



# Life and Death Decisions

February 2006

## Who Decides?

Medical technology has greatly extended American lives. These days, death often does not come as a natural event but as the result of complex decisions. Any decision about death is an intensely personal one. But as a society, we have a shared interest in choosing what kinds of options are available to us at the end of life, how they are accessed, and what rules are involved.

### APPROACH ONE

#### Preserve Life

We have a collective moral responsibility to do everything possible to prevent death. As long as there is the ability to maintain life, our skills should be employed in sustaining it. Only when death is imminent and inevitable should we allow nature to take its course and focus on relieving pain and making the patient comfortable.

### APPROACH TWO

#### Maintain Quality of Life

Medical advances make it possible to keep people alive long after they are conscious, indeed, long after life seems worth living. Sometimes withdrawing life support is appropriate even when further treatment would help the patient live longer. People should be able to get care that takes into account their quality of life and acknowledges death as a natural occurrence.

### APPROACH THREE

#### My Choice, My Right

People should all have the right to decide whether they want to live or die. We have the right and responsibility to have control over our own care. We should expand the options available to all of us at the end of our lives to include the right to seek help from our physicians in ending our lives when death is inevitable, and suffering makes life unendurable.



# Approaches and Choices: Choice Work and NIF

If you're preparing to moderate a National Issues Forum, then you've become familiar with the structure of deliberative dialogue that NIF supports. Discussion guides, starter tapes, and deliberative forums focus on approaches, also called "choices" or "options" in NIF material.

And you know that each approach represents a distinctly different way of approaching an issue, with its own set of benefits, drawbacks, and tradeoffs.

This structure undergirds the basic premise of public deliberation—that citizens in a democracy have a responsibility, and need opportunities, to make choices about how they want to live together, how they want to act together, and how they want their government to function.

Sometimes, forum participants find these uses of the word *choice* confusing. Some assume that they are being asked to choose one of the approaches. And, of course, they are not.

Many moderators find it helpful to clarify, at the beginning of the forum, that the work of the forum is to weigh each approach, to "work through" consequences and tradeoffs, and to form a shared sense of what's at stake in the issue. They make it clear that, by developing shared directions for public action, forum participants are laying the foundation for making public choices together.

## If This Is Your First Experience as a Moderator:

### **You don't have to be an expert on the issue.**

Reading the issue book thoroughly, considering questions that get to the heart of the issue, and thinking through the essence of each approach is the critical part of preparation.

### **Stay focused on what the forum is about—deliberation.**

Your natural curiosity and your interest in understanding diverse views will be your greatest assets; they're probably what got you here in the first place. So use them to ask questions that probe the underlying motivations of each approach, the tradeoffs it might require, and the willingness of the participants to recognize them.

### **Keep the discussion moving and focused on the issue.**

No matter the level of experience, most moderators find timekeeping to be a challenge. National Issues Forums examine complicated issues, worthy of deep discussion. Sometimes it's hard to move on to another approach with so much more that could be said. But in order to deliberate—to really make progress on the issue—participants need the opportunity to weigh all the major approaches.

### **Reserve ample time for reflections on the forum.**

Between allowing time for participants to lay out their personal concerns about the issue at the beginning of the forum and the demanding work of deliberating in depth on each of the approaches, it's easy to find yourself at the end of the forum with little time left to reflect on what's been said. But, in many ways, this is the most important work the group will do—if they have time to do it. Explain clearly at the outset that it is important to reserve this time, and then enlist the participants' support in working with you to preserve it.

# Your Role as a Moderator:

- to provide an overview of the process of deliberation—the rationale for the kind of work the participants are getting ready to do
- to ask questions that probe deeply into what's at stake in the issue and in each choice
- to encourage participants to direct their responses and questions toward one another
- to remain neutral throughout the discussion, while encouraging participants to explore all facets of their own and others' opinions
- to keep track of the time, so participants can move through a discussion of each of the major approaches and into an ending period of reflections

# The Role of the Recorder:

- to support deliberation by reminding forum participants of their key concerns, the areas of greatest disagreement, and the benefits and tradeoffs their discussion highlighted
- to serve as a written record of the group's work that might feed into future meetings of the group or additional forums
- to help inform other members of the community about the outcomes of the deliberation
- to capture the tensions, tradeoffs, and common ground for action
- to express main ideas in clearly written, brief phrases

# Forums or Study Circles – or Both?

Many NIF convenors choose to organize single forums around issues of concern in their communities. Most single forums last two to two and one-half hours.

Many others, however, arrange multiple sessions (study circles) to allow participants greater opportunities to examine issues in depth. Some groups set aside time for two meetings; others might devote a separate session to each approach. And still others plan ahead of time for a session after the forum to come back together to consider next steps.

Some communities begin their examination of an issue in a large group forum and then break off into smaller groups for subsequent sessions. The reverse also can be helpful—starting in small groups and culminating in a larger community forum.

National Issues Forums is about encouraging public deliberation. The needs of your community will drive the schedule in which deliberation can best occur.

# Guidelines for National Issues Forums and Study Circles

The **moderator** will guide the discussion, yet remain neutral.

The **moderator** will make sure that:

- Everyone is encouraged to participate.
- No one or two individuals dominate.
- The discussion will focus on the approaches.
- All the major choices or positions on the issue are considered.
- An atmosphere for discussion and analysis of the alternatives is maintained.
- We listen to each other.

At the beginning of deliberative discussion, most moderators review these guidelines with participants.

## The Importance of the Questionnaires

Questionnaires play an important role in your local forum and in the national NIF network. Filled out after the forum, they serve multiple purposes. They give participants an opportunity to reconsider their views in light of the experience they have just had. And they give an opportunity to add to what was said or heard in the forum.

The questionnaires also serve a vital role outside of the forum. As a means of capturing what happened in the forum, they provide information that can be used to communicate participants' views to others—to officeholders, to the media, and to other citizens.

Nationally, a report on the outcomes of the forums on a given issue is produced each year, based on extensive interviews with moderators and the

questionnaires that forums generate. Some communities use questionnaires as part of reports on the outcomes of local forums.

So it is very important that you, as the forum moderator, take a few minutes to gather and return the questionnaires to the National Issues Forums Institute. Please include the Moderator Response sheet on page 12 with your contact information so that follow-up for the national report is possible.

Return the completed questionnaires to:

National Issues Forums Institute  
100 Commons Road  
Dayton, Ohio 45459-2777

## Communicating about Your Forums

Another important role of the moderator is to communicate with the NIF network about the forums you are conducting in your community. Please post the dates and locations of your forums by e-mail at [forums@nifi.org](mailto:forums@nifi.org).

## Questions to Promote Deliberation of the Issue

As you examine this issue with forum participants, you will undoubtedly think of questions that are at the heart of what makes it compelling. Many of these questions will arise during the forum, based on responses of the participants to you and to each other. This issue lends itself to storytelling and can evoke strong emotions, which could derail the deliberation if the moderator allows them to. While you need to be sensitive to accounts of participants' personal experiences, it is just as important that you keep the deliberation on track with regard to the broader underlying concerns raised by this issue. Moderators often find it helpful to develop, ahead of time, some general questions that will focus participants on the core ideas in each approach. Here are some possibilities:

### **A P P R O A C H O N E**    Preserve Life

- What should be the role of physicians in treating terminally ill patients?
- Should patients be kept alive against their will?
- Medical care given at the end of life is particularly costly. What effect, if any, should this have on life and death decisions?
- Is there any point at which we should give up hope that a seriously ill patient may recover?

### **A P P R O A C H T W O**    Maintain Quality of Life

- How important should quality of life be as a determinant in life and death decisions?
- Though health-care providers are legally required to honor provisions of a living will, many don't. What can, or should, be done about that?
- If hospice care is to be available to everyone, would it have to be integrated into all hospitals? Would you support spending public funds for this purpose?
- If heavy doses of narcotics required to relieve severe pain are also likely to hasten death ... what then?

### **A P P R O A C H T H R E E**    My Choice, My Right

- Do all people have a right to decide when and how they will die?
- Surveys show that many physicians quietly help suffering, terminally ill patients die. While this is not legal in most states, is it wrong?
- Currently, Oregon is the only state that has enacted a "right to die" law. If such laws became more common, what kinds of abuses might follow?
- Should parents or guardians be given the right to end the lives of comatose patients who cannot make this decision themselves?

# >> Comparing Approaches

**M**edical technology has greatly extended American lives. These days, death is sometimes not just a natural event. Doctors can keep a person's body alive seemingly indefinitely. In many cases, death involves a decision—to stop treatment, to forego treatment altogether, or to shift from actively seeking recovery to seeking comfort, even, in some cases, to speed the fatal moment.

Any decision about death is an intensely personal one. But as a society, we have a shared interest in choosing what kinds of options are available to us, how they are accessed, and what rules are involved.

This issue weaves together a number of threads, all of which have strong arguments going for them. On the one hand, we must do everything possible to preserve life and reduce discomfort. In that regard, we can do so much more now than ever. On the other hand, there are those who say medical science can go too far, that we must take into account quality of life as well as quantity of life. We have allowed medicine to intervene past the point when it is appropriate, keeping people who would have been dead 50 years ago physically alive yet mentally absent. And there are others who say that the issue has little to do with what medicine can or cannot do—that it is a matter of individual rights. Who decides for me what care I will receive, and whether I live or die? Those who hold this view say that people have a right to die in the manner they desire, and it is up to the law to make sure that they are able to act on their choices.

This summary is designed to help citizens talk about the question of what to do at the end of life. It focuses on the public as well as personal aspects of this very intimate question. It lays out three views that we might take on the issue, and corresponding options for action.

## APPROACH ONE

### >> Preserve Life

We have a collective moral responsibility to do everything possible to prevent death. As long as there is the ability to maintain life, our skills should be employed in sustaining it. Only when death is imminent and inevitable should we allow nature to take its course and focus on relieving pain and making the patient comfortable.



#### What can be done?

- Strengthen medical practices in end-of-life care so that all possible efforts are made to treat and cure.
- Increase training in pain management.
- Recognize that for some, the desire to give in or hasten death is a common stage among the terminally ill.
- Make sure that the same standard of care is afforded those who are no longer likely to be cured.

#### In Support

- Life is a precious gift and we have a collective moral obligation to do all we can to preserve it.
- We never know when a new cure will be discovered; it is wrong to give up trying.
- Medicine cannot only prolong life, but can make the end of life much more comfortable than ever before.

#### In Opposition

- Just because we can extend a life by many advanced new techniques, does not mean we should.
- A great deal of money is spent in prolonging life—and suffering—unnecessarily.
- Taken to its extreme, this approach just forestalls an inevitable, natural process: death.

#### A likely tradeoff

- Heroic efforts to prolong life may occasionally have a dramatic payoff but it drives up the costs of health care for everyone else.
- Sometimes, "preserving life" means going against the wishes of some or all family members, and at times even the patient.
- For the patient, the results of efforts at "life preservation" can come with pain, paralysis, and other extreme discomfort.



APPROACH TWO

>> Maintain Quality of Life

Medical advances make it possible to keep people alive long after they are conscious, indeed, long after life seems worth living. Sometimes withdrawing life support is appropriate even when further treatment would help the patient live longer. People should be able to get care that takes into account their quality of life and acknowledges death as a natural occurrence.



**What can be done?**

- Increase spending on training for palliative care.
- Do a better job of connecting patients and their families to existing resources for handling death.
- Encourage more people to draft advance directives or living wills.
- Institutionalize hospice care so it is less reliant on volunteers.

**In Support**

- Life is more than just existence—its quality needs to be taken into account.
- Many people “recover” from illnesses only to find that they face new and insurmountable obstacles—quadriplegia, inability to eat without assistance, immobility.

**In Opposition**

- All life is sacred, not just life of a certain “quality.”
- We owe it to people to do all we can to keep them alive for as long as possible.
- A number of patients “wake up” after long periods of unconsciousness that doctors say are permanent. This approach denies all those people the chance to awaken.
- No one can say what level of quality of life is appropriate for a person except the person him- or herself. Asking anyone other than the patient to make such determinations is not right.

**A likely tradeoff**

- Hospice is a good option but not available to all who could benefit from it.
- All states recognize the legality of advance directives, or living wills. But, the system is confusing and living wills are not always honored.
- This approach may lead some doctors to cease treating patients prematurely, even when it is otherwise possible to sustain life.

APPROACH THREE

>> My Choice, My Right

People should all have the right to decide whether they want to live or die. We have the right and responsibility to have control over our own care. We should expand the options available to all of us at the end of our lives to include the right to seek help from our physicians in ending our lives when death is inevitable, and suffering makes life unendurable.



**What can be done?**

- Reorient public policy to recognize individuals' rights to determine their own ends.
- Make it legal and acceptable for physicians to assist patients to end their lives.
- Require insurers to provide benefits to the families of terminally ill patients who choose to hasten their death.

**In Support**

- It should be our right to decide our own fate.
- The present system denies people the right to choose.
- It is unfair that terminally ill patients on life support can opt to end their own lives, while others who suffer must endure.

**In Opposition**

- In most major religions and in most societies across the globe, suicide is seen as morally wrong. Dr. Kevorkian is in jail for his work in aiding people to kill themselves when he went too far. It would not be right for individuals to have the kind of autonomy suggested by this choice.
- A right to die might evolve into a duty to die, especially for elderly or disabled patients who may believe that they are a burden on their families.
- Making assisted dying legal removes an important protection against those who may not have the patient’s best interests at heart.

**A likely tradeoff**

- If we accept the importance of peoples’ rights to decide how they will end their life, we also must accept that some people may make decisions that we view as wrong.
- If we support this choice, we will need to make sure that all end-of-life options, including physician-assisted dying, are available to everyone.
- If it is a person's right to plan for their own end, it is also the right of a guardian or parent to make these decisions on their behalf if they cannot do so. This can lead to abuses.

# Suggested Format for an NIF Forum or Study Circle

## Welcome

Let participants know who is sponsoring the forum/study circle. Stress the cosponsorship if several organizations are involved.

## Ground Rules

MAKE CLEAR THAT THE FORUM IS NOT A DEBATE. Stress that there is work to do and that the work is to move toward making a choice on a public-policy issue. The work will be done through deliberation. Review the paragraph “How Do We Do It?” (See page 11.) The responsibility for doing the work of deliberation belongs to the group. Deliberation is necessary because there are competing approaches to solving the problem.

## Starter Video

Explain that the video reviews the problems underlying the issue, then briefly examines three or four public-policy alternatives. In so doing, it sets the stage for deliberation. (Starter videos for each issue book are available from National Issues Forums Publications, P.O. Box 41626, Dayton, OH 45441, phone 1-800-600-4060)

## Personal Stake

Connect the issues to people’s lives and concerns—in the first few minutes—by getting participants to talk about their personal experiences with the issue and to tell their stories. This makes the issue genuine, human rather than abstract. Some questions you might ask include: “Has anyone had a personal experience that illustrates the problems associated with this issue?” “Within your family, or circle of friends, is this an important issue?” “What aspects of the issue are most important to you?” “How does this issue affect people?”



# The Forum/Study Circle Deliberation

**Consistent with what deliberation is, moderators ask basic types of questions in a forum:**

## **What Is Valuable to Us?**

**This question gets at why making public choices is so difficult: the approaches turn on things that people care about very deeply, such as being secure or being treated fairly. This question can take many forms:**

- How has this issue affected you personally? (Usually asked at the beginning.)
- What things are most valuable to people who support this option?
- What is appealing about this approach?
- What makes this approach a good idea—or a bad one?

## **What Are the Costs or Consequences Associated with the Various Approaches?**

**This question can take as long as it prompts people to think about the likely effects of various approaches on what is valuable to them. Examples include:**

- What would result from doing what this approach proposes?
- What could be the consequences of doing what you are suggesting?
- Can you give an example of what you think would happen?
- Does anyone have a different estimate of costs or consequences?

## **What Are the Tensions or Conflicts in This Issue That We Have to Work Through?**

**As a forum progresses, moderators will ask questions that draw out conflicts or tensions that people have to work through. They might ask:**

- What do you see as the tensions between the approaches?
- Where are the conflicts that grow out of what we've said about this issue?
- Why is this issue so difficult to decide?
- What are the "gray areas"?
- What remains unresolved for this group?

# Ending a Forum/Study Circle

Before ending a forum, take a few minutes to reflect both individually and as a group on what has been accomplished. Questions like the following have been useful:

## **I. Individual Reflections**

- How has your thinking about the issue changed?
- How has your thinking about other people's views changed?
- How has your perspective changed as a result of what you heard in this forum?

## **II. Group Reflections**

- What didn't we work through?
- Can we identify any shared sense of purpose or direction?
- What tradeoffs are we, or are we not, willing to make to move in a shared direction?

## **III. Next-Step Reflections**

- What do we still need to talk about?
- How can we use what we learned about ourselves in this forum?
- Do we want to meet again?

# Questionnaire (Post-Forum)

The questionnaire is a way to face the conflict within ourselves. Often we discover aspects of each choice we hold most valuable. Yet, the things we care deeply about are often in conflict. After the forum, please return the questionnaires and the Moderator Response sheet on page 12.

# Suggested Time Line

## **Stages of a Forum/Study Circle**

### **15% for Opening**

- Welcome**—The convenor or moderator introduces NIF program.
- Ground Rules**—Participants review desired outcomes of forum.
- Starter Video**—The starter video sets the tone for the discussion.
- Personal Stake**—Connect the issue to people's lives and concerns.

### **65% for Deliberation**

- Deliberation**—Participants examine all the choices.

### **20% for Ending the Forum/Study Circle**

- Ending the Forum**—Reflect on what has been accomplished.
- Questionnaire**—Participants complete questionnaire.

# NIF Forums and Study Circles

## Why Are We Here? What Are We Going to Do?

We are here to move toward a public decision or CHOICE on a difficult issue through CHOICE WORK.

## How Do We Do It?

Through a deliberative dialogue in which we:

- Understand the PROS and CONS of each approach, its benefits, drawbacks, and tradeoffs.
- Know the STRATEGIC FACTS and how they affect the way the group thinks about each option.
- Get beyond the initial positions people hold to their deeper motivations—the things people consider to be most valuable in everyday life.
- Weigh carefully the views of others; appreciate the impact various options would have on what others consider valuable.
- WORK THROUGH the conflicting emotions that arise when various options pull and tug on what people consider valuable.

## How Can We Know Whether We Are Making Progress?

By constantly testing your group:

- Can your group make the best case for the approach least favored?
- Can your group identify the negative effects of the approach most favored?

## For More Information

To order the *Life and Death Decisions* issue book and starter tape, call 1-800-600-4060, fax (937) 435-7367, or mail to National Issues Forums Institute Publications, P.O. Box 41626, Dayton, OH 45441. Other issue books and tapes may also be ordered from this source.

Moderator guides and forum posters are also available.

For other information and comments, visit the NIFI Web site at [www.nifi.org](http://www.nifi.org) or call NIFI at 1-800-433-7834.

To post the dates and locations of your forums, e-mail: [forums@nifi.org](mailto:forums@nifi.org).

### Moderator Response

After the forum, please complete this brief response sheet and return it with the questionnaires from the forum.

Moderator's Name \_\_\_\_\_

Phone \_\_\_\_\_ Date and location of forum \_\_\_\_\_

Briefly describe the audience of your forum, including city and state, diversity, age of participants, and number of participants.

---

---

---

What elements of this issue seemed most difficult to the participants?

---

---

---

What common concerns were most apparent?

---

---

---

Were there tradeoffs most participants would accept? Describe.

---

---

---

Were there tradeoffs most participants would not accept? Describe.

---

---

---

Did the group identify shared directions for action?

---

---

---

Return with questionnaires to:  
National Issues Forums Institute  
100 Commons Road, Dayton, Ohio 45459-2777  
[www.nifi.org](http://www.nifi.org)