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

Texas Department of Aging and Disability Services
About the Thinking Ahead workbook...

The idea for the Thinking Ahead workbook originally came from California advocates with developmental disabilities who wanted to share their experiences and ideas about how important it is to make end-of-life decisions. During development of the workbook in 2006–07, a focus group of people from three California regional centers guided the project.

The original development and distribution of this workbook in California was made possible by a Wellness Grant through the California Department of Developmental Services (CDDS). CDDS has generously given Texas Department of Aging and Disability Services (DADS) permission to modify and issue this edition of the workbook for use in Texas. DADS Center for Policy and Innovation led the project and DADS Media Services designed the workbook. Many others made valuable contributions to the Texas Edition as it was developed.

The following people and organizations were collaborators in the creation of this workbook in California:

- Alta California Regional Center
- Eastern Los Angeles Regional Center
- Golden Gate Regional Center
- Redwood Coast Regional Center
- California Coalition for Compassionate Care
- Developmental Disabilities Advisory Group
- Board Resource Center ™
- Making Complex Ideas Simple

California Coalition for Compassionate Care provides suggestions for Trusted Person to assist a person with completing this workbook and forms. These are available online at www.finalchoices.org
What’s inside this workbook:

- **Introduction** - How to use this workbook  Page  1
- **Why these choices are important**  Page  2
- **Choosing the Right Person to Help**  Page  3
- **Making Personal Requests**  Pages  4 - 8
- **Making Medical Treatment Choices**  Pages  9 - 11
- **Choosing a Health Care Agent**  Pages  12 - 13
- **Staying in Control**  Page  14
- **Helpful Resources**  Page  15

What’s inside the Advance Care Planning Forms insert:

- Personal Requests Form
- Two Legal Forms to record decisions

1. Directive to Physicians and Family or Surrogates
2. Medical Power of Attorney
Introduction - How to use this workbook

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 Person(s).

3. Complete the Personal Requests Form and both legal forms in the Advance Care Planning Forms insert. Give copies to important people.
Why these decisions are important

We all have to make choices all through our lives.

We want to be prepared to make our own decisions ahead of time. It is important to think about what you want to happen if you become very sick or die.

Choose a trusted friend to help with the decisions, and make a plan.

Thinking about what you want and taking steps to make your decisions known helps make sure you are in control of your life -- now and at the very end.

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.
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 Person 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 Person

I want ________________________________ to help me.

Name

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

Signature ________________________________

Trusted Person
Making Personal Requests

Worksheet

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 Person, 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

Your end-of-life planning includes choices about your final days, where your belongings will go, and how you want to be remembered.
Making Personal Requests

Worksheet

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 or write in other places below.

☐ 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 choice or write in other places below.

☐ Spend time with family and friends.
☐ 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
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.

<table>
<thead>
<tr>
<th>Item</th>
<th>To:</th>
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</thead>
<tbody>
<tr>
<td>Money</td>
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</tr>
<tr>
<td>Clothing</td>
<td></td>
</tr>
<tr>
<td>Furniture</td>
<td></td>
</tr>
<tr>
<td>Equipment</td>
<td></td>
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<tr>
<td>Pets</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

4) Gifts I want to give
Sometimes people donate personal items to charities or other organizations or give special gifts to friends and family members who have been important to them.

Write what you want to give and to whom.

<table>
<thead>
<tr>
<th>Item</th>
<th>To:</th>
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</tbody>
</table>
Making Personal Requests

Worksheet

(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:  

☐ I want to donate my organs.  

☐ I want to donate my body to science.

(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 or celebration.  ☐ Yes  ☐ No

☐ At my place of worship  

☐ At a funeral home  

☐ At my burial place  

☐ Other place  

Mark your choice.
Think about how you want people to remember you at a service or celebration, and write it down.

I would like music played.  
Yes ☐  No ☐

List specific songs or performers:  
________________________________________
________________________________________
________________________________________

I would like people to share their thoughts about me with each other.

Yes ☐  No ☐

Do - Next Steps

1. Put your choices on the Personal Requests Form in the Advance Care Planning Forms insert.

2. Take your completed form and make copies for important people.

3. Save your workbook and the original Personal Requests 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 and near death, 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.

**Quality of life** is different for everyone.

Think about what is important and meaningful to you, and write it down.

X Mark your choices or write in other ideas.

- Being awake and thinking for myself.
- Communicating with family or friends.
- Being free from constant and very bad 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 Decisions

End-of-life planning includes thoughts about quality of life in your final days. Make your decisions about life support treatment and put together your personal plans.
If my doctors say I am likely to die in a short time and life support treatment would only postpone my death:

- [ ] I want life support treatment as long as possible.
- [X] Mark your choice.
- [ ] I do not want any life support treatment.
- [ ] I want someone I know and trust to decide for me.

Do - Next Steps

1. Put your medical treatment choices on the Advance Directive Form (#1 in the insert).

2. You must sign the form in front of two witnesses or a Notary Public. When it is completed, make copies for your Doctor and other important people.

3. Save your workbook and the original form you completed.
Choosing a Health Care Agent

It is important to choose a person who can be your Health Care Agent who can act as your Medical Power of Attorney. Decisions in your Advance Directive Form are carried out by your Health Care Agent.

Think – Who Will Speak for Me?

My 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.

Your Health Care Agent 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.
- Any paid support staff

The Advance Directive Form 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 a Health Care Agent

Plan - My Health Care Agent

End-of-life planning includes deciding who will speak up for you to your doctors. Decide who to ask to be your Health Care Agent and put together your personal plans.

Good to remember!

Some people have court appointed guardians. If you have a guardian, check to see if they may already be your Health Care Agent. Meet with him or her to complete the workbook.

My Decision:

I want __________________________ to be my Health Care Agent and he or she agrees.

Do - Next Steps


2. Sign the Medical Power of Attorney form in front of two witnesses or in front of a Notary Public.

3. Make sure your Health Care Agent 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 planning 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.
Resources

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.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.TexasQualityMatters.org

The Texas Department of Aging and Disability Services (DADS) Quality Matters Web (QMWeb) is a resource of evidence-based best practices meant to help providers doing the right thing in the right way at the right time for the right person in order to achieve the best possible outcome.

www.TexasLivingWill.org

This website was developed to educate and assist people in completing the Texas Advance Directive. Information and forms are available in English and Spanish.