

Talking it Over

A Guide for Group Discussions on
End-of-Life Decisions



COALITION FOR
COMPASSIONATE CARE
OF CALIFORNIA

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Talking It Over can be downloaded at CoalitionCCC.org.
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Introduction

This Discussion Guide was developed in response to concerns voiced by the public and healthcare professionals that:

- Many people never think about their own views and values regarding end-of-life decisions until a crisis hits, when decision-making is most difficult.
- People often have a hard time talking with their loved ones and healthcare professionals about the last phase of life.
- There are few opportunities to consider this sensitive subject in a supportive environment.

In the past, discussions or workshops on end-of-life issues focused mainly on advance directives (documents such as a Living Will or Durable Power of Attorney for Health Care). However, other aspects were often not addressed — how individuals regard the last phase of life, their willingness to talk to their families and healthcare providers, and the values important to them when difficult decisions are needed. Experience has shown that when family members have not talked with each other about end-of-life issues, advance directives may not resolve difficult situations.

Talking It Over provides a means for individuals, in an informal group setting, to explore personal views and interpersonal communication on the subject of end-of-life care. It is designed for members of congregations, community and healthcare organizations, classes and senior groups interested in interactive, small group discussions. Though the Guide can be used by healthcare professionals and experienced facilitators, it is written so that anyone — regardless of his or her background — can feel comfortable using it.

The Discussion Guide provides the format and tools for three inter-related group sessions. However, it does not include a specific discussion about advance directives, a topic which requires more detailed knowledge than nonprofessional discussion leaders may have. If you want to include an advance directives workshop as part of your program (and many of your participants may want this), see page 26 for information on finding speakers.

In addition to the format for the three sessions, the Guide also includes:

- How to Use this Discussion Guide
- Role of the Discussion Leader
- Tips for Recruiting Participants
- Working with Different Ethnic/Cultural Groups
- Related Topics / Finding Speakers
- Additional Material

Meeting Preparation

Face the thing you fear, and you do away with that fear.

Author unknown

How to Use this Discussion Guide

The three sessions included in *Talking It Over* are designed to be held consecutively, for example, once a week for three weeks. Each of the sessions takes one to four hours, and each builds on the work of the previous one. The titles are:

- Session 1: Exploring your Personal Views
- Session 2: Talking with Loved Ones
- Session 3: Making Tough Decisions

Materials for each of the three sessions include:

- Background information for the discussion leader that describes the purpose of the tools being used in the session.
- A step-by-step outline of the session to assist the discussion leader.
- The tools that form the basis for most of the discussion.

Adapt the Guide to your needs

Talking It Over can be adapted to the needs and interests of different groups, settings and available time. You may choose to conduct only one or two sessions, combine sessions, use different discussion tools or develop a longer series with additional topics. For example:

- If you are working with a faith community, you may want to include relevant scriptures or religious teachings.
- If you already are conducting a workshop on advance directives, consider adding one or more of these sessions.
- If you are working with different ethnic or cultural groups, refer to page 22 for suggestions on adapting the format and content.
- If you have a large group (e.g., in a classroom or conference setting), present the discussion tools to the full group, then break into smaller groups for discussion. The optimal group size for interactive discussion is 8 to 12 people.
- If you have a group that is experienced with this subject, they may be ready for more detail about medical, legal or spiritual aspects of end-of-life care.

However *Talking It Over* is used – whether in small groups or large, on its own or as part of a longer series – its purpose is to help people think and talk about their experiences and views on end-of-life issues.

The Role of the Discussion Leader

As discussion leader, your role is to help those attending get the most out of their participation. First and foremost, you must be comfortable with this subject yourself in order to facilitate discussion with others.

Though you are not expected to be an expert on death and dying (nor do you need to be a professionally trained educator, facilitator or healthcare provider), there are some aspects of this role that are particularly important in making these sessions a valuable experience for participants – and for you, as well.

Setting the right tone for interactive discussion

- Clarify your role at the beginning of the session – that you are not there to lecture or to provide answers but rather to lead the discussion.
- If participants do not know each other well, have self-introductions at the start of each session. You may also want to ask each person to say something about him/herself, such as why he/she is attending. It also helps to have name tags when the group is a new one.
- At the first session, it is useful to mention some ground rules:
 - There are no right or wrong answers.
 - Everyone's view is respected.
 - We're all here to learn from each other.
- Encourage each person's participation in the discussion. Bring quiet participants into the conversation by asking what they think, but if they seem reluctant, do not insist.

Useful techniques

- Use the example questions in the Session Outline to stimulate discussion, but don't feel bound to stay with these questions or to ask them all.
- Avoid focusing on your own views or experience; however, if participants are hesitant to begin, you may want to break the ice with a personal observation or experience.
- After asking a question, allow the group to guide the discussion through the exchange of views and experiences. If you ask a close-ended question (one that can be answered yes or no), encourage further discussion with an open-ended question, such as "Why do you think so many people have a difficult time?"
- Remember that silence is also OK. People sometimes need to have a moment to think or reflect before responding.
- If you are confused by someone's response, chances are others also may be. Ask for clarification.
- Pay attention to the amount of time you have so that you don't have to end the discussion abruptly. It's helpful to alert the group when there are only a few minutes left.

Be prepared

- For some participants, this topic may bring up memories of the loss of loved ones. Since emotional responses are common, it's a good idea to have a box of tissues on hand.
- Personal stories are often the cornerstone for these discussions. But if an individual story goes on too long, you may need to gently move the attention to others in the group.
- If you are asked a question that you can't answer (for example, a medical or legal question), acknowledge that you don't know. Others may know the answer or someone may volunteer to find out. Sessions that explore more detailed medical or legal issues can be scheduled for another time (see Related Topics/Finding Speakers, page 26).

Tips for Recruiting Participants

In some settings – classrooms, adult day care, support groups – you may have a captive audience because they are part of an established group. However, you may be scheduling this series of discussions as a new program without confirmed participants. Optimal size for discussion groups is 8 - 12, and there are things you can do to encourage good attendance.

Create an appealing message

- When publicizing the sessions, use inviting, eye-catching titles. Be creative. Most people are **not** drawn to a program announcing "death and dying" as the subject.
- Focus on the role people play in caring for their loved ones. Although many would rather not consider their own mortality, people are quite concerned and interested in how they can care for a family member.
- If you are arranging a new program in a specific setting, have a person in a leadership position announce and/or recommend it. Do not rely on written announcements alone. If potential participants are people you know, don't be shy – the most effective way to recruit is for **you** to personally invite them!
- One way to encourage attendance is to include those who have personal experience with this topic. People generally respond well when told that their experience can help others.

Consider logistics

- When seeking a setting for the program, consider community-based organizations (such as faith communities, senior groups, adult education classes and service clubs) that regularly schedule meetings on a variety of topics. Such organizations often welcome new program ideas and speakers.
- Find out the hours and days that attract the best attendance. If possible, try not to compete with other programs being held at the same time.
- When publicizing the program, create and circulate a simple flyer; ask people to RSVP. A good discussion is difficult if there is low attendance (fewer than eight). It is also helpful to call everyone one to two days in advance with a reminder of the meeting.
- Arrange the room to encourage interaction. Have people sit in a circle or around a table where they can see one another. Adjust lighting, room temperature and noise level, if possible, to make the room conducive to comfortable conversation.
- Provide refreshments. A snack and drinks are usually enough and create a comfortable, relaxed environment. If refreshments will be provided, announce it on the program flyer. Food has a mysterious way of attracting interest!
- If needed, arrange for childcare or transportation – these are common barriers, particularly for working parents, people on fixed or low incomes and seniors.

Session 1

Exploring Your Personal Views

The deep question is: "How do you want to live? How do you want to be in this period of your life?"

Michael Lerner, M.D.
Healing of the Mind by Bill Moyers

Background Information for Discussion Leader

The purpose of this session is to help participants:

- Consider the variety of views on dying.
- Reflect on influences that have shaped their views about death and dying.
- Feel more comfortable discussing their views openly with friends and loved ones.

Tools Used in Session 1

Views on Dying

This page includes quotes and comments from well-known individuals, authors and poets, as well as others thinking about or facing their own death or that of a loved one. Presented as a collage of thoughts, Views on Dying helps participants understand some of the issues without delving into personal discussions.

Personal Reflection

This questionnaire helps participants begin reflecting on influences and experiences that have shaped their views about death and dying. Question 5: "What about the process of dying concerns you most?" introduces the importance of sharing these concerns with a loved one. As the follow-up activity, participants are asked to take home a blank questionnaire and share it with a family member or friend.

Before the session, make sure you have the following materials:

- Name tags and marker pens (if needed)
- Box of tissues
- Enough copies (double-sided) of Views on Dying for participants
- Enough copies (double-sided) of Personal Reflection for participants (and extras for them to take home)
- Pencils or pens for participants
- Session outline

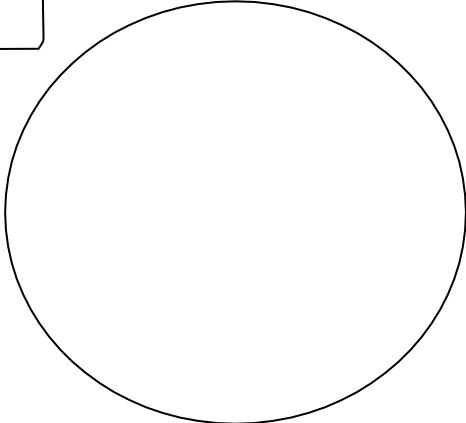
Session Outline 1

Discussion Leader	Participants
<p>Introductions (if needed)</p> <p>Explain your role and ground rules (see page 3).</p> <p>Present purpose of session:</p> <ul style="list-style-type: none"> • To consider the variety of views on dying • To reflect on influences that have shaped your views about death and dying • To feel more comfortable discussing your views openly with friends and loved ones 	<p>Self-introductions.</p>
<p>Distribute Views on Dying</p> <p>Example questions for discussion:</p> <ul style="list-style-type: none"> • Which of these quotes/statements did you like and why? • Are there any that you didn't like or didn't understand? 	<p>Group discussion.</p>
<p>Distribute Personal Reflection with pens/pencils</p> <p>Example questions for discussion:</p> <ul style="list-style-type: none"> • Which question was the most difficult for you to answer and why? • Did any of the questions make you feel uncomfortable? • Had you ever thought about these issues before? <p>If you haven't done so, be sure to discuss question #5: What about the process of dying concerns you most?</p> <p>Example questions for discussion:</p> <ul style="list-style-type: none"> • Is your concern based on someone else's experience? • Have you shared your concern with anyone? • Did it make any difference talking about it? 	<p>Each person completes questionnaire.</p> <p>Group discussion.</p> <p>Group discussion.</p>
<p>Suggest follow-up activity: Take home a blank copy of Personal Reflection and ask a family member or friend to complete it. Then discuss the differences and similarities in how you both answered the questions.</p> <p>Announce the topic for the next session: "Talking with Loved Ones about End-of-Life Decisions"</p>	<p>Take home one (or more) copies of Personal Reflection</p>

Views on Dying

If I'd know I was gonna live this long,
I'd have taken better care of myself.
Eubie Blake, Jazz musician

Don't let go too soon, but
don't hang on too long.
Tuesdays with Morrie
by Mitch Albom



Often it comes down to a question of whether
or not I can let go of this clinging on to life.
Or can I let go of my mother or father? Do I
trust that if I let go I will be upheld in grace
and peace?
Chaplain Hank Dunn

Everybody has got to
die, but I have always
believed an exception
would be made in my
case.
Author William Saroyan
on his deathbed

In the beginning God,
in the end God.
Bishop Desmond Tutu

With the energy of mindfulness, we can calm things down, understand
them, and bring harmony back to the conflicting elements inside us.
Thich Nhat Hanh
Vietnamese monk

Bodies last longer than brains,
support systems or
savings accounts.

Another Country
by Mary Pipher Pipher

Death is an event in life. It
is something that occurs in
life rather than something
that occurs to life.

Days of Grace
by Arthur Ashe

People have the natural
capacity to affirm and
embrace life in the most
difficult of
circumstances.

Do not go gentle into that good night,
Old age should burn and rave at close of
day;
Rage, rage against the dying of the light.

The deep question is,
how do you want to
live? How do you
want to be in this
period of your life?

Michael Lerner, M.D.

The reason that I don't
regret dying is that I
have had a really good
time.

Author Studs Terkel

Death is just a distant rumor to the young.

Andy Rooney

Personal Reflection

(Check all the answers that apply)

1. Who died in your first personal experience with death?
 - Grandparent/great-grandparent/Parent
 - Brother or sister
 - A child
 - Other family member
 - Friend or acquaintance
 - Stranger or a public figure
 - Animal or pet
2. When you were a child, how was death or dying talked about in your family?
 - Openly
 - With some sense of discomfort
 - As though it were a taboo subject
 - Do not recall any discussion
3. What does death mean to you?
 - The end; the final process of life
 - The beginning of a life after death; a transition, a new beginning
 - A kind of endless sleep; rest and peace
 - End of this life, but survival of the spirit
 - Other (specify):

4. What about your own death concerns you most?
 - I could no longer have any experiences.
 - I am afraid of what might happen to my body after death.
 - I am uncertain about what might happen to me if there is a life after death.
 - I could no longer provide for my family.
 - It would cause grief to my family and friends.
 - There would be some things left undone.
 - I have no concerns about my death.
 - Other (specify):

5. What about the process of dying concerns you most?
 - It would be long and painful.
 - Being a financial burden to my family
 - Causing my family to suffer
 - Being dependent on others to care for me
 - Losing control of my mind and body
 - I am not concerned about the process of dying.
 - Other (specify):

6. How large a role has religion played in your attitude toward death?
- A very significant role
 - Influential, but not a major role
 - A relatively minor role
 - No role at all

7. If you were told that you had a limited time to live, how would you want to spend your time until you died?
- I would pursue personal pleasures (travel, adventure, chocolate).
 - I would prefer being alone: reading, thinking or praying.
 - I would shift from my own needs to a concern for others (family, friends).
 - I would try to tie up loose ends.
 - I would try to do one important thing.
 - I would make little or no changes.
 - Other (specify):

8. If or when you are married or have a long-term partner, would you prefer to outlive your spouse/partner?
- Yes, I would prefer to die second and outlive my spouse/partner.
 - No, I would rather die first and have my spouse/partner outlive me.
 - It doesn't matter to me.
 - This question doesn't apply to me.

9. If you had a choice, what kind of death would you prefer?
- Sudden, unexpected death
 - Quiet, dignified death
 - Death in the line of duty
 - Death after a great achievement
 - There is no "appropriate" kind of death.
 - Other (specify):

10. What is one thing you would want to say to someone special before you die?

Questions based in part on Edwin Schneidman's "You and Death: An Exercise."

Session 2

Talking with Loved Ones

Legal documents to express our wishes are not enough to prepare us for our final days. We must talk honestly with our loved ones, our clergy and our doctors and nurses about the choices we would make if confronted with a chronic or terminal illness.

Rosalyn Carter from a *Washington Post* article

Background Information for Discussion Leader

The purpose of this session is to help participants:

- Consider why it is difficult to talk about this topic with family.
- Identify ways to become more comfortable talking with loved ones.

Tools Used in Session 2

Talking in Advance

This scenario illustrates two important points about end-of-life decision-making:

- That these decisions are faced by people of all ages, not just older people.
- That difficult decisions are made even harder when there has been no conversation prior to the crisis.

The purpose of the discussion is to have participants imagine themselves in this situation and recognize the importance of talking to loved ones before a crisis.

John and Marsha and/or Ellie Williams

Tension exists in both of these scripted conversations between family members. The conversations show the difficulties people face when trying to discuss what they want at the end of life, even when they care deeply about one another. *Use one or both, depending on available time and the interest of the group.*

The questions for discussion ask participants to imagine these situations in their own families, think about how they might talk with their loved ones and how their family might react. Encourage participants to share with each other any approaches that have worked for them in initiating and talking about their wishes with family and close friends. The follow-up activity gives them a chance to apply what they have learned.

Finding Your Way booklet (optional) – This booklet is available for sale at CoalitionCCC.org and can be a helpful discussion-starter for individuals and their families. Encourage participants to read it after the session.

Before the session, make sure you have the following materials:

- Name tags and marker pens (if needed)
- Box of tissues
- Extra copies of Personal Reflection questionnaire for those not present at last session
- Enough copies of John and Marsha and/or Ellie Williams for participants
- Finding Your Way booklets for all participants (optional)
- Session outline

Session Outline 2

Discussion Leader	Participants
<p>Introductions and ground rules, as needed.</p> <p>Present purpose of session: To consider why it is difficult to talk about this topic within families To identify ways to become more comfortable talking with loved ones</p>	<p>Self-introductions.</p>
<p>Follow-up from previous session: Did anyone ask a family member or friend to complete Personal Reflection? If so, questions for discussion: Were they willing to complete it? Did you discuss the responses? Were there surprising differences?</p>	<p>Share experiences.</p>
<p>Read “Talking in Advance” aloud to the group.</p> <p>Example questions for discussion: If this were you making the decision for your spouse, would you know what to do? If you were in a coma tomorrow, would your closest relative know what to do for you?</p>	<p>Share reactions to the scenario.</p>
<p>Distribute either John and Marsha or Ellie Williams</p> <p>Discussion leader reads the introduction (in italics). Ask for volunteers to read the roles out loud.</p> <p>Example questions for discussion about John and Marsha: Do you relate more to John or Marsha? Why? Does it matter that John and Marsha have different views? What would you do if you and your loved one had different views? Has anyone had a family situation where this was a problem?</p> <p>Example questions for discussion about Ellie Williams What do you think Ellie wanted to talk about with her daughter? What did you think about Peggy's reaction? If you were Ellie, what would you do after this conversation? Do you think this conversation is typical in families? Has something like this happened in your family?</p>	<p>Each participant has a copy while listening to it read aloud.</p> <p>Group discussion.</p> <p>Group discussion.</p>
<p>Distribute <i>Finding Your Way</i> and suggest follow-up activity: Read the booklet and talk with a loved one about what would be important to you at the end of life.</p> <p>Announce the topic for the next session: “Making Tough Decisions.”</p>	<p>Take home <i>Finding Your Way</i>.</p>

Talking in Advance

Peter and Susan are a young couple. They have two children, are active in their church and have many close family members living nearby. But their lives change dramatically one night when Peter is in a head-on crash and suffers a severe head injury.

One year later Peter remains in a coma, unable to speak or interact with others. A breathing machine keeps him alive. His doctor tells Susan that it is extremely unlikely Peter will ever wake up.

The doctor then asks Susan whether Peter would want to continue in this condition or have the breathing machine turned off. Susan doesn't know. She and Peter had never talked about what to do if one of them were in this situation. It had never occurred to them.

After many discussions with other family members, Susan decides to have the doctors turn off the breathing machine, and Peter dies. Months later Susan still worries if she did the right thing. She is just not sure she made the decision that Peter would have chosen for himself.

John and Marsha

John and Marsha are a couple whose friend Fred recently died following a three-year battle with cancer. They learned that when he went into a coma, Fred's family decided to stop all treatment and he died shortly afterwards. On the way home from Fred's funeral, John and Marsha begin talking about the family's decision to stop Fred's treatment.

- John: I was surprised to hear that Fred's family stopped the treatment. Weren't you?
- Marsha: Not really. His son told me last month that Fred knew the end was getting near, and he was miserable. I don't think he wanted to keep going. And I think his family knew that.
- John: There must have been something the doctors could have done.
- Marsha: I think they tried everything they could.
- John: Well, his family shouldn't have given up so soon.
- Marsha: You sound kind of angry about this.
- John: It bothers me because the Fred I know wouldn't have done that. It seems that as long as he was alive, there was hope for a cure. I think I would go through about anything to stay alive.
- Marsha: You mean you can't imagine **any** situation where you wouldn't want to continue living?
- John: Yeah, when I can no longer break 90 on the golf course!
- Marsha: Very funny. Well, I think it must have been hard for his family to stop treatment and let him go peacefully. Even when you know the end is near, that can't be an easy thing to do.
- John: Frankly, I really can't imagine being so miserable that I'd want to die sooner rather than later.
- Marsha: Well, I **can** imagine being that miserable! And I wouldn't want you and the children suffering along with me.
- John: I guess the doctor makes these decisions anyway, so maybe we don't even have to worry about it. Right?
- Marsha: I don't think so. I think this was Fred's decision and his family did what he wanted them to do.
- John: We seem to have different ideas about what we would want. What if I have to make that decision for you? Or you for me?

Ellie Williams

Ellie Williams is 73 and has had severe lung problems for many years. Her doctor told her that there are no more treatments to make her lungs better and that she'll get weaker and have more breathing problems over the next few months.

Ellie's husband died several years ago, and she lives alone with the help of her grown children who live nearby. She decides it's time to talk with her daughter, Peggy.

- Ellie: Dear, I want to talk with you about something. I saw the doctor last week, and he told me that there is nothing that can help my lung condition get better. In fact, it's just going to get worse. I'm a little concerned.
- Peggy: You know, the doctors are not always right about these things. I don't think you should take this too seriously.
- Ellie: Yes, perhaps you're right. But the doctor said I will need to make some decisions pretty soon. It would make me feel better if we could talk about this.
- Peggy: Mom, I don't think there is anything to talk about! You're going to be fine, and we can handle things as they come up.
- Ellie: Peggy, I'd feel better if I knew that you and your brother understood my feelings. When your Dad died, it was so hard because he wouldn't tell me what he wanted. Honey, I know this isn't easy, but not talking about it won't make it go away.
- Peggy: Mom, what are you talking about? It's not time yet. You're going to be around for years!
- Ellie: But that's the problem. I don't think I want to hang on forever, with machines keeping me alive, and you and your brother fighting over who has to take care of me.
- Peggy: Oh, Mother! You're being silly. Everything is fine - there is nothing to worry about. Oh my gosh, it's late. I've got to get going before the stores close. Bye, Mom. Quit worrying. I love you.
- Ellie: I love you too, dear.

Session 3

Making Tough Decisions

Often it comes down to a question of whether or not I can let go of this clinging on to life. Or can I let go of my mother or father? Do I trust that if I let go I will be upheld in grace and peace?

Chaplain Hank Dunn
Letter to the Editor, *Washington Post*

Background Information for Discussion Leader

The purpose of this session is to help participants:

- Identify things to consider when making decisions for a loved one.
- Think about those who could provide support when facing the end of life.

TOOLS USED IN SESSION 3

Making Decisions for a Loved One

This exercise is intended to help people think about how they would make end-of-life decisions for a family member or close friend. Be sure to include in your discussion the final question listed on the outline: What would you want to tell your closest relative/friend **now** so he/she knows what to do in the future?

Facing Death

Next, participants are asked to consider their responses to receiving bad news about their own health. They are asked to imagine that they are facing a terminal illness and to answer a series of questions. Ask participants to answer the questions in writing first, and then open it up for discussion.

Before the session, make sure you have the following materials:

- Name tags and marker pens (if needed)
- Box of tissues
- Enough copies of Making Decisions for a Loved One for participants
- Enough copies of Facing Death for participants
- Pencils or pens for participants
- Photocopy of Response Form for you to record responses at the meeting
- (Optional) Enough copies of Additional Material (page 27) to distribute at the end for participants to take home
- Session outline

Session Outline 3

Discussion Leader	Participants
<p>Introductions and ground rules, as needed.</p> <p>Present purpose of session:</p> <p>To identify things to consider when making decisions for a loved one.</p> <p>To think about those who could provide support when facing the end of life</p>	<p>Self-introductions.</p>
<p>Follow-up from previous session:</p> <p>Did anyone talk with a family member or friend about his or her own views on end-of-life care? If so, questions for discussion:</p> <p>Did you feel comfortable talking about it?</p> <p>How did your family/friend respond?</p>	<p>Share experiences.</p>
<p>Distribute Making Decisions for a Loved One.</p> <p>Ask participants to read along while you read aloud, then take a few minutes to have them write their responses.</p> <p>Example questions for discussion:</p> <p>What was most important in helping you make a decision? Why?</p> <p>What was least important and why?</p> <p>What did you decide you would do?</p> <p>If you were the 78-year-old in this scenario: What would you want done and why?</p> <p>Would your closest relative/friend know what to do?</p> <p>What would you tell your closest relative/friend now so he/she knows what to do in the future?</p>	<p>Each participant answers questions in writing.</p> <p>Group discussion.</p>
<p>Distribute Facing Death</p> <p>Read introductory paragraph aloud and ask participants to take a few minutes to write their responses.</p> <p>Starting with question #1, ask them to share what they have written.</p> <p>Record responses to Questions 4 and 5 on the Response Form.</p>	<p>Each participant writes responses.</p> <p>Group discussion.</p>
<p>Thank everyone for participating.</p> <p>(Optional: Ask for suggestions for future sessions on this subject.)</p> <p>(Optional: Distribute copies of Additional Material, page 27)</p>	

Making Decisions for a Loved One

Your 78-year-old mother, a widow, has been in a nursing home for five years. She has severe heart disease and now must depend on the help of nurses' aides to do all her daily care. Her mental ability has greatly declined; she is often confused and doesn't remember much from day to day. She is not in pain but tires easily and spends much of her day napping in a chair. When she is awake, she appears quite content listening to music and watching the activities around her. Though she can't remember who most people are, she knows you and seems to enjoy your visits.

Your mother is no longer able to swallow, and her doctor says that in order to get nourishment, she would need surgery to place a feeding tube in her stomach. With a feeding tube, she could live another 6-12 months (the doctor can't say for sure) while continuing to decline. Without it, she probably will live several weeks without additional suffering.

Though your mother has an advance directive naming you as her decision-maker, she had not written down or talked about how she wanted to live her last phase of life. Since she can no longer make her own decisions, the doctor asks you what she would want regarding the feeding tube.

As you consider this decision for your mother, what is of particular importance to you? Check all that apply:

- Having her live as long as possible
- Letting nature take its course
- Her quality of life
- The impact on family members
- Keeping her as comfortable as possible
- The sanctity of life
- Other _____

Based on the above, what do you think you would do?

Facing Death

Imagine that you have not been feeling well for months and go to the doctor for a checkup. After a series of tests, your doctor gives you devastating news - you have a terminal illness. Furthermore, your doctor tells you that most people with this condition live no longer than a year.

1. What do you think would be your first thought, emotion or reaction?
2. Who is the first person you would turn to for support or comfort?
3. What could that person do to be helpful to you?
4. What could your doctor do to be helpful to you?
5. What could others (like your faith community, senior group, community organization) do to provide support during this time?

Resources

Any definition of "dying well" must include respecting patients' wishes, reducing pain, involving caregivers throughout the process, minimizing financial burden and encouraging spiritual growth until the very moment of death.

Rosalyn Carter from a *Washington Post* article

Working with Different Ethnic/Cultural Groups

Cultural and ethnic diversity is found within many organizations, congregations and communities. Among different populations the beliefs and customs vary widely and impact the ways individuals and families discuss death and dying, make end-of-life decisions and communicate about personal, emotionally-charged subjects.

To understand how a variety of groups might respond to the idea of attending discussions on end-of-life issues, we met with individuals from several ethnic/cultural communities and asked ethnic leaders for their insights. These discussions were not held to identify the beliefs of specific groups or to test the Discussion Guide. Instead, the purpose was to learn: 1) how different ethnic groups respond to the concept of small group, interactive discussions as a strategy for advance care planning and 2) what might be effective ways to arrange discussion groups for diverse populations.

Caution about generalizations

Sensitivity to ethnic and cultural diversity may unwittingly lead to unsubstantiated assumptions about individuals and population groups. Just as those within a family who have been raised with similar beliefs and backgrounds can have very different views on any given subject, so may those who share a common cultural background. Though it can be helpful to know in general how different groups tend to respond to issues related to death and dying, that knowledge should be used as a starting point for developing a program, not as a way of categorizing individuals.

Learning about different ethnic/cultural groups

Certainly there are many more ethnic/cultural populations living in our communities than those listed here. The following are intended as examples of different perspectives to consider when you are planning discussion sessions.

Hispanic/Latino participants indicated that:

- Death is not considered a taboo subject, though families differ considerably in how openly they discuss it.
- With the wide variety of countries of origin, customs may vary.
- Discussion groups are a good way to address this subject. Hispanics/Latinos tend to be verbal and relational. They enjoy sharing experiences and learning from others.
- Group discussion is more important than written materials.

African-American participants indicated that:

- The willingness to discuss death and dying varies, but there is no particular cultural taboo.
- Since many African-Americans have a strong religious and social connection with faith communities, congregations are ideal settings for discussion groups.
- Discussions are best led by a known, respected community or religious leader. If the leader is a healthcare professional, an African-American is more likely to have a positive response.

Chinese participants indicated that:

- Traditional Chinese believe it is a bad omen to talk about death.
- When faced with an end-of-life situation, family may discuss it but not with the person who is ill.
- Sessions should be sponsored through an established organization or people won't attend. Attendance is likely to be better if friends are attending.
- Mass media (newspapers, TV, radio) are a common source of information.

Filipino participants indicated that:

- They don't usually talk about death with the ill family member. Some believe that discussion may make it happen or that the person talking about it wants the death to occur.
- The entire family usually makes decisions; often the priest is consulted as well.
- Filipinos look to the church as a place for support and learning about this topic.
- Discussion groups are a good way to address this subject and provide information on resources and related issues.

Japanese participants indicated that:

- The older Japanese generation is especially reluctant to discuss this topic. Though not fearful of death, talking about it can be a bad omen.
- Younger adults may be more accepting of open, direct conversations.
- Japanese tend to be reserved about discussing personal or emotional topics and, therefore, don't find the discussion group format appealing.
- They are more interested in learning new facts/information by attending presentations by experts.

Vietnamese participants indicated that:

- They are not preoccupied with concerns about "what if?" They have close family and community ties and trust that the best decision will be made.
- The oldest child often makes end-of-life decision for a parent. He/she may consult with others in the Vietnamese community but not with the dying person.
- It would be taboo for the younger generation to raise the subject with their parents, although they might discuss the subject with their peers.
- Vietnamese tend not to discuss personal/emotional issues openly.
- They are interested in factual, practical information, have a high regard for experts and respond to meetings convened by community leaders.

Among participants indicated that:

- They don't speak of impending death to the dying person. Elders of family/clan meet regarding decisions that must be made.
- Clan leaders and shamans are often used as liaisons between their people and the healthcare system.
- They do not typically hold discussion groups and would be unlikely to convene a group around this topic.
- Radio talk programs and newsletters are common sources of information.

Planning your sessions

To address the interests of different groups, the discussion leader needs to understand:

1. The participants' acceptance of this subject as a topic to explore.
2. The participants' willingness to engage in active discussion.

Following are some suggestions when working with an unfamiliar cultural/ethnic group:

- Meet with several members and ask them to identify topics of interest (for a starting point, see page 26), or have them review the Guide's materials for appropriateness to their cultural interests and concerns.
- Ask potential participants to complete a survey asking their opinion on what should be covered.
- Research written materials regarding specific populations.
- Make changes, as needed, in the discussion tools in this Guide to reflect the situations or circumstances that this population experiences.
- If a group is clearly not interested in a particular aspect of the program (e.g., discussing personal values), focus on topics the group wants.
- Translate the handouts (discussion tools) into the appropriate language. Even when literate and bilingual, individuals often prefer reading materials in their native language.
- Investigate when, how and where this particular group likes to meet. The more familiar the setting, the easier it is to recruit participants.
- Arrange for the program to be sponsored by a well-known community organization. Ask respected leaders to convene and/or announce the program.
- Target the 35-to-50-year-old age group. It is common for the older generation to have stronger ties to traditional beliefs and customs and to be more reluctant to discuss topics related to dying. Adult children often see themselves bridging the traditional beliefs of their elders with modern practices of American society.
- Sometimes native-born Americans are perceived to have more authority and knowledge than those of participants' own ethnic background, but sometimes not! Ask your prospective participants what is important to them.

- Enlist the help of appropriate religious communities to connect with a particular population. Ethnic groups may have strong spiritual backgrounds and religious affiliations.

A valuable resource

Culture and Nursing Care: A Pocket Guide. Written to help improve nursing practice, this spiral-bound guide includes information for 24 different ethnic/cultural groups on a variety of healthcare-related topics, including death rituals, family relationships, communication, spiritual/ religious orientation. Published by the University of California, San Francisco School of Nursing Press, 1996. For information on ordering, call (415) 476-4992 or <http://nurseweb.ucsf.edu/www/book4.htm>.

Related Topics / Finding Speakers

You may want to hold additional sessions on related topics – either as part of this series or later. Listed below are some ideas for other session topics:

- Spiritual or emotional issues around death and dying
- Understanding the physical process of dying
- Learning about hospice services
- Palliative care: what we should expect from our healthcare providers
- How do we know when it's time to let go?
- The cost of dying – what Medicare and insurance pays for and what it doesn't
- Advance directives:
 - How to complete an Advance Health Care Directive, including choosing a surrogate and making sure your choices are respected
 - Other useful forms, such as Five Wishes (see page 27) or POLST (Physician Orders for Life-Sustaining Treatment)
- Life-sustaining measures (feeding tubes, ventilators, CPR, etc.): understanding how they work and when to use them
- Planning your funeral or memorial service
- Grief and bereavement issues
- Caring for the caregiver
- Other cultural views on death and dying
- How our faith community views these issues
- Learning about organ donation
- Home funerals; burial/cremation

Speakers

Any of the topics listed above can be offered - you just need to find someone in your community who knows the subject! Fortunately, that's not too hard to do. First, check with your local coalition, if you have one. A list of coalitions is available at CoalitionCCC.org/who-we-are/local-coalitions/. If that is not an option, ask if anyone within your own organization or congregation is familiar with the topic or knows someone who is. In your community, the best source is your local hospice program. It usually has speakers available or can identify knowledgeable professionals for a variety of topics. You can also check with the patient education department of your hospital; local colleges that have courses on Death and Dying; and the medical society in your area.

A listing of most of the state's hospice programs can be found through the California Hospice & Palliative Care Association (CHAPCA) website: calhospice.org or call 916-441-3770. State hospice associations in other states can be located through the National Hospice and Palliative Care Organization at nhpco.org.

Additional Resources

The following resources can be used to augment your discussion groups or you may photocopy this page to give to meeting participants.

- **Advance Health Care Directive.** An advance directive form can be obtained from most hospitals. Check with the Patient Education, Social Services or Chaplaincy department. A directive can also be purchased from the California Medical Association at 1-800-882-1262 or www.cmanet.org. Advance directives for all states can be downloaded from the Caring Connections website at: www.caringinfo.org or call 1-800-658-8898.
- **Five Wishes.** This is a reader-friendly advance directive (AD) that addresses the medical wishes as well as the personal, emotional and spiritual wishes of seriously ill persons. Legal in most states, including California, Five Wishes is a valuable discussion tool. Available through Aging with Dignity at 1-888-594-7437 or www.agingwithdignity.org.
- **The Decisions series.** This is a six-part set of articles used as bulletin or newsletter inserts to help people understand end-of-life issues. Particularly useful in congregations, community organizations, classroom settings or with the print media. Available through Center for Healthcare Decisions at (916) 333-5046 or www.chcd.org.
- **Finding Your Way: A Guide for End-of-Life Medical Decisions.** This is an easy-to-read 13-page booklet to help those who are planning before serious illness occurs, or considering whether to initiate or withdraw life-sustaining treatment when the end of life is near. Available through Coalition for Compassionate Care of California at (916) 489-2222 or www.CoalitionCCC.org.

Other Sources for Materials

Hospitals, hospices, health plans and other healthcare organizations commonly have Patient/Health Education departments or libraries where a selection of videos and other materials may be available on loan.

The National Hospice and Palliative Care Organization has educational materials available at www.nhpc.org.

For information about the Coalition for Compassionate Care of California, visit CoalitionCCC.org.

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