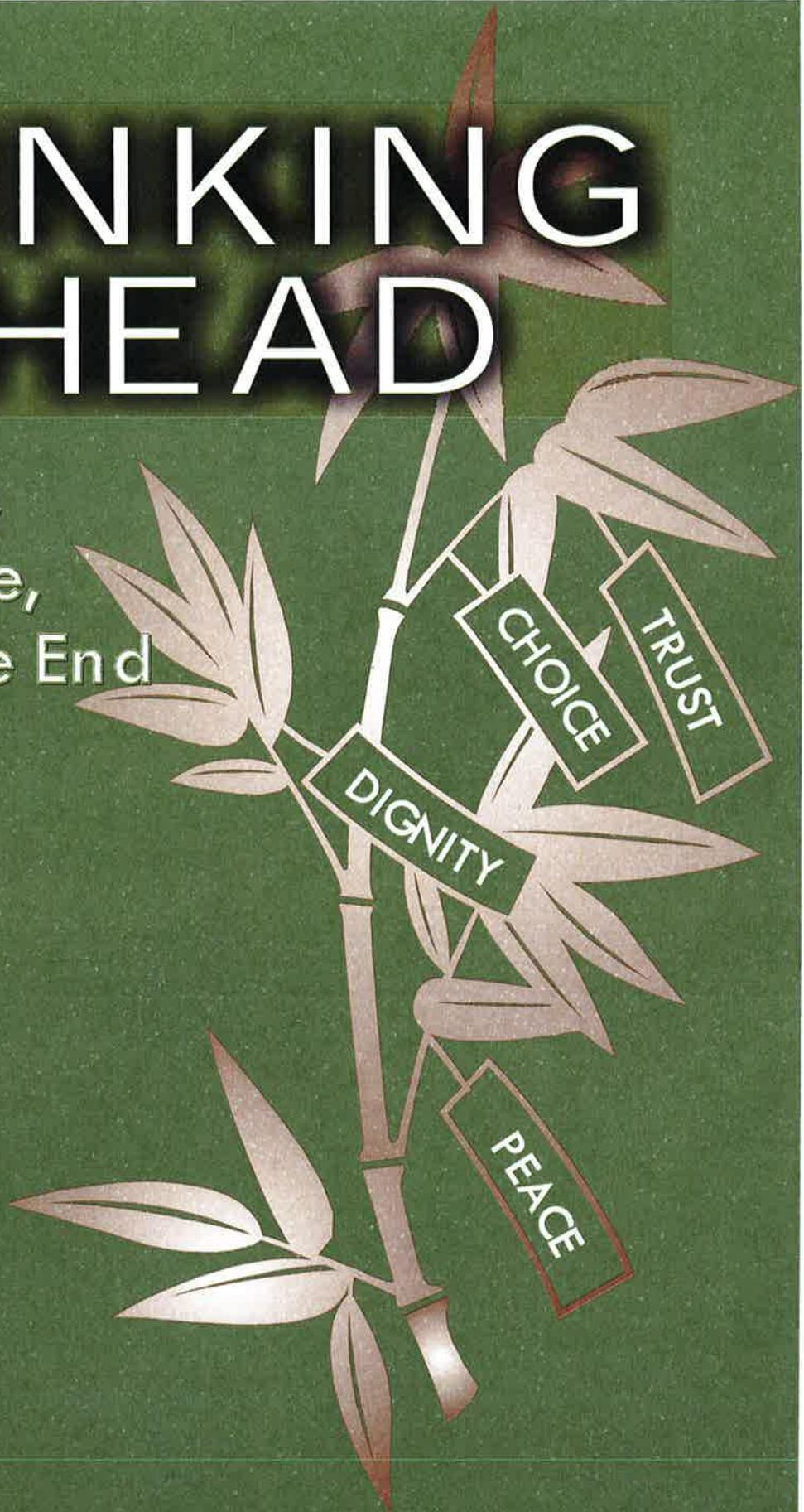


THINKING AHEAD

My Way,
My Choice,
My Life at the End



"There is life, and there is death. You don't know what's going to happen today or tomorrow so you have to be prepared."

Connie Martinez, 2008

Introduction



Today more than ever, you are making important decisions. Living your life your way also means making choices about the end of your life. You probably know someone, a family member, support person or friend, who has died. Talking about death and dying is hard, but being prepared for that time makes sure your choices are respected. Making your own decisions shows you are in control, now and up through the very end.

This **Thinking Ahead** workbook provides a way to advocate for what you want in life support treatment and other end-of-life choices. Complete these pages and you will be prepared. You will have a plan to share with important people in your life.

1

Review the whole workbook before making your decisions or writing down your choices.

2

**Take your time to complete the workbook.
Take 2 or more sessions.
Use support from a Trusted Helper.**

3

**Complete the Personal Requests and Advance Directive forms on the back pages.
Give copies to important people.**

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Making Your Decisions

Making important decisions means taking time to think carefully, deciding on your choices, then taking action with support.



THINK What is important to you.



PLAN Choose what you want.



DO Complete the forms and let people know.

Connie and Betty Think Ahead



Connie Martinez

Connie knows that being an advocate means making choices all through life. When a friend of hers died, she wanted to pay her respects but could not. His body was gone and no one knew what happened.

Connie's friend had been a strong advocate but he had not made his own plans. After he died, other people took over his belongings and his burial. Connie decided this was not going to happen to her. She thought about what was important and made her plan. She took action to make sure she was in control of her life – now and at the very end.



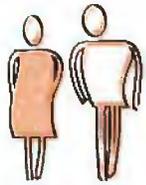
Betty Pomeroy

Betty knows how important it is to make your own choices and have your own plans.

Her brother was in the hospital and very sick. He never told anyone about what he wanted for medical treatment at the end of his life. Because she was the closest person to her brother, the doctor called Betty about making medical treatment choices for him. She alone had to make the decision to let him go.

Because of this, Betty wanted to be prepared herself and make her own decisions ahead of time. She took steps to be in control - now and at the very end.

■ Choosing the Right Person to Help



Everyone needs help when thinking ahead and carrying out plans at the end of his or her life. Choosing a **Trusted Helper** to help you complete this workbook is the first step. This person should be comfortable talking with you about end-of-life choices. Think about who can help you.



THINK - Who Can Help Me

Someone who:

- Knows me well and cares about what is important to me.
- Helps **without** telling me what they think I should do.
- Listens to me and is respectful.
- Will advocate for me.
- Will help me complete this workbook.



PLAN - My Trusted Helper



I want _____ to help me.
Name

As a **Trusted Helper**, I agree to listen, explain and write down what is important without taking over or saying what to do.

Signature _____
Trusted Helper

California Coalition for Compassionate Care provides suggestions for Trusted Helpers to assist a person with completing this workbook and forms. Go to: www.finalchoices.org.

■ ■ Making Personal Requests



Everyone has the right to die with dignity, respect and feeling at peace. When people close to you know what comforts you, they can give the caring support you need. At the end of life, there are important decisions to make about your final wishes. This is the time to think about what you want during your final days.



THINK - My Final Days and After Death

With your Trusted Helper, share your thoughts about how you want your final days of life to be. Ideas to think about:



Where you want to be.
How you want to be cared for.

This is also the time to think about what you want to have happen after your death. Ideas to think about:



Where you want your personal belongings to go.
Your funeral, burial.
How you want to be remembered.



PLAN - Make Personal Arrangements

Connie and Betty knew that end-of-life planning included choices about their final days, where their belongings would go, and how they wanted to be remembered. They made decisions about their final wishes and put together their personal plans.

■ ■ Making Personal Requests

Make a plan about your final days and how you want to be remembered by completing pages 5-7.

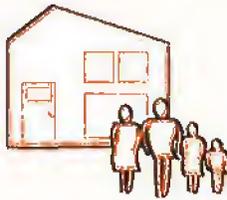
(1) Where I want to be

Near the end of their lives people have choices about the place where they want to spend their final days. Here are some ideas to think about.

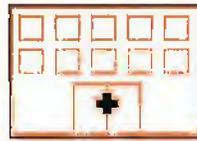
Mark your choice.



My Home



With My Family



Hospital

Other Place

(2) How I want to be cared for

Near the end of their lives, people sometimes make special requests. It is important to let others know what you want.

Mark your choices or write in other ideas.



- ? Have my family and friends near.
- ? Have personal care that helps me feel comfortable.
- ? Have my favorite things around me.
- ? Have my favorite music playing.
- ? Have my religion respected.
- ? Other ways I want to be cared for:

■ ■ Making Personal Requests

(3) Where I want my things to go

Everyone has important things that belong to them. Sometimes people donate personal items to organizations or give them to friends and family members.

Think about where you want your things to go and write it down.

Money _____



Clothing _____

Furniture _____



Equipment _____

Pet _____



Other _____

(4) Gifts I want to give



Sometimes people give special gifts to friends and family members who have been important to them.

Write what you want to give and to whom.

Item: _____ To: _____

Item: _____ To: _____

■ ■ Making Personal Requests

(5) My body

Sometimes people have religious or family ideas that help them decide what happens to their bodies after death.

Think about what you want and write it down.

 ? I want to be buried. Where: _____

 ? I want to be cremated. Where I want my ashes to go:

(6) Being remembered

Having a time to remember is a way people pay their respects and celebrate the life of someone who has died.

Think about what you want and write it down.

I want a funeral service. ? Yes ? No

? At my place of worship _____

? At a funeral home _____

? Other place _____

? I want people to remember me by doing this: _____



DO - Next Steps

1. Put your choices on the tear-out **Personal Requests Form**.
2. Take your completed **Form** and make copies for important people.
3. Save your workbook and the original **Form** you completed

■ ■ ■ Making Medical Treatment Choices

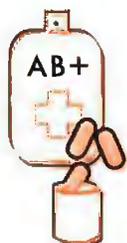


You have the right to make decisions about your health care during your life. There are also medical treatment choices to make at the end. When you are very sick, you need help to make sure doctors know what you want.

This section helps you decide what medical treatment you want or don't want in your final days. It will help you think about your **Quality of Life** and make choices about **Life Support Treatment**.



THINK - My Quality of Life and Life Support



Quality of Life is different for each person. When death is near, there are decisions to make about what life will be like during those final days. It is important that people decide how they want to feel at the end and what Life Support Treatment is right for them.

Thinking about what makes your life worth living will guide you in making your end-of-life choices.



Life Support Treatment is used to help keep people alive when they are very sick and close to death. Treatments can be medicines, breathing machines, tube feeding and drinking, CPR, dialysis and surgeries.

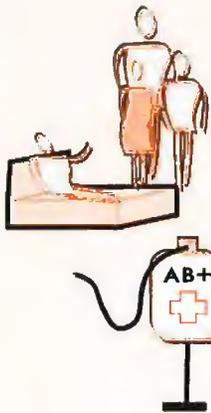
No matter what end-of-life treatment a person wants or doesn't want, doctors must make everyone as comfortable as possible through the very end.

■ ■ ■ Making Medical Treatment Choices

With your Trusted Person, share your thoughts and feelings about what would make up your quality of life at the end.

A person's life quality is different for everyone. Think about what is important to you.

Mark your choices or write in other ideas.



- ? Being awake and thinking for myself.
- ? Communicating with family or friends.
- ? Being free from constant and severe pain.
- ? Not being connected to a machine all the time.

More thoughts I have about my quality of life at the end:



PLAN - Make Life Support Treatment Decision.

Connie and Betty knew that end-of-life planning included thinking about quality of life in their final days. They made decisions about life support treatment and put together their personal plans.

■ ■ ■ Making Medical Treatment Choices



Make your plan about life support treatment choices.

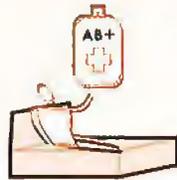
If my doctors say I am likely to die in a short time and life support treatment would only postpone my death:

Mark your choice:



? I want life support treatment as long as possible.

? I do not want any life support treatment.



? I want life support treatment **only** if my doctor thinks it could help.

? I want someone I know and trust to decide for me.



DO - Next Steps



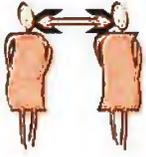
1. Put your medical treatment choices on the tear-out **Advance Directive Form** at the back of the workbook.

2. Take your completed **Form** and make copies for your Doctor and other important people.



3. Save your workbook and the original **Form** you completed.

Choosing an End-of-Life Advocate



It is important to choose a person who can be your **End-of-Life Advocate**, also called a **Health Care Agent**. Decisions in your **Advance Directive** are carried out by your End-of-Life Advocate.



THINK - Who Will Speak For Me?



End-of-Life Advocate (Health Care Agent)

- Is nearby to help me when I need him or her.
- Will speak to doctors, nurses and social workers for me.
- Follows my Advance Directive.
- Is my legal spokesperson when I cannot speak for myself.



End-of-Life Advocate cannot be:

- Your doctor.
- Staff of a clinic/hospital where you get health care.
- Your group home or nursing home operator.
- Staff of a group home or nursing home where you live.

Advance Directive is a document that:



- Has your choices about life support treatment.
- Says who will speak with your doctor when you cannot.
- Guides your doctor about what you want.

Choosing an End-of-Life Advocate



PLAN - My End-of-Life Advocate

Connie and Betty knew that end-of-life planning included deciding who would speak up for them to their doctors. They made decisions about who would be their End-of-Life Advocates and put together their personal plans.

Good to remember!

Some people have **conservators**. If you have a conservator, check to see if they may already be your End-of-Life Advocate.

Meet with him or her to complete the workbook.

My Decision:

I want _____ to be my
Name

End-of-Life Advocate and he or she agrees.



DO - Next Steps

1. Complete the **Advance Directive Form**.
2. Sign the **Advance Directive** with two witnesses.
3. Complete the **Personal Requests Form**.
4. Make sure your End-of-Life Advocate has a copy of both forms.



Staying in Control



When you finish your **Thinking Ahead** workbook and complete the forms at the end, you have exercised your right to live your life, your way – now and at the very end. You will be prepared.

You will have a plan to share with loved ones, your doctor and other important people in your life.

Here are some tips:



1

Get information in ways YOU can understand.



2

Share your plan with important people.



3

Make changes to your plan, if you need to.



4

Make your own decisions.



Advocates Lead Project

The **Thinking Ahead** workbook and DVD project was led by California advocates with developmental disabilities from three regional centers. They wanted to share their experiences and ideas because they know how important it is to make their own decisions now and through the very end. The advocates came together in three focus groups to guide the project and ensure the workbook and DVD reflected their voices.



Alta California Regional Center
Sacramento, CA
Focus Group Participants



Golden Gate Regional Center
San Francisco, CA
Focus Group Participants



Eastern Los Angeles Regional Center
Alhambra, CA
Focus Group Participants



Resources

www.finalchoices.org

California Coalition for Compassionate Care is a statewide partnership of more than 60 organizations dedicated to the advancement of palliative medicine and end-of-life care. It provides helpful information about end-of-life decision making, legislation and forms. Downloadable copy of the Thinking Ahead Workbook and facilitator guideline are available on this site.

www.caringinfo.org

Caring Connections is a program of the National Hospice and Palliative Care Organization, a national consumer and community organization committed to improving care at the end of life.

www.ih4health.org/index.cfm/MenuItemID/266.htm

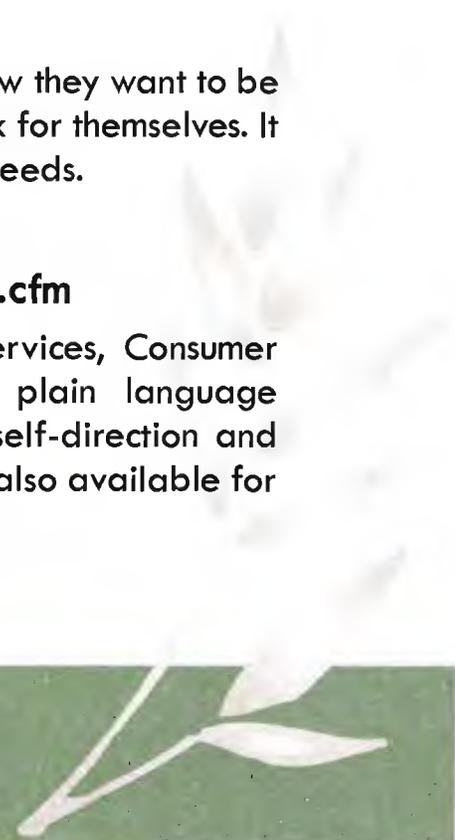
This easy-to-read California Advance Health Care Directive form was created to help people better understand these legal documents.

www.agingwithdignity.org/5wishes.html

The Five Wishes document helps people express how they want to be treated if they are seriously ill and unable to speak for themselves. It includes medical, personal, emotional and spiritual needs.

www.dds.ca.gov/ConsumerCorner/Publications.cfm

The California Department of Developmental Services, Consumer Advisory Committee has developed numerous plain language pictorial publications and DVDs that encourage self-direction and personal choice. The Thinking Ahead Workbook is also available for download.





Acknowledgments



Alta California Regional Center

David Lopez, Consumer Advocate
Terry Wardinsky, MD, Medical Director



Eastern Los Angeles Regional Center

Jesse Padilla, Consumer Advocate
Felipe Hernandez, Chief of Consumer Services



Golden Gate Regional Center

Elizabeth Grigsby, Consumer Rights Advocate
Felice Weber Parisi, MD, Director, Clinical Services
Gabriel Rogin, Strategic Development Coordinator



Connie Martinez - Advocate

Alta California Regional Center



Betty Pomeroy - Advocate

Redwood Coast Regional Center



California Coalition for Compassionate Care

Developmental Disabilities Advisory Group

Judy Citko, JD, Executive Director
1215 K Street, Suite 800, Sacramento, California 95814
Www.finalchoices.org 916.552.7573



Board Resource Center

Making Complex Ideas Simple

Mark Starford, Executive Director,
Charlene Jones, Editor; Donna Aikins, Layout
PO Box 601477 Sacramento, CA 95860
www.brcenter.org 916.574.1023



Personal Requests

These are my personal requests, but it is not a Will.

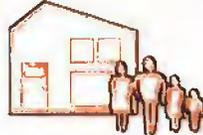
Name: _____

(1) Where I want to be

This is my choice about where I want to spend my final days.



My Home



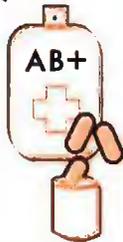
With My Family



Hospital

Other Place

(2) How I want to be cared for



- ? Have my family and friends near.
- ? Have personal care that helps me feel comfortable.
- ? Have my favorite things around me.
- ? Have my favorite music playing.
- ? Have my religion respected.
- ? Other ways I want to be cared for:



(3) Where I want my things to go



Money

Clothing



Furniture

Equipment



Pet

Other



Personal Requests



(4) Gifts I want to give

Item: _____ To: _____

Item: _____ To: _____



(5) My body

? I want to be buried. Where: _____

? I want to be cremated. Where I want my ashes to go:



(6) Being remembered

I want a funeral service ? Yes ? No

? At my place of worship _____

? At a funeral home _____

? Other place _____

? I want people to remember me by doing this: _____



Sign Your Name

Date

Street Address

City

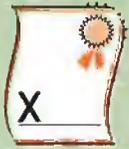
State

Zip Code

Home Phone

Work Phone

Email



Advance Directive

(Name) _____ is my
End-of-Life Advocate (Health Care Agent).

Street Address City State Zip Code

Home Phone Work Phone Email

My End-of-Life Advocate will make decisions for me only if I cannot make my own decisions.



My End-of-Life Choices

During my final days, my quality of life means:

- ? Being awake and thinking for myself.
- ? Communicating with family or friends.
- ? Being free from constant and severe pain.
- ? Not being connected to a machine all the time.
- ? _____

During my final days, my life support treatment decision is:

- ? I want life support treatment as long as possible.
- ? I do not want any life support treatment.
- ? I want life support treatment **only** if my doctor thinks it could help.
- ? I want my End-of-Life Advocate to decide for me.



Advance Directive



Sign Your Name

Date



Print Your Name

Date

Address

City

State

Zip Code

For Witnesses:

As a witness, I promise that (person) _____,
signed this form while I watched. He/she was **not** forced to sign it.

I also promise that:

- I know this person and he/she can confirm their identity.
- I am 18 years or older.
- I am **not** this person's End-of-Life Advocate (Health Care Agent).
- I am **not** this person's health care provider or work for this person's health care provider.
- I do **not** work where this person lives.



Witness Signature

Date



Witness Signature

Date

One witness must not be related by blood, marriage or adoption and not receive any money or property from this person after he/she dies.