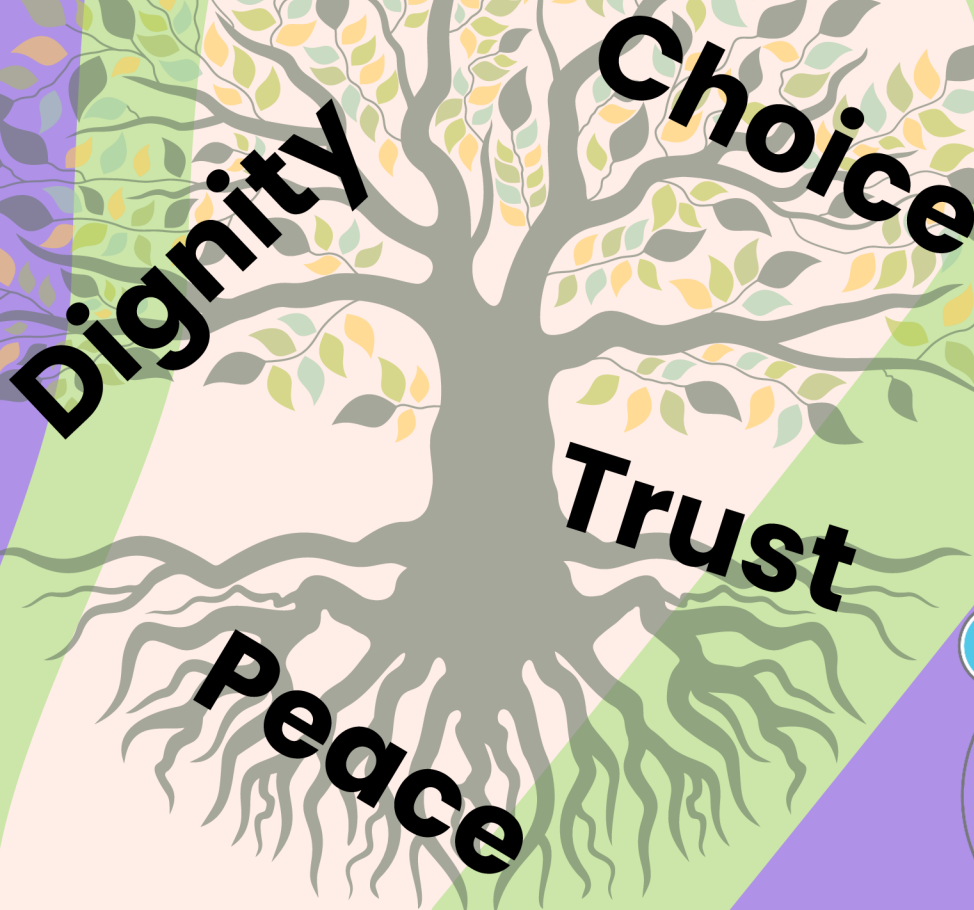


Thinking Ahead

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 Marinez, 2008



Dignity
Choice
Trust
Peace



The idea of this Thinking Ahead workbook originally came from California advocates with developmental disabilities, which led to the creation of their workbook in 2006–07. Then in Texas, The Department of Aging and Disability Services modified the booklet and created the Texas edition. Five Wishes is yet another end-of-life planning material that was created in copyrighted in 2020 from Aging with Dignity Inc. In 2023 Stone Belt Arc received a grant from the Indiana Bureau of Disability Services, and a portion of this grant was to fund the research and creation of this material for the state of Indiana. The resources above were used to influence the final outcome of Indiana's Thinking Ahead workbook.

The ultimate goal of this book is to equip and empower people with intellectual/developmental disabilities (I/DD) to plan ahead and think about their end-of-life wishes and after-death plans. Many people with I/DD are not given the opportunity to think, plan, and prepare these plans and share these wishes. Our hope is to change that!



Sarah VanderZee McKenney, D. Min., M.Div.
Spiritual Support and Volunteer Coordinator at Stone Belt Arc



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INTRODUCTION – How to use this workbook

Today 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 and writing down your choices.

2

Take your time to complete the workbook. Take 2 or more sessions. Use Support from Trusted Person (s).

3

Complete the FORMS and give copies to important people.



Why these decisions are important



We all 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/person 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



THINK – What is important to you



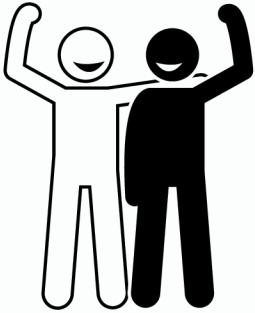
PLAN – Choose what you want



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 their 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:

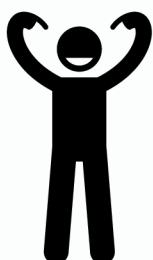
- Knows me well and cares about what is important to me.
- Helps without telling me what they think I should do.
- Listens to me and is respectful.
- Will advocate for me.
- Will help me complete this workbook.



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



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.



- 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.



- 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.



My Home



With my Family



Hospital



Hospice/Nursing
Home/Other

(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.



Have my family and friends near.



Have personal care that helps me feel more 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 thing 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: _____

Item: _____ To: _____

Item: _____ To: _____

Item: _____ To: _____

Item: _____ To: _____

Item: _____ To: _____

Item: _____ To: _____





(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: _____

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 _____

☐ Other place _____

I want people to remember me by doing this _____



I want this/these people to lead service _____



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 and/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**.
2. Take your completed **Form** and make copies for important people.
3. Save your workbook and the original **Form** you completed.





ADDITIONAL Questions

to help you finalize your wishes:

- ☐ I don't want to be in pain. I want my Doctor to give me enough medicine to make my pain go away even if that means I will be drowsy or sleep more than I would otherwise.
- ☐ If I show signs of depression, nausea, shortness of breath, or hallucinations, I want my care givers to do whatever they can to help me.
- ☐ I wish to be kept fresh and clean at all times especially if I am not able to control my bowel or bladder.
- ☐ I wish to have personal care such as teeth brushing, hair brushing, nail clipping, and shaving as long as it doesn't cause me pain or discomfort.
- ☐ I wish to have visitors and people with me until the end.
- ☐ I wish to have members of my faith community told that I am sick so they can pray for me.
- ☐ I wish to be cared for with kindness and cheerfulness, not sadness.
- ☐ I wish to have pictures of my loved ones in my room by my bed.





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 to 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 in 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.



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 to **YOU!**

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



- ☐ 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 about my quality of life at the end: _____

Additional Questions to help make decisions are located at the end of Chapter 4



Plan – Make Life Support Treatment Decisions

End-of-life planning includes thoughts about quality of life in your final days. Make you decisions about life support treatment and put together your personal plans.



Make your plan about life support treatment choices.

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



- ☐ I **want** life support treatment as long as possible.
- ☐ 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 choices on the **Personal Requests Form**.
2. Take your completed **Form** and make copies for important people.
3. Save your workbook and the original **Form** you completed.



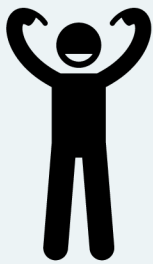
Choosing a Health Care Representative

It is important to choose a person who can be your **Health Care Representative** (also known as an **End-of-Life-Advocate**.) This person carries out your **Advance Directive** (your planned wishes.)



THINK – Who will speak for me?

My Health Care Representative:



- Is nearby to help me when I need them.
- 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 Representative cannot be:



- Your Doctor.
- Staff of a clinic/hospital where you get healthcare.
- 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.



Plan – My Health Care Representative

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

Good to remember! Some people have a court appointed guardian/s. 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
Name

Health Care Representative if they agree.



DO – Next Steps

1. Complete the **Advance Directive Form**.
2. Sign the Advance Directive Form with two witnesses.
3. Complete **Personal Requests Form**.
4. Make sure your **Health Care Representative** has a copy of both forms and any other legal forms necessary.



Staying in Control

When you finish **THINKING AHEAD** workbook and complete the forms at the end, you have exercised your right to live your life self-directedly, 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.



IMPORTANT!



RESOURCES

Palliative Care Information Center

<https://www.in.gov/health/cshcr/indiana-health-care-quality-resource-center/palliative-care-information-center/>

Indiana Advance Directive Resource Center

<https://www.in.gov/health/cshcr/indiana-health-care-quality-resource-center/advance-directives-resource-center/>

Indiana Bureau of Disabilities Services

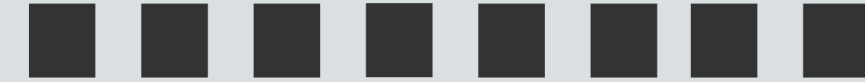
<https://www.in.gov/fssa/ddrs/developmental-disability-services/>

- Email: BDS.Help@fssa.in.gov
- 800-545-7763
- 402 W. Washington St., Rm. W453, MS46
Indianapolis, IN 46207-7083

Indiana Disability Rights

<https://www.in.gov/idr/>

- Email: info@IndianaDisabilityRights.org
- 800-622-4845
- 4755 Kingsway Drive, Suite 100, Indianapolis,
IN 46205



Resources Continued

Indiana Institute on Disability and Community

<https://www.iidc.indiana.edu/index.html>

- Email: iidc@indiana.edu
- 812-855-6508
- 2810 E Discovery Parkway Bloomington IN 47408

Indiana Arc of Indiana

<https://www.arcind.org/>

- 800-382-9100
- 143 W. Market Street Suite 200 Indianapolis, IN 46204

Indiana Donate a Life

Sign up: <https://www.donatelifeindiana.org/show-your-support/sign-up/>

Resources Continued

GLOSSARY

- **Hospice:** Hospice is specialized medical care for people who are expected to live for about six months or less. It comes into play when a cure for the illness is not possible, and the focus shifts to managing symptoms and improving the person's quality of life. Hospice services can be provided at home, in someone else's home, in a hospital, nursing home, or at a dedicated facility called a Hospice House.

Example: When someone has a terminal illness and their treatment options are limited, they may choose hospice care to ensure comfort and support during their final months.

- **Palliative Care:** Palliative care is an approach to care that aims to enhance the quality of life for patients and their families dealing with serious, life-threatening illnesses. It focuses on identifying, assessing, and treating pain and other challenges, whether they are physical, emotional, social, or spiritual. Palliative care can be provided alongside other medical treatments.

Example: A cancer patient undergoing chemotherapy may also receive palliative care to manage pain and address emotional concerns, improving their overall well-being.

- **Life Support:** Life support refers to techniques and procedures that can sustain life temporarily when an organ or organs are failing. It includes interventions like mechanical ventilation (breathing support), CPR (cardiopulmonary resuscitation), tube feeding, and dialysis. These measures help the body function until it can resume on its own or until a more permanent solution is found.

Example: If someone experiences a severe injury that affects their ability to breathe on their own, they might be placed on a ventilator as a form of life support until their condition stabilizes.

- **Organ Donor:** An organ donor is a person who willingly donates one or more of their organs for transplantation to help someone else in need. Organ donation is a generous act that can save lives or significantly improve the health of individuals with organ failure. Organs commonly donated include the heart, kidneys, liver, lungs, and pancreas.

Example: Someone who has passed away but chose to be an organ donor can provide the gift of life to another person by donating their organs for transplantation.



Acknowledgements

We would like to thank the following organizations for their dedication and effort to pioneer the creation of a workbook and resources dedicated to ensuring that people with disabilities have their voices heard when they are planning for the end-of-life.

Because of Agencies like these, we are able to make this workbook available to Hoosiers and their families.

Texas Department of Aging and Disability Services –
<https://www.hhs.texas.gov/services/aging/long-term-care/aging-disability-resource-center>

Coalition for Compassionate Care of California –
info@coalitionccc.org , Phone: (916) 489-2222

Five Wishes – <https://www.fivewishes.org/> Five Wishes is an easy-to-use legal document that covers medical, legal and personal/spiritual wishes, portions of which are excerpted herein with permission. Five Wishes meets all Indiana legal requirements

ADVANCE DIRECTIVE FORM

Health Care Representative Name

Legal Address

City

State

zipcode

Home Phone

Work Phone

Email

My Health Care Representative will make decisions for me only if I cannot make my own decisions.

- ☐ 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 FORM

Sign your name**Date**

Print your name**Date**

Address**City****State****Zipcode****For Witnesses:**

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

I also promise that:

- I know this person and he/she/they can confirm their identity.
- I am 18 years or older.
- I am NOT this person's Health Care Agent.
- I am NOT this person's health care provider or work for this person's health care or services 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/they dies.

Personal Requests Form

NAME: _____

(1) Where I want to be

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

			
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My Home	With my Family	Hospital	Hospice/Nursing Home/Other

(2) How I want to be cared for

This is how I want to be cared for in my final days.

- ☒ ☐ Have my family and friends near.
- ☐ Have personal care that helps me feel more 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 FORM

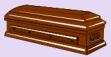
Write what you want to give and to whom.

Item: _____	To: _____
Item: _____	To: _____
Item: _____	To: _____
Item: _____	To: _____
Item: _____	To: _____
Item: _____	To: _____
Item: _____	To: _____
Item: _____	To: _____



(5) My Body

✗ Think about what you want and write it down.



☐ I want to be buried. Where: _____



☐ I want to be cremated. Where: _____

☐ Where I want my ashes to go: _____

☐ I want to donate my organs.



☐ I want to donate my body to science.

(6) Being remembered

✗ I want a funeral service or celebration. ☐ yes ☐ no



At my place of worship _____

At a funeral home _____

Other place _____

I want people to remember me by doing this _____

I want this/these people to lead service _____





PERSONAL REQUESTS FORM

ADDITIONAL Questions

to help you finalize your wishes:

- ☐ I don't want to be in pain. I want my Doctor to give me enough medicine to make my pain go away even if that means I will be drowsy or sleep more than I would otherwise.
- ☐ If I show signs of depression, nausea, shortness of breath, or hallucinations, I want my care givers to do whatever they can to help me.
- ☐ I wish to be kept fresh and clean at all times especially if I am not able to control my bowel or bladder.
- ☐ I wish to have personal care such as teeth brushing, hair brushing, nail clipping, and shaving as long as it doesn't cause me pain or discomfort.
- ☐ I wish to have visitors and people with me until the end.
- ☐ I wish to have members of my faith community told that I am sick so they can pray for me.
- ☐ I wish to be cared for with kindness and cheerfulness, not sadness.
- ☐ I wish to have pictures of my loved ones in my room by my bed.

NOTES

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



Dignity

Choice

Trust

Peace



BDS

Indiana Bureau of
Disabilities Services

The Bureau of Disabilities Services envisions a community where all people have equal access and opportunity to realize their good life. We are committed to partnering with individuals, families and professionals to ensure person centered services that empower people with disabilities and their families by connecting them to the resources and supports to live their best life. Our core value is that all people have the right to live, love, work, learn, play and pursue their dreams.