

MAKING DECISIONS ABOUT YOUR MEDICAL CARE

Your Way

**A Guide to Help You
Stay in Charge**

Published by

H.E.L.P.

**Healthcare & Elder Law
Programs Corporation**

A non-profit information resource for older adults



YOU HAVE THE RIGHT to be in charge of your medical care. You can accept or decline care, based on your feelings and views about life and what's important to you.

If you become ill and can't tell others what you want, you'll need other people to exercise your rights and make decisions for you. Even so, you can stay in charge of your medical care by

- ▲ acting ahead of time, and
- ▲ selecting the people who will make decisions for you (and naming them in a Power of Attorney for Health Care or similar document), and
- ▲ using this Guide to sort out your feelings and views, and communicate them to your decision-makers.

This Guide is not a Power of Attorney for Health Care

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Selecting Your Decision- Makers

YOU NAME one or more decision-makers when you complete and sign a Power of Attorney for Health Care or similar document. Your decision-maker's job is to make decisions about your medical care, on your behalf.

Select carefully. The best decision-maker for you is a person you can communicate with and who

- ▲ will be available when needed,
- ▲ will be able to ask questions and get good answers from medical professionals,
- ▲ will make the medical care decisions that you would make (whether or not they agree with you), and
- ▲ will be able to “stand up” for you, be your advocate, and deal with others who might disagree with what you want.

Select your decision-makers. **Then make sure you communicate!**

Instructions for Your Decision- Makers

BY USING THIS GUIDE, you instruct each of your decision-makers that

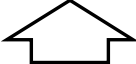

- ▲ You know that they may be called on to make decisions on your behalf.
- ▲ You know that their responsibility is to follow your wishes and to make the decisions that you would make.
- ▲ You have provided your responses in this Guide to help them understand your wishes, what's important to you, and how you feel about life, living, medical care, even death.
- ▲ You have provided your responses in this Guide to help them know better how to decide for you.
- ▲ The fact that you may have left part of this Guide blank should not be interpreted as having any particular meaning.



Getting Started

This Guide provides Topics A through H. You may respond to whichever Topics or portions of Topics that you wish. It's your choice. In each Topic, the "right" answers are the ones that express YOUR views.

Find your **Current Situation** in the chart, check its , and follow its **Suggested Path** through this Guide. Please use ink, and write legibly.

Current Situation	Check One	Suggested Path
<p>My health is excellent now.</p> <p>I have lots of energy.</p> <p>I don't expect to make medical care decisions very soon, but I want to plan and communicate for the future.</p>	<p><input type="checkbox"/></p>	<ol style="list-style-type: none"> 1. Work through Topics A, B and C (pages 6, 7, and 8). 2. If you find the approach in a Topic comfortable, follow the suggestions at the end of that Topic. 3. Review the remainder of the Topics, and work on as many as you want.
<p style="text-align: center;"></p> <p>I'm somewhere in between.</p> <p style="text-align: center;"></p>	<p><input type="checkbox"/></p>	<ol style="list-style-type: none"> 1. Work through Topics A, B and C (pages 6, 7, and 8). 2. If you find the approach in a Topic comfortable, follow the suggestions at the end of that Topic. 3. Do as much as you are able.
<p>My health is poor now.</p> <p>I don't have much energy.</p> <p>Medical care decisions must be made soon. I need to communicate now.</p>	<p><input type="checkbox"/></p>	<ol style="list-style-type: none"> 1. Work through Topics A and H (pages 6 and 15). 2. If your energy permits, work through Topic B (page 7), and then Topic C (page 8). 3. Take on other Topics when you feel you are able.

Yes, You Can Change Your Responses Later

THINGS CHANGE. Later, if you want to change your responses in this Guide, go ahead and do so. Mark the changes and add your initials and the date. If you want to make major changes, you might want to do a new Guide. Be sure to communicate your changes to your decision-makers!

When You've Finished

SIGN AND DATE below:

Print Your Name:

Sign Your Name:

Print the Date:

Communicating

USE THIS GUIDE to help communicate. Discuss this Guide and your responses with your decision-makers. Make sure they understand how you feel.

Keep this Guide with your important papers. Make sure your decision-makers know where to find it.



TOPIC A:

Permanent Unconsciousness

Situation

- You have become unconscious (no awareness, no pain, no suffering); and
- Medical testing indicates that your unconsciousness is permanent; and
- Your life expectancy is uncertain.

Instructions

- ▲ Read each **Statement** about medical care.
- ▲ If you agree with a statement, check “I Agree” in the **Yes** column for that statement.
- ▲ Use the **My Comments** column to provide your thoughts about any of the statements.

Find the approach of Topic A comfortable? Topics D and E (pages 9 and 10) also use this approach.

Statement	Yes	My Comments
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I want to prolong my life, and to receive all medical care available to prolong my life.

I Agree

I do not want to receive medical care that only prolongs my life, *except that I do want to receive artificial nutrition and hydration.*

I Agree

I do not want to receive medical care (including artificial nutrition or hydration) that only prolongs my life.

I Agree

TOPIC B:

Quality of Life, Views of Others, and More

My most important goals for the future are:

I fear or worry about:

The following activities make life worth living for me:

Life would no longer be worth living, if the following activities were no longer available to me:

In making decisions for me, I want my decision-makers to obtain the views of these people:

In making decisions for me, I want my decision-makers to ignore the views of these people:

My religious tradition and/or spiritual views tell me the following about illness, medical care, death or dying:

I feel that pain is:

Find the approach of Topic B comfortable? Topic F (page 11) also uses this approach.



TOPIC C:

What's Important, What Isn't

For each **Subject** where you have a view, circle the number that best expresses that subject's **Importance** to you. Describe other matters that are highly important to you under **Additional Highly Important Matters**.

Subject	Importance low → high	Subject	Importance low → high
Being in Charge of		Religious Beliefs	
• My money	1 2 3	• Following my beliefs	1 2 3
• My meal selections	1 2 3	• Attending services	1 2 3
• How I spend my time	1 2 3	• Meeting with my priest, minister, advisor	1 2 3
• When I do things	1 2 3		
• Where I live	1 2 3	Personal Needs	
• Who I spend time with	1 2 3	• Preparing meals	1 2 3
Enjoyment		• Feeding myself	1 2 3
• Traveling	1 2 3	• Controlling my bladder/bowels	1 2 3
• Listening to music	1 2 3	• Dressing myself	1 2 3
• Reading	1 2 3	• Bathing myself	1 2 3
• Thinking	1 2 3	• Moving about without help	1 2 3
• Being creative	1 2 3	Family and Friends	
• Sexual experiences	1 2 3	• Communicating with them	1 2 3
• Watching television	1 2 3	• Recognizing them	1 2 3
• Theater, Movies	1 2 3	• Not being a burden to them	1 2 3
• Dancing	1 2 3	• Being with them when I die	1 2 3
• Sports	1 2 3	• Not leaving painful memories	1 2 3
• Singing	1 2 3	• Leaving money to them	1 2 3
• Playing a musical instrument	1 2 3		
• Playing games	1 2 3		
• Having pets	1 2 3		

Additional Highly Important Matters

Find the approach of Topic C comfortable? Topic H (page 15) also uses this approach.

TOPIC D:

Inability to Recognize and Communicate With People

Situation

- Because of a disease or accident, you have become permanently unable to recognize and communicate with people; and
- You are conscious (aware of surroundings, able to feel pain and suffering); and
- Your life expectancy is uncertain.

Instructions

- ▲ Read each **Statement** about medical care.
- ▲ If you agree with a statement, check “I Agree” in the **Yes** column for that statement.
- ▲ Use the **My Comments** column to provide your thoughts about any of the statements.

Statement	Yes	My Comments
<p>I want to prolong my life, and to receive all medical care available to prolong my life.</p>	<p><input type="checkbox"/> I Agree</p>	<div style="background-color: #cccccc; height: 360px;"></div>
<p>I do not want to receive medical care that only prolongs my life, <i>except that</i> I do want to receive artificial nutrition and hydration.</p>	<p><input type="checkbox"/> I Agree</p>	
<p>I do not want to receive medical care (including artificial nutrition or hydration) that only prolongs my life.</p>	<p><input type="checkbox"/> I Agree</p>	
<p>Added Facts: While in this situation, you contract an additional illness (pneumonia, urinary tract infection, etc.) that could be cured or reversed. The additional illness could cause your death if left untreated. Assume care will be given to keep you as comfortable as possible.</p>		
<p>I want to receive all medical care that could possibly cure the additional illness.</p>	<p><input type="checkbox"/> I Agree</p>	<div style="background-color: #cccccc; height: 252px;"></div>
<p>I do not want to receive medical care for the purpose of curing the additional illness.</p>	<p><input type="checkbox"/> I Agree</p>	



TOPIC E:

**Terminal
Illness**

Situation

- You have a disease or condition that cannot be cured or reversed. You will die within six months unless you receive life-prolonging treatment. Life-prolonging treatment would only serve to prolong your life; and
- You are able to recognize and communicate with people; and
- You are conscious (aware of surroundings, able to feel pain and suffering).

Instructions

- ▲ Read each **Statement** about medical care.
- ▲ If you agree with a statement, check “I Agree” in the **Yes** column for that statement.
- ▲ Use the **My Comments** column to provide your thoughts about any of the statements.

Statement	Yes	My Comments
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I want to prolong my life, and to receive all medical care available to prolong my life.

I Agree

I do not want to receive medical care that only prolongs my life, *except that I do want to receive artificial nutrition and hydration.*

I Agree

I do not want to receive medical care (including artificial nutrition or hydration) that only prolongs my life.

I Agree

Added Facts: While in this situation, you contract an additional illness (pneumonia, urinary tract infection, etc.) that could be cured or reversed. The additional illness could cause your death if left untreated. Assume care will be given to keep you as comfortable as possible.

I want to receive all medical care that could possibly cure the additional illness.

I Agree

I do not want to receive medical care for the purpose of curing the additional illness.

I Agree

TOPIC F:

Additional Feelings and Views

Your Most Serious Illness

My most serious illness was:

I felt that the medical care I received was:

I felt that the persons who provided my care were:

Your Current Health

I feel that my current health is:

Your Current Medical Care

I am now receiving medical care for:

I feel that the medical care I receive is:

I feel that the persons who provide my care are:

Your Feelings about Medications, in General:

I feel that medications are:



TOPIC F continues:

Additional Feelings and Views

Living Arrangements

My current living arrangements are:

I like the following things about my current living arrangements:

I dislike the following things about my current living arrangements:

I feel that my future living arrangements should:

Receiving Blood Transfusions or Organ Transplants

I feel that receiving blood transfusions would be:

I feel that receiving organ transplants would be:

Money for “End of Life” Medical Care or Heirs

If I had to choose between spending my money on (i) my “end of life” care, vs. (ii) passing it on to my heirs, I would:

TOPIC F continues:

Additional Feelings and Views

Hospice Care

Hospice care is a care approach available to a person who is terminally ill (death expected within six months). The hospice care focus is not on curing the illness, shortening or prolonging life, but on comfort and quality of life. Care focuses on symptom and pain management, keeping the person comfortable, and supporting family and caregivers.

If I were terminally ill, I feel that hospice care would be:

The Meaning of “Death”

To me, “death” means:

Physician-assisted Suicide

“Physician-assisted suicide” includes acts by a physician (such as prescribing medication for a patient to self-administer) that allow a patient to accelerate or select the time of the patient’s death. Today, physician-assisted suicide is not legal in California.

I feel that physician-assisted suicide:



TOPIC G:

Life, Death and Pain Management

Instructions

- ▲ Read each **Statement** about medical care.
- ▲ If you agree with a statement, check “I Agree” in the **Yes** column for that statement.
- ▲ Use the **My Comments** column to provide your thoughts about any of the statements.

Statement	Yes	My Comments
The length of my life is important, but the quality of my life is also important.	<input type="checkbox"/> I Agree	
I want to live as long as possible, without regard for the quality of my life.	<input type="checkbox"/> I Agree	
I fear death.	<input type="checkbox"/> I Agree	
I want to be kept as comfortable and as free of pain as possible.	<input type="checkbox"/> I Agree	
I want treatment to alleviate pain at all times, even if it hastens my death.	<input type="checkbox"/> I Agree	
If they will relieve my pain, use other approaches (examples: acupuncture or hypnosis) instead of pain medication.	<input type="checkbox"/> I Agree	

TOPIC H:

Your Life, at the End

If you could plan the circumstances at the end of your life (when you are close to death), what would you choose?

Persons Present

Location and Surroundings

Continue focusing on the circumstances you would want at the end of your life. For each **Subject** where you have a view, circle the number that best expresses that subject's **Importance** to you.

Subject	Importance low → high	Subject	Importance low → high
Comfort		People	
• Keep my mouth and lips from becoming dry	1 2 3	• Have someone with me whenever possible	1 2 3
• Keep me fresh and clean	1 2 3	• Hold my hand	1 2 3
• Give me massages	1 2 3	• Touch me	1 2 3
• Keep the room smelling fresh	1 2 3	• Be cheerful	1 2 3
• Play my favorite music	1 2 3	• Say goodbye to me	1 2 3
• Talk to me	1 2 3	• Keep pictures of my loved ones near me	1 2 3
• Tell me stories	1 2 3	• Talk to me on the telephone	1 2 3
• Tell me jokes	1 2 3	• Forgive me for my misdeeds	1 2 3
• Keep my hair neat, teeth clean, face shaved	1 2 3	• Be alone	1 2 3
• Read poems to me	1 2 3		
• Play books on tape for me	1 2 3	Religious/Spiritual	
• Have my pet(s) with me	1 2 3	• Read to me from the Bible, Torah or Koran	1 2 3
		• Read to me from inspirational works	1 2 3
“End-of-Life” Care		• Pray out loud for me	1 2 3
• Receiving all medical care	1 2 3	• Have my priest, minister or rabbi visit with me	1 2 3
• Living as long as possible	1 2 3	• Give me the “last rites”	1 2 3
• Living without pain	1 2 3	• Ask people to pray for me	1 2 3
• Being clear-headed	1 2 3		
• Dying without lingering	1 2 3		
• Dying at home	1 2 3		



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Copies of this Guide may be obtained from H.E.L.P. Call (310) 533-1996 or go to www.help4srs.org for more information.

Preparation and distribution of this edition was made possible by a generous grant from The Ahmanson Foundation.

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REMINDER: Things Change. Keep Your Documents Up to Date!

As time passes, things change. You could move. A decision-maker you've selected could move or become unavailable. Your relationships could change. Your feelings and views could change. Changes can cause your Power of Attorney for Health Care or similar document or your Guide responses to become out of date. Here are some thoughts about keeping up to date.

REVIEW YOUR DOCUMENTS AND GUIDE . . .

- ▲ At least annually (suggestion: do your review at "income tax time").
- ▲ Any time there has been a significant change in your life, relationships or location.

CHECK FOR THE FOLLOWING:

- ▲ Is your decision-maker available, and able to be your advocate?
- ▲ Has your relationship with your decision-maker changed?
- ▲ If you stated feelings or views, are they still your feelings or views?

AS CHANGES ARE NEEDED:

- ▲ Prepare and sign a new Power of Attorney for Health Care or similar document.
- ▲ Change the responses in your Guide (with dates and your initials), or prepare a new Guide.
- ▲ Communicate your changes to your decision-makers.