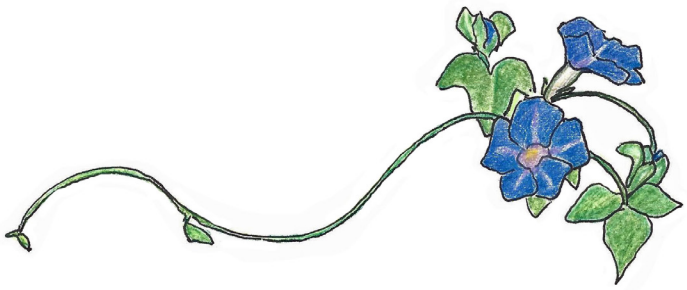
Making a **Plan**
Thinking **Ahead**

MY Way • MY Choice • MY Plan



Making a Plan – Thinking Ahead helps you think about what care you want and do not want if you can't speak for yourself. It empowers you to have your wishes known and honored if you are unable to guide your own care because of serious illness.

The Community Network Journey Project 2018

Part I: Workbook

About This Workbook

Making a Plan – Thinking Ahead was produced by a collaboration between the Behavioral Health Division, County of Sonoma (BHD), the Community Network for Appropriate Technologies, the Coalition for Compassionate Care of CA (CCCC), and Goodwill Redwood Empire.

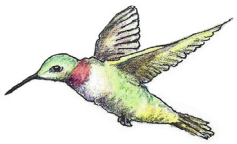
Illustrations by Gloria Potter,
Community Network Journey Project

v. 11/18

Introduction

Living life your way involves making important decisions. It also means making choices about serious illness and the end of your life. You probably know someone, a family member, support person or friend, who is seriously ill or has died. Reflecting on their experience may help you think about what you do and do not want for yourself if you become seriously ill.

Talking about this can be difficult. Being prepared for such a time will help make sure your choices are known and respected. Making your own decisions allows you to be in control now and when you are unable to guide your care, even up through the end of life.



This workbook provides a way to advocate for what you want in terms of crisis care, life support treatment, and end-of-life choices. When you complete this workbook and forms, you will have exercised your right to live your life your way now and through serious illness and at the end of life. 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. Do this at a pace that is comfortable for you.**
2. **Take your time to complete the workbook and the forms in Part II. If possible, get help from a person you trust (Trusted Helper).**

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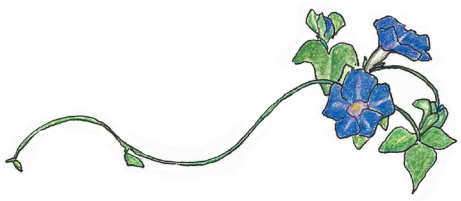
Part I: Workbook

Part II: Forms

Advance care planning forms are available in a separate workbook.



Making Your Decisions

Making important decisions means taking time to think carefully, deciding on your choices, and then taking action with support from people who can help you have your wishes known and honored. You may want to make notes as you do this and take your time. Be sure you review everything carefully before you complete and sign the forms in Part II Forms booklet.

THINK — What is important to you?

PLAN — Choose what you want.

DO — Complete the forms and share with people who know and care about you

A. Choosing the Right Person to Help

Everyone can use support when thinking ahead about serious illness and carrying out plans for the end of life. Choosing a person you trust (**Trusted Helper**) to help you complete this workbook and forms could be very helpful. This person should be comfortable talking with you about your values, serious illness, and end-of-life choices.

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 and the forms.

PLAN —My Trusted Helper

A Trusted Helper should be willing to listen, help explain things and help write down what is important without taking over or saying what to do. This person could be anyone you trust who you would like to help you, and who is willing and able to do this for you. If you have a Trusted Helper, **please write their name here**:

I want _____ to help me and this person is willing to do this for me.

B: Personal Requests About My Care

Everyone has the right to choose what health care they want (or hope for) when very sick, and to die with their wishes respected, feeling at peace. When people close to you know your preferences and what comforts you, they can give the care and support you need.

When facing serious illness or the end of life, there are important decisions to make about your wishes. It is better to think about what you would want before you are very sick or in crisis.

THINK — If Seriously Ill What Would You Want?

With your Trusted Helper, share your thoughts about how you want your care if you were seriously ill. Some ideas to think about and questions to ask yourself and talk over include:

Where would I want to be?
How would I want to be cared for?
What is most important to me?

This workbook and the forms in Part II will help you to think about all of these things and make your wishes known.

PLAN – Make Personal Arrangements

Planning should include choices about the care you want to receive, where your belongings would go, and what you want to happen when you die. Decisions about your wishes can be made using this workbook and the forms in Part II to put together your personal plan. The following pages will help you think about this and make your plan.

(1) Where I want to be

When seriously ill or near the end of your life, you have choices about where you would like to receive needed care. Here are some ideas to think about.

Mark your choice(s)

❑ At home ❑ Hospital ❑ Other place (where?)_____

❑ With people who know and care about me ❑ With my loved ones

❑ I trust those who know me best to make the best choice for me then.

❑ I don't know at this time

Notes

(2) How I want to be cared for

When seriously ill or near the end of life, you may have some special requests. It is important to let others know what is important to you.

Mark your choices or write in other ideas:

- ❑ Have my loved ones near.
- ❑ Have my pet(s) with me.
- ❑ Have personal care that helps me feel comfortable.
- ❑ Be awake and aware as long as pain and suffering aren't too great.
- ❑ Have my favorite things around me, including: _____

  _____

  _____
- ❑ Have my favorite music playing, including: _____

  _____

  _____
- ❑ Have my religious, cultural or spiritual practice respected.
- ❑ Other ways I want to be cared for: _____

  _____

  _____
- ❑ I would not want:
- ❑ Other things important to me: _____

  _____

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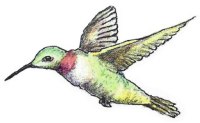
C: Making Medical Treatment Choices



You have the right to make decisions about your health care during your life. If you become very sick, you can help to make sure doctors know what you want by planning ahead. This section helps you decide what medical treatment you want or don't want if you are coping with serious illness or at the end of life. It will help you think about your **Quality of Life** and make care treatment choices.

THINK – My Quality of Life and Care Desired

Quality of Life is different for each person. Some people think of quality of life as those things that make your life worth living. When you are seriously ill, or death is near, there are decisions to make about what life will be like. It is important that people decide how they want to feel and what medical care is right for them.

Thinking about what makes your life worth living will guide you in making your choices about care through serious illness and the end of life. No matter what treatment you want or don't want, doctors and healthcare providers should be able to help make you comfortable even through the end of life.

Life Support Treatment is used to try to keep people alive when they are very sick or close to death. Treatments can be medicines, breathing machines, tube feeding, artificial hydration, CPR, dialysis, surgeries or involuntary hospitalization or treatments.

Palliative Care (pronounced pal-lee-uh-tiv) is specialized medical care for people with serious illness. It focuses on providing patients with relief from the symptoms, pain and stress of a serious illness – whatever the diagnosis.

The goal is to improve the quality of life and relieve suffering for both the patient and the family. Palliative Care providers work with a patient's other health care providers to provide an extra layer of support. It is appropriate at any age and at any stage of serious illness, and can be provided together with curative treatments.

THINK – What is important to you?

With your Trusted Helper, share your thoughts and feelings about what would make your life worth living if you are seriously ill or at the end of life.

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 even if that means I could be too sleepy to think clearly or communicate.
- ❑ Not being connected to machines for many days.

More thoughts I have about my quality of life in serious illness or at the end of life.
(Please clarify) _____

_____

_____

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PLAN – Make Life Support Treatment Decisions

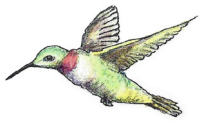
Planning for serious illness and the end-of-life includes thoughts about quality of life. It is important to make decisions about life support treatment and put together your personal plans. **Make your plan about life support treatment choices and mark your choices.**

❑ I **want** life support treatment ***only*** if my doctor thinks it could help me have the quality of life I want.

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 for as long as possible.
- ❑ **I do not** want any life support treatment.
- ❑ **I want** someone I know and trust to decide for me.

DO – Choose a Health Care Agent



D: Choosing a Health Care Advocate

It is important to choose a person who can be your **Health Care Agent**. Decisions in your **Advance Health Care Directive** are carried out by your Health Care Agent. This could be your Trusted Helper **IF** your Trusted Helper is willing and eligible to do this for you.

If you have no one you trust to serve as your Health Care Agent, you can still share your other wishes. It remains very important for you to complete these forms. That way your healthcare providers and others can know and honor your wishes.

THINK – Who Will Speak For Me?

Health Care Agent

- Someone who knows and cares about me.
- Is my legal spokesperson for medical decisions when I cannot speak for myself.
- Is nearby to help me when needed.
- Will speak to doctors, nurses and social workers for me.
- Follows my Advance Directive.

Health Care Agent <u>cannot</u> be:

- Your doctor or health care providers.
- Staff of a clinic/hospital where you get health care.
- Your group home, residential care or nursing home operator or staff where you live.
- Your LPS Conservator if you are LPS (mental health) conserved.

An Advance Directive is a document that:

- Has your choices about care desired when seriously ill or at life's end.
- Says who you want to speak with your doctor and other service providers when you cannot.
- Guides your doctors about the care you want or don't want.
- Is legally binding and gives your Health Care Agent legal standing.

PLAN – My Health Care Agent

Planning for serious illness and the ending of life includes deciding who will speak up for you to your doctors and other service providers. It is important to decide who could be your Health Care Agent, put together your personal plans and complete an Advance Health Care Directive to help guide your care if you are unable to do that yourself.

You could have your Trusted Helper be your Health Care Agent if that person is willing **<u>and</u>** eligible, and you would like that person to do that for you.

Even if you don't name a Health Care Agent, it is important to complete the other sections of the Advance Directive so that health care providers know what is important to you.

DO – Name Your Health Care Agent

I want _____ to be my **Health Care Agent** and this person agrees.

Phone #/Relationship _____

If this person is <u>not</u> available, then alternate(s) who have agreed to serve as my Health Care Agent include:

_____

Alternate 1: Name Phone/Relationship

_____

Alternate 2: Name Phone/Relationship

(Even if you don't name a Health Care Agent, it is important to complete the other sections of an Advance Directive so that health care providers know what is important to you.)

DO - Next Steps

1. <u>Complete</u> the **Advance Directive** in Part II Form A.
2. <u>Complete</u> the **Personal Requests Form** in Part II Part II B.
3. <u>Sign</u> the **Advance Directive** with two witnesses or a notary.
4. Make sure your Health Care Agent and other important people in your life have a copy of both forms.
   - ❑ Check here if you need help making copies or distributing your Advance Directive to your health care providers or others.

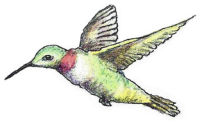
<u>If you have a Conservator – Important to read!</u>

California law provides that any adult is presumed to have capacity to make an Advance Directive. Lanterman-Petris-Short (LPS) conserved persons are not considered incompetent by reason of conservatorship. If you are on a LPS conservatorship you retain the right to make treatment decisions and to complete an Advance Directive unless there is a determination that you lacked capacity at the time you made treatment decisions and completed your Advance Directive.

A conservator may not be designated as your health care agent unless the Advance Directive is otherwise valid, you as the conserved person are represented by legal counsel and the lawyer signs a certificate of advisement. **Reference**: Disability Rights CA (DRC) AHCD for Mental Health-A Trainer's Manual, "Problem Solving" Item h including footnotes, page 29. DRC is California's Protection and Advocacy System. For free DRC legal assistance call 1-800-776-5746. www.disabilityrightsca.org

Your Trusted Helper or Health Care Agent could help you with this. After you complete your Personal Requests form and your Advance Directive, share your completed forms and talk about them with your conservator and others who you want to know your wishes including health care providers.

Notes



Staying in Control

When you finish your workbook and complete the forms in Part II, you have exercised your right to live your life, your way – now, with serious illness, and at the end of life. You will be prepared. You will have a plan to share with loved ones, your doctor and other important people in your life.

- ❑ Check here if you need help doing this.

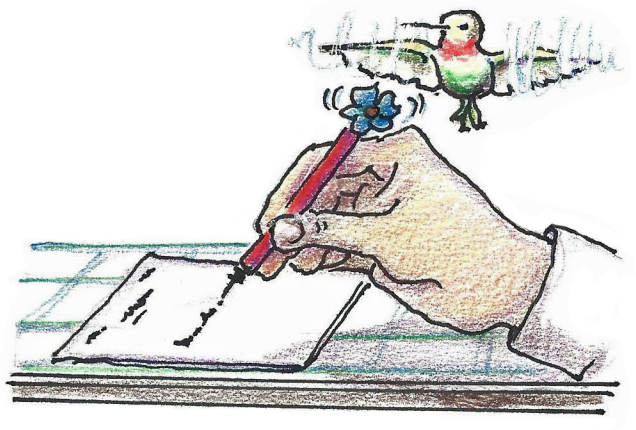
Here are some other tips when thinking ahead:

1. Speak up for yourself and ask if you don't understand.
2. Get information about your illness, treatments and choices you may be asked to make in ways YOU can understand.
3. Share your plan and Advance Health Care Directive with people close to you and other important people including your health care providers. Ask your primary care team and hospital to add a copy to your medical record.
4. Make your own decisions when you are able to do so.
5. As things change over time, make a new Personal Plan and Advance Health Care Directive if need be.

In Part II you will also be asked to think about what you would like to have happen when you die, so it is good to be thinking about that too. You may also want to make notes for when you share your completed forms with people who know and care about you including your doctors and other health professionals.

Please use the following **Notes** page to write out any other things you might want to remember when you complete the forms that are contained in **Part II - Forms**.

Notes



Useful Resources

CaringCommunity.org

Journey Project website for people thinking about, planning for, or living with serious illness and end-of-life issues. **Making a Plan – Thinking Ahead Workbook** and **Forms** may be accessed here along with other resources helpful for people living with mental health challenges.

CoalitionCCC.org

Coalition for Compassionate Care of California provides helpful Information about advance care planning, palliative care, end-of-life decision making, legislation and forms. Educational materials include simple decision aids about CPR, Ventilation, Tube Feeding and Artificial Hydration.

www.PrepareForYourCare.org

Interactive website by UCSF's Rebecca Sudore, MD, author of the easy-to-read California AHCD. Designed to help patients/families understand treatment choices and do advance care planning.

www.iha4health.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.disabilityrightsca.org Disability Rights California (DRC)

DRC works to bring about fairness and justice for people with disabilities. DRC serves as California's protection and advocacy system and provides free legal assistance regarding disability issues at 1-800-776-5746. DRC publishes an Advance Health Care Directive for Mental Health (AHCD-MH) and also an AHCD-MH Trainer's Manual with many helpful resources both available on the DRC website. 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.

About This Workbook

Making a PLAN – Thinking AHEAD is designed as a guide to help people advocate for themselves and stay in control of their lives through the very end.

The work was prompted by the Life Care Planning/Supportive Care (LCP/SC) Integration Pilot for the Older Adult Team (OAT), Behavioral Health Division, (BHD) County of Sonoma and developed with the skillful assistance of the OAT Pilot Peer Advisors Work Group. In support of this effort, the Coalition for Compassionate Care of California (CCCC) generously gave permission to Susan Keller and the Community Network for Appropriate Technologies (CNAT) to modify an existing Workbook, ***Thinking Ahead – My Way, My Choice, My Life at the End***, to include advance care planning for serious illness working in concert with OAT and CCCC. During the pilot phase, the new Workbook was called "Thinking Ahead 2." CNAT is a long-standing member of the CCCC and a consultant for the OAT LCP/SC Integration Pilot Project.

Making a PLAN – Thinking AHEAD was made possible with funding from the County of Sonoma Department of Health Services Behavioral Health Division and the California Health Care Foundation (CHCF) which works to ensure that people have access to the care they need, when they need it, at a price they can afford. Visit www.chcf.org to learn more about CHCF. Major in-kind contributions were made by BHD, CNAT, CCCC and Goodwill-Redwood Empire.

The original ***Thinking Ahead*** workbook was created by CCCC and its partners as a guide to enable developmentally challenged people to advocate for themselves and stay in control of their lives through the very end. Focus groups from three California regional centers and CCCC's Developmental Disabilities Advisory Group helped guide the original project. The ***Thinking Ahead*** workbook and DVD with related stories were published and made possible by a 2006–2007 Wellness Grant through the California Department of Developmental Services, and are available at www.coalitionccc.org.

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