisions



Section 1

Understanding The Issue

Marlene S. Stum, Family Social Science

Objectives

In recent years, medical science has made major advances in life-sustaining technology, enabling individuals to survive illnesses and injuries that were once fatal. Respirators, artificial nutrition, and kidney dialysis are only a few examples of the technological advances that save lives and/or prolong the natural process of dying. At the same time that these advances save lives, they also create complex dilemmas and decisions regarding life and death for individuals, their families, health care providers, the courts, and society. When a patient is no longer able to make or communicate his or her own preferences and decisions about health care, the dilemmas can be even more difficult and complex.

The purpose of Section 1 is to help participants:

- 1) gain an understanding of the complex ethical, legal, medical, economic, and policy issues involved in health care decision making for all age groups;
- 2) become aware of the problems and dilemmas a lack of planning ahead for health care decision making can create; and
- 3) think about and discuss personal reactions and experiences related to life and death health care decision making.

Why Is Health Care Decision Making An Issue?

Individuals of all ages face the risk of terminal illness, irreversible injuries from an accident, and irreversible chronic illnesses. What will happen if an individual is unable to make or communicate his or her preferences or decisions regarding health or personal care? Who will decide whether to resuscitate a terminally ill patient, continue a feeding tube for a young accident victim in a permanent coma, or try antibiotics for a pneumonia-stricken, advanced-stage Alzheimer's patient? Will a patient's religious beliefs about dying be known or respected? How should such decisions be made and on what basis? These are examples of the critical questions being addressed by families, health care providers, and the courts.

The 1990 Supreme Court case regarding Nancy Cruzan, a 32-year-old accident victim in Missouri, has raised awareness of the need for individuals of all ages to plan ahead for the possibility of not being able to make or communicate one's own decisions about health care. As a result of her accident, Nancy Cruzan was in a coma, with no hope for improvement. She was being kept alive by a feeding tube. Her parents fought to have the feeding tube removed to have their daughter die with what they felt was dignity. In this case, the hospital administration denied the family's request. The Supreme Court ruled that the family did not have "clear and convincing evidence" that Nancy would have wanted the treatment stopped. According to the court, there were not any clear instructions or preferences left by Nancy regarding the kind of care she would have wanted in such a situation.

The Supreme Court did recognize that competent adults have the right to control their medical care, including the right to have life-sustaining treatments stopped. The court also indicated that individuals who do not make their wishes known prior to becoming incompetent must depend upon the policies set by state legislatures concerning matters of stopping or foregoing life-sustaining care. In a later Missouri court ruling, Cruzan's feeding tube was allowed to be removed based on new evidence from her friends regarding her wishes and new input from her physician.

Who Should Be Concerned?

The implications are that individuals of all ages need to think through their preferences regarding health care and leave clear and convincing evidence for others to use if they are unable to communicate or make their own decisions. The definition of clear and convincing evidence is evolving. Legislatures and courts are attempting to clarify policies so that individuals and families understand their rights and can plan ahead. It is important that individuals be aware of the likelihood of being faced with life and death health care decision making, begin to ask the right questions, and develop personal perspectives on how to deal with the issue. There are no magic formulas or right answers. Each individual, in cooperation with his or her family, friends, and health care providers has to think through difficult dilemmas about life and death and develop a plan based on his or her own preferences.

While many believe that only older adults need to think about planning ahead for life and death decisions, it is important to recognize that accidents and cancer are common causes of death for younger adults as well. Nancy Cruzan was young and did not have a terminal illness. Instead, she suffered an unexpected accident. It is especially important for single individuals without close family members or friends to make a special point of planning ahead.

Planning Ahead Eases Future Decisions

Will most adults who are in permanent comas, suffering from Alzheimer's disease, AIDS, or terminal cancer plan ahead and express their preferences regarding life and death health care decisions? Reality is that even though individuals know it is important to have a will to distribute their assets and property, a majority do not have an up-to-date will. Most adults have not made arrangements for their own funerals. Fewer have thought about or shared their preferences regarding life and death health care decisions. Even fewer have left what physicians, ethics committees, or the states would consider *clear and convincing evidence* of their wishes.

Whenever a task is perceived to be unpleasant or appears that it can wait, it is easy to procrastinate and do nothing. Many individuals admit that they feel discussing and planning for life and death health care decisions is important but just don't get around to it. It is easy to assume that for some reason you, a family member, or a friend will not have to deal with such decisions. "It won't happen to me" is a common excuse for not making plans today. Does this sound familiar?

Realistic Expectations Of Others

Many individuals assume that family members or friends would be consulted and would be willing to step in and make the best health care decisions for them. "I just assume the kids will take over and do it for me," Margaret responded when asked whether she had talked to anyone about making health care decisions for her in the event she was unable to. Margaret, 77, has been widowed for 17 years, lives alone, and is in relatively good health. "The kids would consult each other and I am sure they would reach a decision between them." Her kids are 41 and 47 and live 20 and 800 miles away. Margaret trusts her children completely and expects that they can agree on a decision. Family members and close friends are typically involved in a variety of life and death dilemmas and decisions. Most individuals with family tend to prefer to keep health care decisions in the family if possible. Research has found that the elderly are most likely to expect (in order) first spouses, then children, siblings, friends, doctors, and finally lawyers to make decisions if they are no longer able to do so for themselves. Physicians, hospital policies, and hospital ethics committees often provide some checks to prevent family or friends from making inappropriate or irresponsible decisions.

Need To Discuss

Even though many adults prefer other family members or friends to make health care decisions for them, such issues are not often discussed among those expected to be involved. It is common instead to hear comments such as: "It's just one of those things that is a general understanding between my husband and myself" or "I just assume they will be able to do what I would want them to do." While the assumption is that close family members or friends will be able to make decisions based on the beliefs and values of the patient, research findings suggest that this is not always so.

When family members, friends, and health care providers do not share preferences and expectations, the chances for frustration and difficult decisions occur. The potential for conflict and disagreements among family members about the choice a family member would have wanted may increase. Feelings of guilt, abandonment, resentment, and concern for financial and emotional burdens are not uncommon among individuals involved in making health care decisions for others.

Most people don't like to think about being dependent on another, not being healthy, death or dying, or not being competent enough to make their own decisions. Avoiding talking about such issues and not planning ahead is often an easier approach in the short run but it also avoids the tough issues the future might bring. Taking the time to sort out preferences and share them with others increases the chance that decisions will be based on what the patient would have wanted.

Examples Of Dilemmas And Decisions

Worksheet 1-1 presents the stories of six families that faced health care decisions when one of their family members became incapacitated. These case studies are designed to help you understand how complex the dilemmas and decisions can be across the lifecycle. While you may want a list of possible or right answers to the questions, there are none. Instead, there are a variety of possible approaches, preferences, and viewpoints which should become clearer as you complete additional sections of the self-study.

Suggested uses for Worksheet 1-1:

- Read over the case studies and use the questions as a way to begin to understand how complex life and death health care decision circumstances can be. Also begin to think about personal preferences, reactions, and concerns.
- Begin to develop a list of additional questions and concerns.
- Discuss the case studies with other family members and friends with the goal of sharing thoughts and concerns, not debating the right answer or convincing others that your opinion is right.

Personal Reaction And Experience

After reviewing the case studies and discussing the questions, use Worksheet 1-2 to think about and explore your own experiences in relation to health care decision making. Many individuals have had various experiences with life and death decision making but may not have thought about them or spent time sharing and discussing these experiences with others.

Additional Questions And Concerns

The issue of life and death health care decision making raises a variety of very important questions which will continue to be addressed from a variety of perspectives. The following is a partial list of concerns being considered by individuals, families, policymakers, and health care providers. What do you think?

- What is the appropriate role of family, friends, health care providers, states, ethics committees, or others in an individual's decision making?
- Who is in the best position to judge whether benefits of treatments outweigh the burdens? How do you know the benefits or burdens to a patient who is unable to communicate?
- Are individuals focusing too much on fears of a lingering death?
- Is society becoming more or less tolerant of illness and limitations?
- Could the right to make decisions about treatments and the dying process become interpreted as a duty for some individuals to die?
- Will the illiterate, less privileged, or indifferent be at risk for over- or under-treatment if they do not share their preferences?
- How does an individual best plan ahead knowing that decision-making circumstances are not predictable?

What additional questions and concerns do you have?

References

- Bernard, L., G. McLeod, and G. Saika. 1986, August. Patient attitudes to discussing life-sustaining treatment. *Arch Intern Med*, 146:1613-1615.
- Davidson, K., and R. Moseley. 1986. Advance directives in family practice. *The Journal of Family Practice*, 22(5):439-442.
- Diamond, E. et al. 1989. Decision-making ability and advance directive preferences in nursing home patients and proxies. *Gerontologist*, 19(5):622-626.
- Henderson, M. 1990. Beyond the living will. *Gerontologist*, 30(4):480-485.
- High, D. 1988. All in the family: Extended autonomy and expectations in surrogate health care decision-making. *Gerontologist*, 28(supplement):46-51.
- High, D., and H. Turner. 1987. Surrogate decision-making: The elderly's familial expectations. *Theoretical Medicine*, 8:303-320.
- Legal Counsel for the Elderly. 1987. *Decision-making, incapacity, and the elderly*. Washington, DC: Legal Counsel for the Elderly.
- Zweibel, N., and C. Cassel. 1989. Treatment choices at the end of life: A comparison of decisions by older patients and their physician-select proxies. *Gerontologist*, 29(5):615-621.

Worksheet 1-1

Life and Death Health Care: Decisions and Dilemmas Six Case Studies

FAMILY #1

Peg and Rich Ball have two children ages 5 and 7. Peg, who is 35, has just been diagnosed as having terminal cancer. Peg chose not to have chemotherapy because the doctor told her that in her type of cancer there was only a small chance that radiation would help and due to the side effects expected. She has been at home as much as possible but recently went into a coma and is not able to make her own health care decisions.

Peg and Rich had informally discussed their wishes and neither wanted to have life-prolonging treatment used if faced with a terminal illness. Peg's parents and brother want to do everything to keep her alive for as long as possible and are angry about Rich's decision not to resuscitate her if her heart stops beating and that there should be no tube feeding. Rich is feeling guilty, confused, pressured, and alone.

Discussion Questions

- a) If you were Peg, what type of health care decisions would you want made for you? Why?
- b) Who should be the main decision-maker for Peg? Why?
- c) If you were Rich, what would you do to handle the situation and keep the family together?
- d) What could have been done ahead of time to avoid the guilt and confusion about Peg's life?
- e) Do you think this is a realistic family situation?

FAMILY #2

Jack is an 86-year-old widower without any close relatives. He has diabetes and a mental disorder, and is unable to make medical decisions for himself. Jack has developed blood poisoning in his left leg and the doctor has determined that he will die in a short time if the leg is not removed.

Jack had appointed his close friend, Bill, as a proxy decision-maker for him but did not give Bill any specific directions about types of treatment. Jack had expressed concerns and fears about not being treated because of his age and mental abilities. Jack had also said to Bill, "I trust you to do the right thing for me."

Discussion Questions

- a) If you were Bill, what decision would you make? What information about Jack's life could you use to help you decide?
- b) If you were Jack, what decision would you want your friend to make?
- c) Is there other information about Jack and his health that would help in making a decision?

FAMILY #3

Mary is 19 years old and was an excellent gymnast until her accident. Last month at district competition she fell from a 12-foot bar and broke her spine. She has had two operations and it is unlikely that she will ever walk again. Mary is in a coma and unable to make her own health care decisions. The doctors are recommending that she be fed by placing a tube in her stomach to keep her alive and are uncertain about her chances of coming out of the coma.

Mary's parents do not know what to do. What about her quality of life in the future? Her parents strongly believe that God intends for life to be sacred but they also believe that there are limits to what human existence can mean. They know of other cases where people have survived with time and prayers. How do they weigh the burden and the benefits for Mary? In addition to Mary, they have two other children, ages 12 and 17, to consider.

Discussion Questions

- a) If you were Mary's parents, what would influence your decision?

- b) If you were Mary, what decision would you want your parents to make? What would be the most important thing that you would like them to consider?

FAMILY #4

Anna is 87 years old. She has been in the nursing home for three years because her physical health had deteriorated to the point where she could not take care of herself. Her daughter, Sue, and her family live in the same community. Anna has another daughter in St. Paul and one in Arizona. Sue has been the one responsible for most of the decisions about Anna's health and finances during the last few years.

Anna refused to discuss her opinions about receiving certain types of treatment or care to extend her life and has no formal living will. Her health has deteriorated over the past few months and she has been judged to be incompetent of making her own care decisions. Anna is conscious and repeatedly tells the aides that she does not want any tubes used to keep her alive. Her doctor wants to use tube feeding to prolong her life.

Sue believes that she should respect her mother's wishes and not extend her life with tube feeding. Her sisters do not agree. They argue that they do not really know what their mother's wishes are and that everything should be done to prolong her life.

Discussion Questions

- a) If you were Anna and could talk to your daughters, what would you tell them to help them make the best decision for you?

- b) What would you do if you were Sue?

- c) What could be done to ease such conflicts in other families?

FAMILY #5

Jeff, age 23, was recently in a serious car accident. He is presently in a coma and cannot breathe without the help of a ventilation machine. All test results show that it is very unlikely that he will ever come out of the coma. His doctor has said that even if he comes out of the coma Jeff's functioning level would be uncertain. The doctor is asking his family whether or not the ventilator should be removed.

Jeff has been living with his mother in Minnesota; his father lives in Iowa. His parents were separated ten years ago and had joint custody of Jeff until he reached adult status. Jeff's parents have very different views about the appropriate health care for him. His dad feels very guilty about removing the ventilator, wants to prolong Jeff's life, and feels that Jeff was always very tolerant of pain. Jeff's mom seems extremely concerned about the quality of life her son might have, and feels strongly that prolonging his life would be very unfair and stressful. In addition to Jeff's parents, his girlfriend and several other close friends say that they had talked about what they would want if injured and remember Jeff's comments. Jeff had said he would never want any heroic measures and hated the thought of being kept alive by machines if there was no hope of recovery. Jeff and his parents had never shared views about such issues before and are not sure whether to trust his friends' input.

Discussion Questions

- a) If you were Jeff's mother or father, what decision would you make for him? Why?
- b) What decision would you want your family or friends to make if you were in a situation like this? How sure are you about this decision?
- c) What could be done to help Jeff's parents come to some decisions about the ventilator?

FAMILY #6

Mr. Swenson is 60 years old and is in the hospital after suffering a stroke two weeks ago. He is no longer in danger of dying from the stroke, but his physical and mental abilities have not improved since it occurred. He requires total nursing care. His left side is paralyzed, and he is unable to feed or bathe himself. He is mentally confused, and he does not recognize his family.

Prior to the stroke, Mr. Swenson had agreed to having a pacemaker inserted to help a chronic heart condition. He was going to contact his doctor to schedule the operation the day he had the stroke. He had been told by his physician that without the pacemaker, he would die of heart failure within a year; with the pacemaker he could reasonably expect to live ten to twenty years. The doctors cannot tell for certain how much he will recover from the stroke. It is likely that he will remain in his present condition; but there is always the possibility that he might regain some of his physical and mental abilities.

Mrs. Swenson, his wife, is 55 and in reasonably good health. She continues to work part time. They have \$50,000 in a savings account and use the interest from this account to supplement her wages. The combined income has been enough to meet living expenses. They also have a small private health insurance policy which will cover most of the hospital expenses, including the pacemaker. The insurance would not cover the expenses of long-term nursing home care, which would have to be paid if the pacemaker is inserted and he remains physically and mentally handicapped from the stroke. Medicaid (the state assistance program) would pay for his nursing home care once they met the guidelines, but would limit Mrs. Swenson's income and the assets she could keep as a spouse. She's concerned about her financial security if she lives to be 80 or 90. Each of their kids have several children of their own ready to start college and their family budgets are stretched very thin. None of the kids feel they could afford \$22,000 a year, which is what it would cost for the nursing home care. They also have concerns about their mother's financial security.

Discussion Questions

- a) Imagine that you were in a situation like the one above. If you were Mr. Swenson, would you want your family to decide to have the pacemaker implanted?
- b) How sure do you feel about your choice?
- c) If you were one of the children, what factors would you consider in trying to reach a decision about the implant?
- d) What types of feelings and conflicts do you think Mrs. Swenson and the four children and their families are experiencing in trying to reach a decision?

Worksheet 1-2

Life And Death Health Care: Decisions And Dilemmas Personal Reactions And Experiences

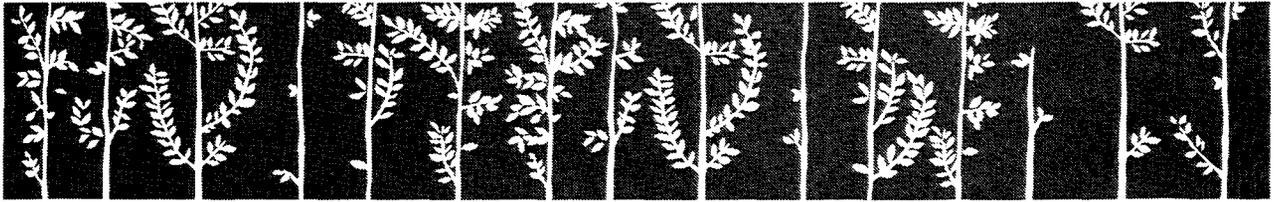
1. What surprised you about your responses to the case study situations or questions in Worksheet 1-1?

2. What did you learn about yourself from thinking or talking about the case studies?

3. If you discussed the case studies with others:
 - What surprised you about other participant's responses to the cases and questions?
 - What did you learn about others from discussing the cases?
 - What did other individuals say that did *not* surprise you? That is, what did others say that you could have predicted?

4. What are examples of health care decision-making dilemmas and decisions that you, family members, or others have experienced?
 - Who was involved?
 - What decisions had to be made?
 - How did the individuals come to a decision?
 - Were there strong agreements, disagreements, reactions, or concerns about how the decision was made or about the final decision?
 - What did the individuals involved wish would have been done differently?

Taking Control of Life and Death Health Care Decisions



Section 2

Sorting Out Preferences

Marlene S. Stum, Family Social Science

Objectives

Taking control of life and death health care decision making requires thinking about some tough issues while a person is competent and able to consider what is most important to them. Regretfully, many individuals and families avoid difficult subjects and put off planning until it is too late. Health care decision making is no exception. Individuals need time to think about what is important to them, understand the choices and consequences of decisions, and "try on" certain decisions to see how they feel.

The purpose of this section is to help participants:

- 1) know where to begin by identifying critical questions to address when planning for life and death decisions; and
- 2) increase awareness and consciousness of personal preferences regarding life and death decision making.

An Important Step: Knowing Your Own Preferences

The more aware or conscious people are of what is important to them, the better decisions and plans they can make. Many people, however, are not used to planning ahead for life and death health care decisions. This means that most people do not know where to begin nor the important questions to address. Planning for life and death decisions involves sorting out preferences regarding:

- who should be involved in care decisions,
- the role of certain medical procedures,
- the role of spiritual beliefs,
- concerns and fears about medical care and the dying process,
- where one prefers to be cared for when dying,
- finances and health care,
- quality and length of life,
- formal and informal planning approaches, and
- the role to play in other individuals' health care decisions.

Thinking through these topics and sorting out what is important to you is an important process before you can share with others or attempt to prepare legal documents such as a living will. Sorting out preferences typically requires ongoing thinking and discussion over a period of time. Most people are not prepared to answer such critical questions on the spot.

How To Begin

Worksheet 2-1 entitled "Life and Death Health Care Decision-making Preferences" has been designed to help individuals begin to sort out what is most important in relation to health care if they are unable to make or communicate decisions. This worksheet can be used in a variety of ways:

- 1) it can be used individually to sort out personal preferences;
- 2) as a tool to share preferences with others; and/or
- 3) as a tool to help write a living will or develop a Durable Power of Attorney for Health Care.

Sorting Out Personal Preferences

- Individuals are encouraged to have their own working copy of the worksheet in order to help develop their own perspectives and opinions in response to the questions. The questions will not be easy for most people to answer. Many will require thinking time, ongoing discussion with close family or friends, as well as more information-gathering to feel comfortable with the answers.
- The glossary of terms in the last pocket of the self-study folder will be an important resource to use when unfamiliar terms are found in the worksheet. A special attempt has been made to define basic medical terms in the glossary.
- Participants are encouraged to record responses to the questions in some way. Some may choose writing out their responses, while others may find it easier to verbally record their answers on a tape recorder. It is not uncommon for individuals to procrastinate writing down or committing themselves to certain answers. The most common reason given is because of potential changes in medical technology, family members, or their own lifestyle and preferences. In our society, change is a given. However, change should not be used as an excuse to avoid planning for life and death decisions. Reassessment of preferences should be a part of the ongoing planning process. If changes in preferences occur, they can be shared as needed.

- Remember that there are no "right" answers. Individuals are encouraged to develop their own perspectives and opinions versus answering as they think others might want or expect them to, or by taking for granted that what is important for someone else is automatically important to them.
- Don't expect to answer all of the questions in one, two, or even three sittings. Give yourself plenty of time to think about and reflect on the answers.

Sharing Preferences With Others

- In addition to developing and recording one's preferences about life and death decision making, it is important to share those preferences with individuals who may need to know. Knowing a person's responses to the questions may prevent family members, friends, health care providers, or clergy from having to guess someone else's preferences. Preferences can be shared in ongoing discussions, or by leaving recorded responses to part or all of the worksheet questions with selected individuals. Information shared in the worksheet may help to clarify or supplement preferences not stated or reflected in more formal legal documents.

Writing Legal Documents, Such As A Living Will Or Durable Power Of Attorney

Knowing and stating one's preferences about life and death decision making is the first step in making decisions about legal planning options. Specific details included in a living will or in a Durable Power of Attorney for Health Care should reflect the preferences of the person initiating the planning. Too often, lawyers are confronted with individuals who haven't thought through their preferences and are asked by clients to "tell me the right way to fill in the blanks." Having sorted through the questions on the worksheet will help prepare individuals and lawyers to develop more appropriate legal planning tools.

For More Information

In many cases, sorting out preferences requires gathering more information and input from family, friends, or professionals. Sorting out spiritual beliefs, medical procedures or practices, or expectations of family members and friends are a few examples of areas where more information and discussion may be necessary. Determine what information is needed, the best source(s) of the information, and begin to ask questions. Remember that sorting out and refining preferences is an ongoing process.

Worksheet 2-1

Life and Death Health Care Decision-Making Preferences

These questions will help individuals think about their health care decision-making preferences and wishes. The more conscious people are of what is important to them, the easier it will be to make better decisions. Try answering the following questions for yourself. Knowing the answers to these questions can be helpful if you choose to write legal documents such as a living will or want to informally share with others.

What Are My Decision-making Preferences?

1. It is a good idea to sign a legal document called a *living will* that says what medical treatments I do and do not want if I have a terminal illness and can no longer make decisions for myself? Yes ___ No ___

Do I have a living will? Yes ___ No ___

Date written: _____

Document location: _____

Who knows about it? _____

2. It is a good idea to sign a legal document called a *Durable Power of Attorney for Health Care Decisions* that allows someone else to make health care decisions for me if I am not able to make them for myself? Yes ___ No ___

Do I have a Durable Power of Attorney for Health Care? Yes ___ No ___

Date signed: _____

Document location: _____

Who knows about it? _____

3. It is a good idea for my family and friends to informally share their preferences about health care decisions? Yes ___ No ___

Have preferences been shared? Yes ___ No ___

Date: _____

Who was present? _____

4. I want to donate parts of my body to someone else at the time of my death? Yes ___ No ___

Have I signed an organ donation document? Yes ___ No ___

Date written: _____

Document location: _____

Who knows about it? _____

Who Do I Want Involved?

5. When I think about how I want to handle my health care decision making, which of the following are important to me? *Check all that you feel are important.*

It is very important for me to have specific input while I am competent to do so.

It is important for me to identify specific people that I want to be involved if I'm unable to make my own decisions.

In general, I feel that I can trust others to make the best decisions for me without much input.

I really prefer not to have input now; I believe that what will be, will be.

6. Who would I choose to make health care decisions for me if I was not able? List in order of preference (i.e., specific family, friends, doctor, clergy, others).

7. Do the people listed in question 6 all know that I want them to be involved? Yes ___ No ___

Comments: _____

8. Have they agreed to make decisions for me? Yes ___ No ___

Comments: _____

9. Have I have discussed my preferences for medical care and decision-making expectations with these people? Yes ___ No ___

Comments: _____

10. Do I expect the people listed in question 6 to support my preferences about medical treatment? Yes ___ No ___

Comments: _____

11. If there are disagreements, whose decision should prevail?

Who knows about this? _____

12. Do I feel that I could not trust certain family, friends, or professionals? Yes ___ No ___
If so, I would *not* want the following people involved in making health care decisions for me:

13. a. Do I like and trust my doctors? Yes ___ No ___
Comments: _____

b. How involved do I want my doctor(s) to be in my health care decisions?
Should my doctors:

• help with understanding medical treatments and possible outcomes? Yes ___ No ___

• recommend options for family and friends to consider? Yes ___ No ___

• make *final* decisions about medical treatment with input from family and others? Yes ___ No ___

What Are My Wishes About Medical Procedures And Health Care?

14. When I think about needing medical care or dying from a *terminal illness*, I get really concerned about . . .

15. While suffering from an illness and dying cannot be pleasant, it can be made more unpleasant. For me, making an illness or dying more uncomfortable or unhappy would mean . . .

16. Have I discussed life-prolonging types of medical treatments with my doctor? Yes ___ No ___
Comments: _____

17. Do I understand how these treatments extend life? Yes ___ No ___
Comments: _____

What Can I Tell Others To Help Guide Decision Making?

19. Health care decisions often involve complex circumstances and difficult choices. Having some sense of the factors that are most important to an individual can help them weigh options and choices. Read each statement and on a scale of 0 to 4, rate how important each of the items are to you. For this scale, 4 means extremely important and 0 means not important at all.

Decision-Making Guides	Not Important At All	Somewhat Important			Extremely Important
	0	1	2	3	4
Letting nature take its course.					
Preserving my quality of life.					
Recognizing my spiritual beliefs and traditions.					
Letting me live as long as possible, regardless of quality of life.					
Considering the amount of burden I would be to others.					
Considering my age at the time.					
Being comfortable and as painfree as possible.					
Leaving good memories for my family and friends.					
Making a contribution to medical research and teaching.					
Being able to relate to family and friends.					
Considering my level of physical limitations.					
Considering my level of mental limitations.					
Being able to leave some money to family or friends.					
Recognizing that my life is sacred, no matter what its quality.					
Being able to die in a short while rather than lingering on.					
Considering the dollar cost involved and who would have to pay.					

Do I Play A Role In Others' Health Care Decisions?

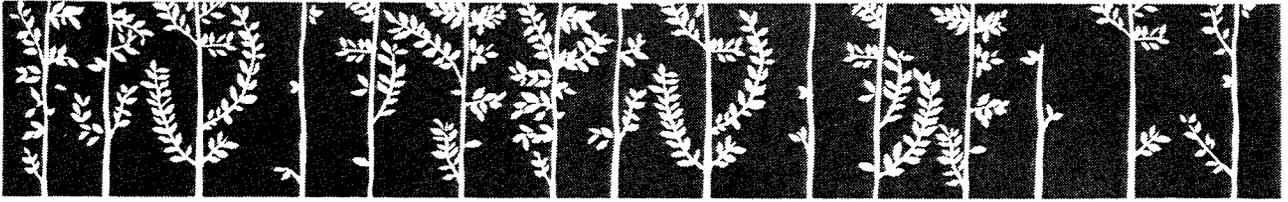
25. Do I have family members or friends who expect me to make health care decisions for them if they are not able? Yes ___ No ___
If so, list them.

26. Have I agreed to do so and in what circumstances? Yes ___ No ___
Comments: _____

27. Do I know enough about their preferences and wishes to make appropriate decisions for them? Yes ___ No ___
Comments: _____

List any additional thoughts you might have:

Taking Control of Life and Death Health Care Decisions



Section 3, Part 1

Myths And Facts About Planning Options

Marlene S. Stum, Family Social Science

Objectives

While many people understand the importance of leaving a will to help distribute their property and assets after they are gone, few really understand the importance of preserving one's autonomy regarding personal health care. With the 1990 Cruzan Supreme Court case came an increased awareness of the need for individuals of all ages to think through their preferences regarding health care and to leave "clear and convincing" evidence for others to use if they are unable to communicate or make their own decisions. Ideally individuals will plan ahead for the potential of incapacity when they are still competent and in a non-crisis situation. For most people, this requires learning about new and different planning options and terminology.

The purpose of this section of the self-study is to help participants increase their understanding of:

- 1) the facts regarding health care planning options;
- 2) the purposes and potential advantages and limitations of specific informal and formal planning options (inside chart);
- 3) state-specific policies and forms relating to life and death health care planning; and
- 4) how to critically analyze what action to take given personal preferences and situations.

Autonomy And Patient Rights

Autonomy, or the right to self-determination, is an ethical and common law principle that is generally supported as a basic right of patients in the health care system. Patients in the health care system have the following specific rights which help to preserve individual control and autonomy:

- The right to participate in medical care decision making.
- The right to receive complete information about their medical conditions.
- The right to refuse medical treatment.

HEALTH CARE PLANNING OPTION COMPARISONS

	Living Wills	Durable Power of Attorney for Health Care	Informal Sharing
Purpose	A legal document allowing expression of intentions regarding medical treatment when terminally ill.	A legal document in which an individual (the principal) appoints an agent (attorney-in-fact) to make health care decisions if the principal is unable. A <u>Durable</u> Power of Attorney continues on in cases of incapacity or disability of the principal.	To increase understanding of personal preferences regarding life and death decision making
Benefits	<ul style="list-style-type: none"> • Allows person to express wishes in advance • Increases control over quality of life if terminally ill and incapacitated • May allow proxy decision-maker to be designated • Reduces decision-making burden for family, friends, and professionals 	<ul style="list-style-type: none"> • May apply to a variety of personal or health-care related situations where decisions are necessary; therefore going beyond only a terminal illness • Individuals can increase the possibility that their preferences will be met by selecting a person to make decisions in their behalf. • Avoids the time and expense of legally appointing a surrogate decision-maker after incapacity • Can eliminate conflicts over who should be making decisions for a patient • Document often allows a principal to express preferences and guidelines to assist an agent in future decision making 	<ul style="list-style-type: none"> • Improved decision making by health care providers, family, friends, proxies, and agents • Reduced feelings of frustration, confusion, and guilt; also reduced burden on people making decisions for an incapacitated person • Clarification and expansion of values and preferences not allowed or written in legal documents or model forms • Ongoing dialogue helps to clarify preferences about death and dying and quality and length of life issues

	Living Wills	Durable Power of Attorney for Health Care	Informal Sharing
Limitations	<ul style="list-style-type: none"> • Effective only in cases of terminal illness, certified by one or more physicians • May not be valid during pregnancy • May not allow control over withdrawal or withholding of artificial feeding • If model form required, may allow no discretion as to contents • Lack of uniformity among state statutes makes universal acceptance impossible • Document may not be found or known about by right people at the time decisions need to be made • Guidelines or wishes may not help make clinical care decisions if too vague or too specific • Focus on specific treatments can limit helpful information on person's values, preferences, and desired outcomes 	<ul style="list-style-type: none"> • Validity in states without specific legislation has not been settled. However, the concept of a common law power of attorney has been valid in all 50 states for other types of decisions. • Just naming someone you can trust as an attorney-in-fact does not mean that the person is aware of your values or preferences about health care decisions. • Designated agent may be required to make very difficult decisions for the principal • A Durable Power of Attorney document may not be found or known about by the right people at the time decisions need to be made. 	<ul style="list-style-type: none"> • Informal sharing through non-legal documents (written, verbal, taped) does not guarantee that health care decisions will be made accordingly. • Controversies about what an individual said or shared at different points in time may arise. • Not everyone will be willing to share. • Discussion can be difficult and involves taking some risk.
Execution Requirements	<ul style="list-style-type: none"> • 18 years of age • Competent and of sound mind • Written voluntarily • Signed/dated in the presence of two witnesses • May require model form to be valid • May specify qualifications of witnesses and additional signature procedures 	<ul style="list-style-type: none"> • 18 or more years • Of sound mind and mentally competent • Written voluntarily • May require specific language to extend beyond incapacity of principal • May require a model form or other formalities to execute 	<ul style="list-style-type: none"> • Skills in communicating about sensitive issues • Willingness to respect different viewpoints • Time commitment for ongoing discussions
Ability to Change	<ul style="list-style-type: none"> • Revocable at any time by declarant 	<ul style="list-style-type: none"> • Revocable at any time • May require witnesses and or recording to revoke 	<ul style="list-style-type: none"> • At any time

	Living Wills	Durable Power of Attorney for Health Care	Informal Sharing
Differences in States	<ul style="list-style-type: none"> • Forty-one states allow some form of living wills and the variations are critical to understand. • Consult state requirements to avoid controversy and confusion. 	<ul style="list-style-type: none"> • Important differences exist in the 50 states. Some states have authorized the creation of a Durable Power of Attorney for Health Care decisions and others are considering specific legislation. • State statutes and attorneys knowledgeable about Durable Powers of Attorney should be consulted. 	<ul style="list-style-type: none"> • Does not apply
For State-Specific Information	<ul style="list-style-type: none"> • State Board on Aging or Area Agency on Aging • Concern for Dying 250 West 57th Street New York, NY 10107 (distributes regulations and forms for each state) 	<ul style="list-style-type: none"> • State Board on Aging or Area Agency on Aging • Concern for Dying 250 West 57th Street New York, NY 10107 (distributes regulations and forms for each state) 	<ul style="list-style-type: none"> • Does not apply

Keep in mind that the right to refuse health care treatment is not absolute. The state has four interests that must be balanced against an individual's right. States have an obligation to:

- 1) preserve life;
- 2) protect the interests of innocent third parties;
- 3) prevent suicide; and
- 4) maintain the ethical integrity of the medical profession.

A majority of patients in the health care system are able to make their own decisions. What happens when individuals become ill or injured and cannot make or communicate decisions for themselves? How can individuals maintain control and self-autonomy? Patient rights have been legally extended to individuals unable to make decisions about their care. It is important to recognize that an individual, whether competent or incompetent, has the right to accept or reject life-sustaining procedures. If there is no clear and convincing evidence of what a person would prefer, policies set by state legislatures will determine how and what decisions are made.

If there is no living will or third party appointed to help guide decision making about a patient, family members are frequently relied upon to serve as surrogate decision makers. Surrogates are called upon to make a "substituted judgment," or the same treatment decision the person would make if competent. While family members are often considered to be in the best position to know what a patient would have chosen, preferences are often unknown or uncertain. Therefore, in many cases, decisions are based on what is considered to be in the "best interest" of the patient. Informal sharing of preferences by family and friends can increase the chances that others are prepared to make surrogate decisions based on the patient's preferences versus their own.

Questions on who is most appropriate to provide a substituted judgment and how decisions should be made are still being defined by the courts. Laws differ on the role of family and friends between states. More and more hospitals and nursing homes have ethics committees which may become involved in sorting out final decisions. Court-appointed guardians or conservators may also be involved in health care decisions. The need for clear and convincing evidence is further encouragement for individuals to plan ahead to express their wishes before they no longer are able.

Comparing Planning Options

Planning ahead for incapacity can take on different shapes and forms depending on whether a person prefers more formal or informal approaches, or some combination of both. The more formal approaches to planning include legal documents such as advance directives (i.e., living wills, Durable Powers of Attorney for Health Care). Informal planning approaches do not include

legalized documents but a sharing of preferences with people who may be in a position to need to know. It is important that individuals understand the purposes, benefits, and limitations of using both informal and formal planning approaches. The chart on pages 2-4 offers a comparison of possible options for planning ahead and leaving clear and convincing evidence: living wills, Durable Power of Attorney for Health Care, and informal sharing.

What's Right For Me?

Each individual needs to fully understand the facts about available planning options and think through the implications for him- or herself as well as for other individuals who may be involved such as family, friends, or physicians. There are no right or magic formulas as to the best way to plan ahead. Working through the questions on Worksheet 3-1 may help individuals and their family and friends think through the potential implications of the formal and informal planning options given their own preferences and situations.

Understand State Policy

Given the differences in state policies regarding planning options, it is essential that individuals search out specific details about their state policies before doing any formal planning. Review the following section, Section 3, Part 2, for state-specific information.

Additional Planning Tools

Worksheets 3-2 and 3-3 have been prepared to help individuals know how to proceed if they choose to prepare a living will or a Durable Power of Attorney for Health Care document regardless of where they may live.

References

- Caplan, A. 1990. *The values baseline -- A solution or an obstacle to enhancing the autonomy of the elderly?* Working paper, University of Minnesota.
- Center for Social Gerontology. 1989. *Headnotes on critical legal issues affecting older persons*. 1(1). Ann Arbor, MI: Center for Social Gerontology, Inc.
- Center for Social Gerontology. 1989. *Headnotes on critical legal issues affecting older persons*. 1(2 & 3). Ann Arbor, MI: Center for Social Gerontology, Inc.
- Emanuel, L., and E. Emanuel. 1989. The medical directive: A new comprehensive advance care document. *JAMA*, 261(22):3288-3293.
- Legal Counsel for the Elderly. 1987. *Decision-making, incapacity, and the elderly*. Washington, DC: Legal Counsel for the Elderly.
- Living Will Coalition. 1989. *Questions and answers about the adult health care decisions act*. St. Paul, MN: Living Will Coalition.
- Minnesota State Bar Association. 1990. *Elderlaw 1990*. Minneapolis, MN: State Bar Association Continuing Legal Education.
- Sabatino, C. 1990. *Health care powers of attorney*. Washington, DC: American Bar Association.

Worksheet 3-1

Comparing Planning Options

1. What experiences have you, other family members, or friends had with the different ways to plan ahead for health care decisions in times of incapacity? The following points will help you summarize your thoughts.
 - What types of planning options have people had experience with?
 - What were some of the benefits and limitations of the different planning approaches?
 - How did individuals involved react and feel about their experiences?
 - What would individuals do differently next time?
2. Use the grid on the back of this worksheet to help talk about and/or write out the possible implications of the formal and informal options for yourself, family members, or friends. Such a discussion can help clarify the most appropriate directions for the individuals involved. Talking about the various options with close family and friends may also help increase an understanding of possible differences in opinion on various planning approaches.
 - Given the discussion, how will you and others choose to plan ahead?
 - What needs to be done to carry out the plan?

For Myself, My Family, or Friends . . .

Questions to Consider	Potential Benefits?	Potential Problems?	Concerns Include . . .	General Reactions? (positive/negative)
Planning Options				
Living Wills				
Durable Power of Attorney for Health Care				
Sharing Preferences and Wishes Informally				

Worksheet 3-2

Checklist For Preparing A Living Will

1. Talk with family members and close friends about what would be important if you became terminally ill. Think about and discuss different options, treatments, and decisions before trying to put anything in writing. Most people need to think through their beliefs about death and dying, the role of medical treatments, religious beliefs, and other critical issues before trying to fill in the spaces or know which boxes to check on model living will forms.
2. Talk with your physician or health care providers who can describe the various kinds of treatments that might be involved and share the potential implications of choosing or not choosing such treatments. Understand what is meant by reasonable medical procedures, life-sustaining and life-prolonging treatments.
3. If naming a proxy is allowed in the living will, think about the people you trust. Who really understands you and knows your preferences? Who might be a good proxy? Talk with them and see if they really do understand you as well as you think they do. Would they be willing to serve as a proxy?
4. Consult the appropriate state statute to make sure the declaration will be valid. Ask the following questions about the state requirements:
 - Is a model form required? If not, are there sample forms provided to assist in writing?
 - What signatures and witnesses are required?
 - Are the witnesses qualified?
 - Are there additional requirements if the person is in a nursing home?
 - Is the maker competent and of sound mind?
 - Are there other documents or statements of intentions regarding health care decisions?
 - Does the maker wish to express intentions about medical treatments (continuing or withdrawing)?
 - Is the definition of terminal illness and process of documentation fully understood?
5. Once completed, copies of a living will declaration should be made and shared with your doctor and other health care providers, close family members, friends, clergy, and any other individuals who might be involved in caring for you. A copy should also be part of your official medical records. Keeping a living will locked in a safety deposit box limits its use and availability when needed.
6. Make a plan to review the living will on a regular basis to incorporate any changes that may have occurred, either in your own thoughts or preferences, or in the situation around you.

Worksheet 3-3

Checklist For Durable Power Of Attorney For Health Care

1. Check to see if your state has a statute which authorizes a Durable Power of Attorney for Health Care decisions. Are there any limitations to the use of a Durable Power of Attorney? Is certain language required to make the power truly "durable"?
2. If there are no specific state statutes, talk to a lawyer, preferably one who specializes in disability planning.
3. Are there specific requirements about witnesses, recording, or notarizing?
4. Does the principal realize the implications of naming an agent for certain types of decisions?
5. What personal and health-related decisions does the principal want to give away? These could include: access to medical information and records; employing and discharging medical personnel; refusing or consenting to specific procedures; pain relief; or arranging for care and lodging in a hospital, nursing home, or hospice. Make sure it is clear what you want and do not want to accomplish with a Durable Power of Attorney.
6. Does the principal want to address specific decisions or express specific wishes? Think about what you could tell someone in writing that would help them make decisions in your best interest knowing that it is not possible to predict all circumstances that might occur.
7. Who does the principal want to designate as an agent or as alternates? Find out if the person(s) is willing to serve. Not everyone is willing to assume the potential ethical and emotional burdens that can be involved. Keep in mind that the agent(s) named will have a lot of power over your health and care if you become incapacitated. Think about the people you trust, who really understand and know your preferences and beliefs, and who might be willing to serve.
8. Once executed, inform health care providers and other close family and friends about the Durable Power of Attorney for Health Care. A copy could be included in your medical records for accessibility.
9. Make a plan to review the Durable Power of Attorney for Health Care on a regular basis. Preferences of the principal, named agents, and other features of the documents may need to be updated or changed.

Taking Control of Life and Death Health Care Decisions



Section 3, Part 2

Minnesota Myths And Facts

Marlene S. Stum, Family Social Science

Is It Myth Or Fact?

Do you know more facts or myths on how to plan ahead for health care decisions in times of incapacity? Take a few minutes and fillout Worksheet 3-4. This quiz has been developed to help clarify some commonly held misbeliefs about health care decision making rights in Minnesota. Two copies of the quiz are included to encourage other family members or friends to take part. Additional copies can be made so that others can also test their skills. Watch for surprises in your own and others' answers.

Facts About Formal Options

The quiz will introduce you to some rights in Minnesota; however, it is important to know specific state policies about both living wills and Durable Powers of Attorney for Health Care.

Living Will

The Adult Health Care Decisions Act became effective August 1, 1990 and recognized an individual's right to make a health care declaration or living will in Minnesota. The declaration becomes effective only if a person has been diagnosed with a terminal condition and is not able to make decisions for him- or herself. A proxy, which is a person selected by you to make decisions for you, can also be named in the declaration. A terminal condition, as defined by the Minnesota legislature, is an incurable or irreversible condition for which the administration of medical treatment will only prolong the dying process. This broad definition could apply to many types of incapacitation conditions, such as being permanently unconscious.

The enclosed document, "Health Care Declaration," is the basic form which must be followed in Minnesota. In the spaces provided individuals can state personal instructions and preferences about health care, types of life-sustaining treatment, artificially administered sustenance, proxy designation, and additional comments (i.e., religious beliefs). Individuals are encouraged to carefully consider the language and statements made in their living will. Being too vague, too specific, or using terms or phrases that can be misinterpreted can cause problems. Taking the time to clearly express underlying values, preferences, and desired outcomes can help develop a more usable document.

The law states that a person must specifically write in his or her wishes about artificial administration of nutrition and hydration. If a person does not want to receive artificially administered nutrition and hydration, he or she must state this in section 6. As an alternative, a person can also state in section 6 that he or she wishes their proxy to make decisions regarding artificial administration of nutrition and hydration.

To be valid, the declaration must be signed in the presence of two witnesses or a notary public. Neither of the witnesses may be someone entitled to any part of the person's estate, and neither the witness nor the notary may be named as the proxy.

Durable Power Of Attorney for Health Care

Minnesota does not have specific legislation which recognizes a Health Care Power of Attorney; however, such documents can be drawn up by an attorney based on the legally valid concept of a common law power of attorney. No law or court has invalidated such a concept in any of the 50 states. Many individuals have had experience appointing a Power of Attorney for financial matters for an elderly family member. The basic concept is the same, except in this case it involves legally appointing a person to make and communicate designated and selected health or medical decisions.

It is critical to involve a lawyer in the writing of a Durable Power of Attorney for Health Care in Minnesota because there is no official form and yet certain language and procedures are required. Lawyers who specialize in disability planning or issues of the elderly are likely to be the most knowledgeable and prepared to draft such a document. Careful decisions will need to be made about what power an attorney-in-fact should have and at what point in time. Make sure you clearly think about and discuss what you want and do not want to accomplish in such a document.

Taking the time to clearly provide guidelines for the attorney-in-fact to follow when making decisions is recommended. Just as in a living will declaration, individuals are encouraged to carefully consider the language and statements made in the document. Being too vague, too specific, or using terms or phrases that can be misinterpreted can cause problems. Expressing underlying values, preferences and desired outcomes is recommended. Issues of specific treatments and why a person might want the treatment used or not used can be addressed.

For More Information

If you want to read more about the Durable Power of Attorney for Health Care, write to the American Association of Retired Persons, 1909 K Street NW, Washington, D.C. 20049 and ask for a free copy of the booklet "Health Care Powers of Attorney" (Stock No. D13895). This includes general background information and a sample form for consideration (not state-specific information).

Worksheet 3-4

Health Care Decision Making In Minnesota: Do You Know the Facts?

True	False	Don't Know	Fact or Myth?
T	F	DK	1. As of August 1989, a new Minnesota law requires everyone to prepare a living will.
T	F	DK	2. Once a living will is written, it can be changed or revoked at any time, for any reason.
T	F	DK	3. A Durable Power of Attorney for Health Care is illegal in Minnesota.
T	F	DK	4. The laws regarding living wills and other legal documents are much the same in all 50 states.
T	F	DK	5. When a patient is not able to make his or her own medical decisions, physicians will typically consult with family members to help make a judgment about what to do.
T	F	DK	6. There is a special form available to use when drafting a living will.
T	F	DK	7. An individual has the right to specify that every type of reasonable treatment be used to extend his or her life in health care planning documents.
T	F	DK	8. The best place to keep health care planning documents, such as a living will, is in a safety deposit box.
T	F	DK	9. Living will instructions will apply only when you have a terminal illness as opposed to any type of health problem.
T	F	DK	10. Competent patients with untreatable diseases who want to refuse life-prolonging treatment will be considered suicide cases by the courts.
T	F	DK	11. Your doctor is required to tell you whether or not he or she will be willing to comply with the wishes in your living will.
T	F	DK	12. Individuals have the right to name a "proxy" who would make health care decisions for them in case they are not able to do so for themselves.

Answers are listed on the back.

Here Are The Facts!

1. FALSE. As of August 1, 1989, Minnesotans have the right to draft a living will but are not legally required to do so.
2. TRUE. An individual can change or revoke a living will at any time. In fact, reviewing a living will is suggested given the frequent changes that can occur in medical practices, and in families.
3. FALSE. A Durable Power of Attorney for Health Care can be legally written and the courts have recognized the concept of a common law power of attorney. There is no specific statute recognizing Durable Powers of Attorney for Health Care or specifying a form to be used as there is in some states.
4. FALSE. Forty-one of the states in the U.S. have some type of legislation allowing living wills or health care declarations. Not all state laws allow the same forms to be used to write a living will, or allow the same things to be done in the same way, so there are important planning differences to consider.
5. TRUE. Physicians typically consult with family members of a patient, especially when there is no formal document stating the patient's wishes about health care decisions. Family members frequently need to know about a patient's health care preferences in order to make decisions in the best interest of the patient.
6. TRUE. There is a special form available for Minnesota residents to use in drafting a living will. It needs to be signed in the presence of two witnesses or a notary public.
7. TRUE. A common misconception is that individuals must *always* refuse certain types of medical treatments or life-sustaining measures. Living wills allow an individual to state whatever they want about choosing any and all care possible or setting certain types of limits about care.
8. FALSE. Copies of a living will need to be accessible to your doctor, other health care providers, family, friends, clergy, and others who might be involved in caring for you. Therefore, a safety deposit box is probably the last place you should keep a living will.
9. TRUE. Living wills apply only when you have a terminal condition. That is, an incurable or irreversible condition in which medical treatment only prolongs the dying process. Not only must you have a terminal illness for living will instructions to apply, but you must also be unable to make decisions about your care.
10. FALSE. The courts have found that refusing life-prolonging treatment is *not* suicide. They have distinguished between taking affirmative action to end one's life from allowing nature to take its course.
11. TRUE. Your wishes about health care should be discussed and shared with your doctor. If a doctor is not willing to comply with your wishes, he or she is required to let you know and you should find another provider who will meet your needs.
12. TRUE. Individuals can name someone to make health care decisions for them when they are not able to do so. This person would then be responsible for making decisions. Proxies can be named in a living will and also in a Durable Power of Attorney (referred to as an "attorney-in-fact").

Legal Document in Minnesota

HEALTH CARE DECLARATION

All Health Care Declarations (Living Wills)
executed on or after August 1, 1989 must be substantially in this form.

NOTICE

This is an important legal document. Before signing this document, you should know these important facts:

(a) This document gives your health care providers or your designated proxy the power and guidance to make health care decisions according to your wishes when you are in a terminal condition and cannot do so. This document may include what kind of treatment you want or do not want and under what circumstances you want these decisions to be made. You may state where you want or do not want to receive any treatment.

(b) If you name a proxy in this document and that person agrees to serve as your proxy, that person has a duty to act consistently with your wishes. If the proxy does not know your wishes, the proxy has the duty to act in your best interests. If you do not name a proxy, your health care providers have a duty to act consistently with your instructions or tell you that they are unwilling to do so.

(c) This document will remain valid and in effect until and unless you amend or revoke it. Review this document periodically to make sure it continues to reflect your preferences. You may amend or revoke the declaration at any time by notifying your health care providers.

(d) Your named proxy has the same right as you have to examine your medical records and to consent to their disclosure for purposes related to your health care or insurance unless you limit this right in this document.

(e) If there is anything in this document that you do not understand, you should ask for professional help to have it explained to you.

TO MY FAMILY, DOCTORS, AND ALL THOSE CONCERNED WITH MY CARE:

I, _____, being an adult of sound mind, willfully and voluntarily make this statement as a directive to be followed if I am in a terminal condition and become unable to participate in decisions regarding my health care. I understand that my health care providers are legally bound to act consistently with my wishes, within the limits of reasonable medical practice and other applicable law. I also understand that I have the right to make medical and health care decisions for myself as long as I am able to do so and to revoke this declaration at any time.

(1) The following are my feelings and wishes regarding my health care (you may state the circumstances under which this declaration applies):

Four horizontal lines for writing the declarant's feelings and wishes regarding their health care.

(2) I particularly want to have all appropriate health care that will help in the following ways (you may give instructions for care you do want):

(3) I particularly do not want the following (you may list specific treatment you do not want in certain circumstances):

(4) I particularly want to have the following kinds of life-sustaining treatment if I am diagnosed to have a terminal condition (you may list the specific types of life-sustaining treatment that you do want if you have a terminal condition):

(5) I particularly do not want the following kinds of life-sustaining treatment if I am diagnosed to have a terminal condition (you may list the specific types of life-sustaining treatment that you do not want if you have a terminal condition):

(6) I recognize that if I reject artificially administered sustenance, then I may die of dehydration or malnutrition rather than from my illness or injury. The following are my feelings and wishes regarding artificially administered sustenance should I have a terminal condition (you may indicate whether you wish to receive food and fluids given to you in some other way than by mouth if you have a terminal condition):

(7) Thoughts I feel are relevant to my instructions. (You may, but need not, give your religious beliefs, philosophy, or other personal values that you feel are important. You may also state preferences concerning the location of your care.)

(8) **Proxy Designation.** (If you wish, you may name someone to see that your wishes are carried out, but you do not have to do this. You may also name a proxy without including specific instructions regarding your care. If you name a proxy, you should discuss your wishes with that person.)

If I become unable to communicate my instructions, I designate the following person(s) to act on my behalf consistently with my instructions, if any, as stated in this document. Unless I write instructions that limit my proxy's authority, my proxy has full power and authority to make health care decisions for me. If a guardian or conservator of the person is to be appointed for me, I nominate my proxy named in this document to act as guardian or conservator of my person.

Name _____

Address _____

Phone Number _____ Relationship (If any) _____

If the person I have named above refuses or is unable or unavailable to act on my behalf, or if I revoke that person's authority to act as my proxy, I authorize the following person to do so:

Name _____

Address _____

Phone Number _____ Relationship (If any) _____

I understand that I have the right to revoke the appointment of the persons named above to act on my behalf at any time by communicating that decision to the proxy or my health care provider.

Date _____

Signature of Declarant _____

Notarization or witnessing. Your declaration should either be notarized or witnessed. If this declaration is to be notarized, the following should be completed by the notary public.

State Of _____

County Of _____

Subscribed, sworn to, and acknowledged before me by

on this _____ day of _____, 19 _____

Notary Public

If this declaration is to be witnessed rather than notarized, the following should be signed and dated in the presence of two adult witnesses, neither of whom is entitled to any part of your estate under a will or by operation of law, and neither of whom is your proxy.

I certify that the declarant voluntarily signed this declaration in my presence and that the declarant is personally known to me. I am not named as a proxy by the declaration, and to the best of my knowledge, I am not entitled to any part of the estate of the declarant under a will or by operation of law.

Witness _____ Address _____

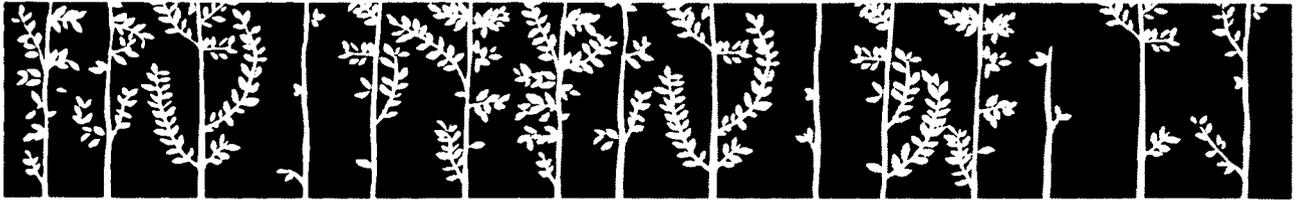
Witness _____ Address _____

Reminder: Keep the signed original in a safe accessible place (not in a Safe Deposit Box).

Give signed copies to your doctors, family, close friend and proxy or alternate proxy named by you.

Make sure your doctor is willing to follow your wishes. Your living will should be part of your medical record.

Taking Control of Life and Death Health Care Decisions



Section 4

Communicating With Others

Marlene S. Stum and Susan S. Meyers, State Extension Faculty

Objectives

Everyone seems to agree that individuals need to talk about health care decision making and what it means for them *before* there is a crisis or someone is not able to communicate. The purpose of this section is to help participants:

- 1) develop skills in bringing up sensitive issues such as life and death health care decisions with family, friends, and professionals;
- 2) increase awareness of techniques to communicate and share at a distance; and
- 3) encourage ongoing sharing and discussion regarding life and death decision making.

The Importance Of Sharing

Sharing feelings about health care decision making is important because communicating has the potential to:

- Help individuals clarify their own preferences and wishes by "bouncing them off" of others with whom they are close.
- Help family, friends, and others understand the preferences of people for whom they may make "substituted judgments" someday. This improves the chance that decisions will be based on what the individual thought was important, not on the beliefs and preferences of others.
- Help reduce feelings of burden, guilt, abandonment, and confusion that people often experience when they are put in the position of making medical care decisions for others.
- Increase awareness of differences in preferences among people. Sharing feelings may also encourage appointing proxies to help eliminate the potential for conflicts and arguments.
- Reduce the stress when critical decision-making points are reached by eliminating surprises.
- Help clear the air about expectations and assumptions held by other individuals.

Avoiding The Issue

For many people, sensitive issues such as changes in health care, increasing dependency, and not being able to make or communicate one's own decisions are difficult not only to bring up, but to talk about in any depth as well. It is hard to approach an issue calmly when there are strong feelings about what is important, what needs to happen, and how things should be done. Sometimes individuals may not agree that health care decision making is even an issue or problem to be addressed. They may refuse to talk about it. There may also be great differences of opinion and conflicting views among family members and friends. Respecting the opinions and decisions of other individuals is essential, even if we do not agree. When individuals have something that is sensitive to share with others, they might be hesitant to bring it up. Have you found yourself using any of the following reasons to avoid an issue? Reviewing the arguments *for* tackling sensitive issues might be helpful.

Reasons Used to Avoid Issues	Remember . . .
The time might be wrong.	There is never an ideal time.
The other person might take it wrong.	If you care and need to share, you can clarify at the time how the information is taken by the other person.
It may not be your place.	Even if you are an in-law, you <i>are</i> a member of the family--and since you came to the family <i>as an adult</i> , you may be in a better position to initiate the subject than other family members.
You might have better information later.	The future will often provide greater information, but if knowledge and feelings are shared <i>at the time</i> , the input of the other person is valued during the process of learning more.
You are scared.	In sensitive issues there is an element of fear, which when shared with loved ones may be minimized.
You are going to use the wrong words.	The feelings and concerns are what is important; any variety of words can express those feelings or concerns.
You want to protect others from your fears, concerns, and feelings.	Imaginations will come up with far worse versions!
You are afraid of conflict or strong reaction.	Some people react strongly or negatively to some sensitive issues because the person is fearful, just as you might be.

Tips On Talking About Sensitive Issues

The following are some tips to keep in mind when you are planning to talk about sensitive topics, such as life and death health care decision making.

- Know *what* you want to bring up. Outline the major points in writing. What role do you want the other person to play (for example, do you want them to listen, to act, to express ideas, or to just be there)?
- Know *why* you want to talk about the sensitive issue. What are your concerns? What prompted the concern *now*? What is to be *gained* by discussing this? What could be *lost* by discussing this (the worst case scenario)?
- *Rehearse* or *practice* what you might say--even if it is just to yourself in the bathroom or car. You may have a close friend who can play the role of the other person to make it more realistic. That person could monitor your voice inflections, words, and body language as well as give the reactions that you think the other person *might* have.
- Choose a *time* and *make an appointment* with the other person, making sure that you are not distracted by telephone, television, radio, or visitors. If the time agreed upon for the discussion is changed because of outside circumstances, make another appointment.
- Use "I-messages" to describe how you *feel*, *why* you want to share this now, *what* the sensitive issue is, and *what* you hope might happen as a result. Avoid "you" messages that focus on what you want the other person to do, say, or feel.
- Keep to the topic agreed upon. Avoid bringing up all other issues that might be loosely related. If the other person goes to other topics, gently, but firmly, return to the topic at hand.
- Be prepared to respond to questions clearly, and attempt to really *listen* to the other person--their concerns, their interpretations of what they heard, and their reactions. Be able to clarify in case your intention was misinterpreted. Provide clear feedback.
- Ask questions for clarification to make sure that you were understood.
- Finish the conversation when the issue you wanted discussed has been clarified, even though there may not be any resolution *at this time*. The more sensitive the issue, the more likely will be the need for some "thinking time" alone. Prepare to resume the discussion at some later agreed-upon time.

- Let the other person know that you appreciate being heard, listened to, and understood.
- *Assess* or evaluate the experience afterwards. You are likely to find that you *anticipated* far worse reactions than actually occurred.

How To Begin . . .

For many people, just beginning a conversation about a sensitive issue is the most difficult part of communicating. Suggestions on ways to open a conversation about health care decision making and examples of bringing up issues in families of different ages and stages follow.

One way to open a conversation is to ask some "what ifs." For example, "Mom, what would you want if you could no longer cook without help, or if your arthritis became so severe you couldn't maintain this house alone?" "What if you were severely injured in a car accident and unconscious . . . what concerns or fears would you have about your care?" "What if you broke your hip and had to stay in a nursing home for care . . . what concerns about your care would you have?"

Any of these "what ifs" can create anxiety--for both of you. You can give some reassurances by saying something like, "Chances are this will never happen, but if it should, I want to know what you want so I can do the right thing."

Another way of opening the conversation is to look for "natural" opportunities to talk. If you wait for several months looking for the "natural" opportunity, you might never find one. It might be better to initiate the conversation yourself. For example, when a friend or relative has a child injured in an accident or a friend has a terminal illness, you can use the situation to introduce the discussion. Or, describe a situation of a friend who recently experienced this sensitive issue (which you want to address). Then, follow the story by asking, "What would you have done if you were in that situation?"

If the other person refuses to talk or denies the possibility of ever having to deal with that, you cannot force their involvement. You do have the right to share your feelings which have prompted this discussion. You can feel better because you made an effort.

Families With Young Children

If children are affected by the sensitive issue, they can be part of the discussion if information is presented *at their level*. Children can read signals that all is not well, and they will make up their own reasons (which are likely far worse) if they don't get straight answers. Most children react better by "bringing them

along" on the decision (such as moving to a new town) rather than just hearing the "bottom line."

If children are *not* affected by the issue, discussions can take place when children are not present. There are occasions when adults want to "get their act together" before sharing with children. In most cases, however, children are aware that there are concerns *long before* the adults are aware of it. (This is one indication of the power of our nonverbal communication.)

Families With Adolescents

Most adolescents can behave with much greater maturity than parents assume, especially when there are sensitive issues that affect them or their loved ones. Because of the complex situations occurring in the lives of many teenagers, some may openly minimize the importance of a sensitive issue because of their own agenda. Others may read much more into the discussion than adults intend. In both cases, the meaning *from the perspective of the adolescent* needs to be understood by the adults. Therefore, adults need to find out *from the adolescent* what he or she thought was said. Then, taking both perspectives into account, the message can be clarified. In addition, adults need to be available at a later time (sometime hours or even days later) to listen, respond to, and clarify concerns that came up after the discussion.

Young Couples

Most young couples enjoy talking about many things, both positive and negative. They may be less prepared to discuss sensitive topics, since "living happily ever after" may be their theme. Individuals may feel there is no reason to even think about negative occurrences, given the slim odds of a life-threatening situation. However, the effect of such a situation on a young couple can be devastating. This is especially true if they never talked about their values, goals, wishes, dreams, hopes, and fears. "If only I knew what he or she would have liked me to do" is a familiar lament.

Middle-aged Adults With Elderly Parents

During young and middle adulthood, we assume that our parents will live forever in good health. As they become older, we begin to recognize potential limits in the later years. Some of these changes occur quickly, after the onset of some major illness or catastrophe. For most, the changes occur gradually and are seldom noticed except by those at a distance who visit infrequently. Both middle-aged adult children and elderly parents have important needs. Sometimes the sensitive issues felt by one generation are not as significant to the other. If

the issue affects one generation and the potential relationship between both generations, the sensitive topic needs to be shared.

Feelings and concerns about "being a burden" may be part of the difficulty in bringing up the topic of life and death decision making. Adult children may hesitate to address the topic fearing that a parent may feel they are an unwanted burden to the family. On the other hand, aging parents may want to bring up the topic to relieve children of the burden of not knowing their preferences, but may feel the children are not interested or concerned.

Elderly Individuals Or Couples

Some retired adults have more time to consider a variety of sensitive issues, and desire to have concerns clarified with their middle-aged adult children. Because of busy schedules and less frequent contact (especially with those at a distance), it is more difficult to initiate or follow up on discussions on sensitive topics. It is most important that the person feels that his or her concerns have been expressed and understood.

Sharing At A Distance

Although it is preferable to share concerns about life and death decision making directly and face-to-face with loved ones, sometimes it is not possible when family members live at great distances from each other or when visits are infrequent.

Because of the infrequent visits, some families "pile up" areas of concern and sensitive issues which need to be addressed, and save them for those occasional visits. When that typically occurs, family visits become looked forward to with less enthusiasm. It is easier for all family members if concerns are shared on a more frequent basis. This can be done, but it takes additional care, consideration, and planning than might be the case with face-to-face communication.

As with direct communication, knowing *what* you want to share, *why* you want to share this *now*, and what your *expectations* for the other person are will all help set the stage.

Communication at a distance can be by phone, letter, cassette tape or videotape, or a combination of one or more. Generally a combination is preferred, since we do *not* remember all of what is said over the phone *and* we tend to "read between the lines" of written correspondence.

When communicating about sensitive issues, separate clearly (in your mind as well as in the communication) between *facts* and *feelings*. If there is information (knowledge or facts) that can be shared in writing between telephone

conversations, it allows both individuals to be communicating from a similar knowledge base. Questions can be clarified. The written information can be gone over together point by point. Feelings about the various points can be expressed, and by stating they are *feelings*, the listener is more able to understand the key points.

Keep in mind that health care decision-making planning options differ in each state. Communication at a distance makes this point even more important. Make sure that the person you are sharing with is developing his or her preferences and plans based on legal options in his or her own state. Checking with knowledgeable local professionals is essential to gain more understanding of options.

Tools To Help Practice Communicating

Reading about how to bring up sensitive issues and improve overall communication with family, friends, and professionals can only go so far! At some point, individuals need to jump in and try various techniques. Trying one or all of the following activities can help improve communication about life and death health care decision making.

Worksheets 4-1 And 4-2

How well can you predict what is important to individuals to whom you are close? Can you predict how important certain values or health care decision-making guides might be? Worksheets 4-1 and 4-2 are designed to help clarify assumptions individuals may have about health care decision-making. Working through these activities, sharing ratings and discussing differences, will help individuals learn more about each other's perspectives on life and death decision making.

Specific directions are included. Two copies of each worksheet are enclosed and additional copies can be made as needed for all participants.

Worksheet 4-3

Discussing life and death decisions and preferences is often just as difficult for professionals such as physicians, clergy, and attorneys as it is for close family and friends. Communicating about this topic is not yet a routine part of regular physician care or attorney visits. Physicians are often reluctant to bring up the subject and patients may hesitate to take up limited and expensive time to discuss their concerns.

Individuals are encouraged to initiate a discussion with professionals such as health care providers, clergy, and or attorneys who may be in a position to need to know life and death health care preferences. Discussions which become routine and are ongoing have the best potential for enabling a professional to understand and clarify a person's life goals and values. Quick, one-time

conversations are the least likely to be helpful. It can also be a challenge to keep the right professional informed given the number of health care providers and other professionals who are involved in our lives, changes that occur, and others who may be involved in an actual decision. This reinforces the need to have preferences recorded in some way and accessible when needed.

Worksheet 4-3 is designed as an initial tool for individuals to use when talking with professionals about this important subject. Additional discussion using the more detailed Worksheet 2-1 in Section 2 of the self-study, as well as sharing any legal documents, is also highly encouraged.

Worksheet 4-1

Making Health Care Decisions: How Well Do You Know What Is Important To Others?

Purpose: To increase awareness and understanding between family and friends regarding health care decision-making issues. Many factors are often weighed when individuals are forced to make decisions about medical treatments or procedures, the use of resources for health care, and quality of life and care. How well can you predict how close family and friends would rate certain factors? How well do others understand what are important decision-making guides to you?

In this activity, participants rate for themselves and for other participants the importance of certain factors that can influence life and death health care decisions. Participants then compare ratings to determine the accuracy of their predictions. Discussion questions follow to help participants evaluate their ratings.

Directions: Each participant in the activity needs his or her own worksheet and should begin by putting the initials of other participants in the appropriate columns.

First, read over the list of decision-making "guides" and think about your own preferences and opinions and how important each item would be in influencing *your* decision-making about medical care. Rate each of the values on a scale from 0 to 10. In this scale, assume 10 means it is extremely important and 0 means it is not important at all. (Note: If you completed Worksheet 2-1 in Section 2 of the self-study, you can copy your ratings from page 6).

Second, think about each individual participating in the activity and using the same scale, rate how important you think each of the items would be in his or her decision making.

Third, after you are done rating yourself and others, all participants should compare ratings of each other and then discuss the following questions.

Discussion Questions

- a. How accurately did participants predict what was important to others?
- b. What surprised participants about the ratings they were given by others?
- c. Is it difficult to accept others' ratings of the items? Which items and why?
- d. What was something *new* that you learned about other participants by working through this activity?

Complete the chart on the reverse page.

Think about a scale from 1 to 10.

- 10 = very important
- 5 = somewhat important
- 1 = not very important

How important is this for you?	Health Care Decision-making Guides	How important is this for others? (Put initials of others participating in boxes.)			
	Letting nature take its course				
	Preserving quality of life				
	Recognizing spiritual beliefs and traditions				
	Length of life, regardless of quality				
	Amount of burden to others				
	Persons age at the time				
	Whether terminal, in a permanent coma, or irreversible chronic illness				
	Dollar cost involved and who would have to pay				
	Being able to die in a short time, rather than lingering on				
	Recognizing that life is sacred, no matter what				
	The level of mental limitations				
	The level of physical limitations				
	Being able to leave some money to family or friends				
	Making a contribution to medical research and teaching				
	Being able to relate to family and friends				
	Being comfortable and as pain-free as possible				

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Worksheet 4-2

A Life Review Of Values: How Well Do You Know What Is Important To Others?

Purpose: To increase awareness and understanding between family and friends regarding values that guide health care decision making. One way to find out what is important to people is to look at how they spend their time, energy, money, and other resources--especially over a long period of time. How well can you predict how important certain values are to others? How well do others understand how important certain values are to you? What does the importance of these values mean for life and death decision making?

This activity is designed to have people think back over their own life and the lives of other participants and to rate the importance of selected values. Participants then compare ratings of the values to determine the accuracy of their predictions. Discussion questions follow to help evaluate the ratings and the implications for health care decision making.

Directions: Each participant in the activity needs his or her own worksheet and should begin by placing the initials of other participants in the appropriate columns.

First, think about how you have tended to spend *your* time, energy, money, and other resources over the years. Which of the values have you spent a lot of resources working toward and appear to be extremely important to you? Which of the values have you spent very little, if any, of your resources working toward and appear to be unimportant to you? Rate each of the values on a scale from 0 to 10. In this scale, 10 means it is extremely important and 0 means it is not important at all.

Second, think about other participants and how you think they have spent their time, energy, money, and other resources over the years. Using the same scale, rate how important you feel each value is to them in the appropriate column.

Third, participants should compare ratings of each other and then discuss the following questions.

Discussion Questions

- a. How accurately did others predict the importance of your values?
- b. Which values were more accurately predicted? Why?
- c. What surprised participants at how others rated their values?
- d. What do you think each of these values might have to do with planning for life and death health care decisions? (e.g., if a person has never put many resources into being autonomous, what might that mean for how they approach health care decision making as an issue?)

Complete the chart on the reverse page.

Think about a scale from 1 to 10.

10 = very important

5 = somewhat important

1 = not very important

How important has this been to you?	Values	How important has this been to others?			
	Having self-respect (self-esteem)				
	Salvation (being saved; eternal life)				
	Autonomy (self-rule and choice)				
	Excitement (a stimulating, active life)				
	Health (physical and mental well-being)				
	Family security (taking care of loved ones)				
	Being capable (competent; effective)				
	Independent (self-reliant; self-sufficient)				
	Courageous (standing up for your beliefs)				

Developed by Marlene S. Stum, Family Social Science, State Extension Faculty, University of Minnesota, St. Paul.
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Worksheet 4-3

Talking With Professionals (Health Care Providers, Lawyers, Clergy)

Professionals such as health care providers may be in a position to need to know answers to the following questions about a person's life and death health care preferences. Individuals are encouraged to share the following:

1. How do you want decisions about your health care to be handled if you are not able to make them yourself?
2. If decisions have to be made, who do you want involved?
3. Have you discussed your expectations and preferences with this person(s)?
4. What specific preferences have you shared?
5. When you think about needing medical care or dying from a terminal illness what concerns or fears do you have?
6. What would make the process of dying more comfortable or peaceful for you? More uncomfortable or less peaceful?

In addition to sharing your own preferences, find out if the professional would be willing, able, or comfortable carrying out your own preferences or wishes. Becoming aware of potential differences or conflicts is critical now to allow other planning to occur if needed.

Taking Control of Life and Death Health Care Decisions



Glossary

Planning Option-related Terms

Advance Directives: Legal documents in which competent individuals can retain some control over their health care decisions in the event they are no longer able to do so for themselves. A living will is the most common example.

Competency: Legally, a patient is considered competent to make a treatment decision if he or she has the ability to understand relevant information about the medical problem and the consequences of the decisions about treatment.

Durable Power of Attorney for Health Care: A legal document that is written to appoint another person to make health-related decisions in times of incapacity.

Guardianship: If a person is declared incompetent to make his or her own decisions, a guardian can be appointed by the court to make a variety of decisions, including those on health care.

Living Will: A legal document in which competent persons can state instructions about the kind of medical treatment they would want if they were terminally ill and not able to speak for themselves.

Proxy: A person legally named to make decisions for another.

Substituted Judgment: The process of making treatment decisions that the person would make if competent. Commonly interpreted as a decision in the person's "best interest."

Surrogate Decision-maker: An individual approved to make "substituted judgments" or decisions for another.

Will: A legal document that is written to have control over what happens to one's property and assets when one dies. This does not involve health care decisions.

Medical-related Terms

Amputation: Surgical removal of a specific diseased body part to benefit the whole body.

Artificial Feeding (food and fluids): In situations where a person is unable to swallow or eat in a manner adequate to sustain life, a tube may be inserted into a vein, through the nose (nasogastric), or directly into the stomach (gastrostomy) for purposes of providing liquid nutrition on an ongoing basis.

Cardiopulmonary Resuscitation (CPR): In the event the heart, blood pressure, and breathing fail to the extent that death is expected within minutes or seconds, rescue measures are taken such as pounding on the chest, inserting a breathing tube into the windpipe, and the

administration of medications and electrical shocks.

Chemotherapy: Drugs used in the attempt to treat and control disease. The chemicals frequently have some side-effects for the patient.

Do Not Resuscitate (DNR): The request that resuscitation (CPR) measures not be initiated because the patient and family in consultation with a physician have requested such an order on the patient's chart. A statement about resuscitation is frequently required for patients with a terminal condition in which resuscitation may serve to only prolong the dying process. Such an order can be reversed at any time and should be reviewed at regular intervals to determine if the DNR order should remain.

Hospice Care: A philosophy of care that exists to provide symptom relief and emotional support for a terminally ill patient and his or her family and friends. Programs may include home-care, hospice center, or hospital-based care where patients design how they want to deal with dying, death, and grief in the last phases of a terminal illness.

Irreversible Chronic Illness: Usually a long-term illness that worsens over time and is not reversible. Treatment is usually for the symptoms instead of the cause, as the cause is usually not known. Persons may be capable mentally and/or physically. Examples include Alzheimer's disease and rheumatoid arthritis.

Kidney Dialysis: A process used to remove unwanted fluid and waste products from the body when the kidneys are unable to do so. The blood is purified by being pumped from a patient's

artery through a kidney machine and returned to the body through the patient's vein.

Life-prolonging Measures: Treatment that is likely to only prolong the natural process of dying when there is not significant hope of functional recovery. Examples could include resuscitation or artificially administered nutrition.

Limited Time Trial: The use of medical measures for a specified period of time to determine whether benefits will outweigh the burdens.

Nutrition and Fluids (hydration): Daily required calories, minerals, vitamins, and fluids needed to maintain body weight and the proper functioning of organs are administered.

Permanent Coma: A state of unconsciousness that is expected to continue; frequently related to a head injury or lack of oxygen to the brain.

Respirator/Ventilator: Mechanical breathing machines that assist a patient's breathing when he or she is partially or totally unable to do so on his or her own. The patient is connected to the machine with a tube directly through the windpipe or through the nose to the windpipe. This provides volumes of air and oxygen adequate to support life.

Terminal Condition: An incurable or irreversible condition that without the administration of life-sustaining treatment will, in the opinion of the attending physician, result in death in a relatively short time. Physicians typically use a life expectancy of six months or less as the definition of a "short time."

Self- Evaluation

Directions: Completing this self-evaluation will help you:

- evaluate what you have learned and completed from the self-study, and
- encourage you to think about what additional plans need to be made and carried out

Remember, taking control of life and death health care decisions is an ongoing process. Decisions should be re-evaluated as preferences, families, and policies change.

What Has Been Completed?			Future Plans? (list plans and set deadlines in space provided)
Understanding and Comparing Planning Options			Understanding and Comparing Planning Options
Yes	No	I realize how complex life and death health care decisions can be.	
Yes	No	I recognize this is an issue for people of all ages.	
Yes	No	I understand more about the potential dilemmas, conflicts, confusion, and disagreements that can be involved.	
Yes	No	I have thought through the life and death health care dilemmas that my family and friends have already experienced.	
Sorting Out Preferences			Sorting Out Preferences
Yes	No	I am more aware of the important questions that I need to answer.	
Yes	No	I have thought about my concerns and fears about terminal illness, irreversible chronic illness, and death and dying.	
Yes	No	I am aware of the concerns about making statements concerning specific medical treatments given how unpredictable circumstances can be.	

What Has Been Completed?**Future Plans?
(list plans and set deadlines in space provided)**

Yes

No

I have identified who I want to be involved in my health care decisions.

Yes

No

I have thought through whether I want to be involved in other's health care decision making.

Yes

No

I am comfortable identifying what role my spiritual beliefs should play in decisions.

Yes

No

I have a better understanding of medical terms and treatments.

Myths And Facts About Planning Options**Myths And Facts About Planning Options**

Yes

No

I am aware of my rights as a health care patient, whether competent or not.

Yes

No

I understand the purpose, advantages, and limitations of living wills.

Yes

No

I understand the purpose, advantages, and limitations of a Durable Power of Attorney for Health Care.

Yes

No

I understand the purpose, advantages, and limitations of informal sharing of preferences in planning ahead.

Yes

No

I have considered the pros and cons of both formal and informal planning options given personal preferences.

What Has Been Completed?			Future Plans? (list plans and set deadlines in space provided)
Yes	No	I understand the facts about my own state policies regarding planning options.	
Communicating With Others			Communicating With Others
Yes	No	I feel more comfortable and confident when talking about this issue.	
Yes	No	I understand how those I am close to want me to be involved in their health care decisions.	
Yes	No	I feel I have a good sense of the concerns and fears, preferences and priorities of those I am close to in case I have to make a substituted judgment for them.	
Yes	No	I can accept the different opinions and viewpoints of those I am close to regarding life and death decisions.	
Yes	No	I have discussed this issue with my health care provider(s).	
Yes	No	Information regarding my preferences is in my medical records.	
Yes	No	My family, physician, and attorney all know whether I have documents that should be considered if decisions need to be made.	

MINNESOTA EXTENSION SERVICE

UNIVERSITY OF MINNESOTA
HOME ECONOMICS

Taking Control of Life and Death Health Care Decisions



Making life and death health care decisions for yourself and others is never easy. It involves:

- understanding several complex issues;
- sorting out personal preferences;
- learning what planning options are available, including living wills and Durable Powers of Attorney for Health Care; and
- communicating with others (including family members, friends, and professionals).

Keeping up with medical advances, understanding state-specific laws, and making up one's own mind all take time and involve many complex issues.

If you are involved in making decisions about life and death health care, or helping others with the same, the new self-study packet *Taking Control of Life and Death Health Care Decisions* may be for you.

This self-study packet has been designed to help individuals, families, and close friends work through the decision-making process together. It was developed and written by Dr. Marlene S. Stum, Department of Family Social Science, University of Minnesota, with support from contributing authors.

The packet features a six-pocket folder including:

- a user's guide (for those individuals ordering the self-study on their own)
- four sections of reading material, worksheets, checklists, quizzes, and discussion questions
- a glossary and self-evaluation

The cost of the entire packet with all of these resource materials is only **\$15.00**. Ask for item number HE-MI-5614-S.

Order Your Copy Today!

For more information on ordering this and other Minnesota Extension Service resources, call or write:

Distribution Center
3 Coffey Hall
1420 Eckles Ave.
St. Paul, MN 55108
Phone 612/625-8173
FAX 612/625-2207

All orders should be prepaid. Add 6.5% sales tax for deliveries to a Minnesota address.

Taking Control of Life and Death Health Care Decisions was developed with a variety of uses in mind. It can be used by:

- family members and/or friends of all ages and types of relationships in informal discussions. This could include parents, adult children, older teenagers, spouses, and close family friends.
- individuals, if no close family members or friends are available or interested in participating.
- small study groups led by a facilitator(s). Each of the self-study sections could be used in a four-week study group on the subject, with individuals preparing for each session on their own. Facilitators can help guide the discussion, answer questions, and provide support.

What Participants Are Saying



I realized that I want to have something to say about what happens to me while I'm able to make that decision.

It was a way to find out other family members' feelings about a subject that doesn't want to be brought up.

Made me aware I have to think more about this. Every day it's in the paper and on TV, but how do I do this as an individual? This helped me get started.

Helped me realize the importance of talking before something happens—knowing you can and should make some decisions now.

I realized that my attitudes about life and death are not as cut-and-dried as I once believed.



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