

The top corners of the slide are decorated with numerous blue and teal butterflies of various sizes, scattered across the light blue background. The butterflies are more densely packed in the corners and become sparser towards the center.

Personal Death Awareness

1. Examine personal views and beliefs about death
2. Achieve a level of comfort in discussing death
3. Define advance care planning and briefly discuss the following related to advance care planning: advance directive, healthcare power of attorney, legacy, living will, life support treatment, cardiopulmonary resuscitation and DNR (do not resuscitate) order, Maine Death with Dignity Act, POLST (physician orders for life-sustaining treatment), funeral and burial choices, financial power of attorney, last will and testament
4. Become familiar with various advance directive forms, including “The Five Wishes”



Examine personal views and beliefs about death

What we believe and how we feel about our own dying and death depends on...

- ✿ our childhood experiences
- ✿ our parents and other influential people in our lives
- ✿ books, articles, blogs we have read
- ✿ our adult life experiences
- ✿ the people and groups we choose to spend our time with





Examine personal views and beliefs about death

**As individuals we are free to understand death and after death
in a way that makes sense to us**

Some of us believe that after death...

- * we will be in the presence of God
 - * we will be in the presence of divine beings
 - * we will reunite with loved ones
 - * we will be born again to continue our life's purpose
 - * we will reincarnate to another form of life
 - * we will return to a life in another plane of existence
 - * we will be punished for our wrongdoings
 - * we will cease to exist
 - * ...



Examine personal views and beliefs about death

As individuals we are free to understand death and after death in a way that makes sense to us

Our beliefs about death and after death make some of us feel...

- * content or peaceful about a life after death
 - * fear of punishment for deeds done or undone in this lifetime
 - * relief that life's struggles will be over
 - * sadness over the thought of losing loved ones
 - * anger at being unable to complete one's aspirations, dreams
 - * fear of the unknown
 - * ...



Examine personal views and beliefs about death

**As individuals we are free to understand death and after death
in a way that makes sense to us**

**As hospice volunteers we must accept the client where s/he is in his or her
faith journey, no matter our own personal views and beliefs about death**

If your client expresses fear when he or she thinks or talks about his or her
impending death

Accept that we all have our own beliefs about what happens to our spirit
after the death of our physical body

Suggest spiritual counsel from a trusted religious or spiritual leader

Pine Tree Hospice has a volunteer chaplain who can help make this a
comforting and supportive part of life's journey



Achieve a level of comfort in discussing death

As a hospice volunteer, we need to be somewhat comfortable with the topic of dying and death

We know our clients and their loved ones
are living these moments in keen awareness of dying and death

Where are you now between your birth day and your death day ???



Birth Day



Death Day

Achieve a level of comfort in discussing death



Birth Day

Death Day

How do you feel about where you are on this time line ?

fearful _____ neutral _____ peaceful

Think now about your dying time... How do you feel ?

fearful _____ neutral _____ peaceful

Think now about being dead... How do you feel ?

fearful _____ neutral _____ peaceful



Achieve a level of comfort in discussing death

As you sit with your dying client, s/he may share feelings of...

FEAR

- being unable to communicate needs
- dying alone
- being a financial burden to family
- inability to complete unfinished business
- loss of control
- loss of dignity
- never seeing loved ones again
- pain
- shattered plans for the future
- life/no life after death
- where the spirit goes
- ...

PEACE / ACCEPTANCE

- joining with divine beings
- continuing a path of spiritual growth
- eliminating pain
- eliminating physical suffering
- reuniting with loved ones
- rebirth into a better life
- ...

? Can you achieve a level of comfort in discussing **all** of these issues with your client ?

If not, begin these conversations over time with someone you know, someone who is not dying



Achieve a level of comfort in discussing death

Given knowledge of a person's end of life wishes,
we can take action to make it happen

How do you want to be treated when you reach the end of your life...what matters to you ?

Who should make health care decisions for you if you are unable to communicate your wishes ?

What medical treatments do you want, and under what circumstances ?

Where do you want to be cared for if you are unable to care for yourself ?

How you want to be remembered ?

What do you want done with your body after your death ?

Topics related to assets, which are usually not addressed in an advance directive

Who should handle your money if you are unable to do so yourself ?

How do you want your possessions/assets distributed after your death ?

It may take some time to address all of these important issues



Achieve a level of comfort in discussing death

“Having THE CONVERSATION”
with someone at the end of life

? How to begin ?

Good tools to help you get started...

Go Wish cards with check list located in Pine Tree Hospice office

Interactive Go Wish on the internet: <https://codaalliance.org/go-wish-game/>

Hello cards (formerly “My Gift of Grace”) located in Pine Tree Hospice office

Five Wishes Advance Directive form

The Conversation Project free guides www.theconversationproject.org

“Prompts for Preferences”



Achieve a level of comfort in discussing death

“Having THE CONVERSATION”

Prompts for *Preferences* *If you were in bed and unable to tell us what matters to you...*

- ☆ How would you describe an ideal way to start your day?
- ☆ What sounds do you find peaceful?
- ☆ Are there any sounds that are disturbing to you?
- ☆ What food brings you comfort?
- ☆ What foods do you dislike?
- ☆ What kind of music do you like?
- ☆ Do you enjoy having some time alone?
- ☆ Do you like having a lot of people bustling around you?
- ☆ What keeps you awake when you are trying to fall asleep?
- ☆ What pictures would you like to be able to see?
- ☆ What brings comfort to you when you hold it?
- ☆ Do you like your feet tucked in under the covers?
- ☆ Do you want a phone or a tablet nearby?
- ☆ Do you like to be read to?
- ☆ Would you like someone to write down things that you want to say to someone?
- ☆ Do you want to be near a window?
- ☆ Do you like background noise, like a television or radio playing softly?
- ☆ Do you want religious books or icons near you?
- ☆ Do you want to hear a funny joke or story from time to time?
- ☆ Do you want caregivers to hold your hand sometimes when they are talking with you?
- ☆ Do you like your feet rubbed? Your hands? Your back?
- ☆ Do you enjoy having your hair brushed? Your scalp massaged?
- ☆ Do you want the lights on all the time?
- ☆ Would you enjoy a visit from a therapy dog or a cat?
- ☆ Do you want your door kept open? Closed?
- ☆ What helps you fall asleep?
- ☆ ?



Achieve a level of comfort in discussing death

“Having THE CONVERSATION”

You can simply open with “Have you thought about...”

Have you thought about how you want us to treat you when you reach the end of your life ? What matters to you ?

Have you thought about who should make decisions for you if you can't tell us what you want ?

Have you talked with anyone about how you want to be treated if you become unable to tell us ?

If you were to suddenly become incapacitated, do we know how you want to be treated ?

Do we know what you want done with your belongings ?



Achieve a level of comfort in discussing death

“Having THE CONVERSATION”

Some “starter questions”

I’d like to help you share your wishes about how you are treated at the end of your life. Would today be a good time to do that?

I have with me a pamphlet called “Five Wishes”. It can help you make clear your wishes about how you are treated if you become unable to express them. May I show it to you now?

Whenever we go into the hospital for treatment we are asked, “Do you have an Advance Directive?” An advance directive tells your caregivers how you want to be treated if you can’t tell them yourself. May I help you prepare an advance directive today?

I notice you don’t have an advance directive. There are two really good reasons for having one. First, it puts you in control by letting your caregivers know how you want to be treated at the end of life; and second, it relieves your family of having to make tough decisions when they don’t know or don’t agree about what you want. May I help you get started with an easy to use advance directive form?



Achieve a level of comfort in discussing death

“Having THE CONVERSATION”

What could you say if the person you are trying to start the conversation with indicates disinterest, or comes right out and says, “I don’t want to talk about it”?

I know it’s hard to talk about it. Your caregivers want to know what your wishes are. I have a list of questions that would help us care for you the way you want to be cared for when you are near end of life. Next time we visit could we take a look at those questions together?

If we know your wishes, we can work hard to make it happen for you. Also, if your family knows what you want, it will be so much easier for them when the time comes. I can help you put your wishes in writing for them.



Achieve a level of comfort in discussing death

“Having THE CONVERSATION”

How can you help someone who has to break the promise to keep a loved one at home?

Reassure them that it can become impossible for a family, even a very loving family, to provide full-time physical care without significant stress

You can ease angst over breaking the promise by asking the dying person what it is about “home” that is most important

- It is usually possible to provide preferences at a long term care facility, *for example*:
 - Quiet or Bustling?
 - Beside a window or in a darkened room?
 - What brings comfort... a picture, or a cherished memento, or a favorite stuffed animal, or a cross, rosary, or other religious item

- Edit the “Prompts for Preferences” list



Define advance care planning and briefly discuss the following related to advance care planning: advance directive, healthcare power of attorney, legacy, living will, life support treatment, cardiopulmonary resuscitation and DNR (do not resuscitate) order, Maine Death with Dignity Act, POLST (physician orders for life-sustaining treatment), funeral and burial choices, financial power of attorney, last will and testament

Advance care planning:

Planning that puts you in control by letting your wishes be known if you become unable to communicate



Advance care planning

Advance directive:

- A legal document that puts YOU in control if you are unable to communicate your wishes; it includes at least:
 - 1) What medical treatments you want AND what medical treatments you do NOT want
 - 2) Who should make healthcare decisions for you
- Does not address your money or your property



Advance care planning

- You can include with your advance directive a list and documentation of important information for others to have in the event of your incapacitation or after your death, which would otherwise be very difficult for them to find; keep the list updated and easily accessible to a trusted person

For example,

- password list
- social security number
- financial account information
- list and location of valuables
- location of insurance policies: life, vehicle, funeral, etc
- location of vehicle titles, deeds to property, etc
- list of meaningful items to be given away to specific people
- list of items or papers that you want disposed of
- special instructions for pets

The Pine Tree Hospice office has a sample “Red Book”; there are many downloadable lists available on the internet



Advance care planning

Healthcare power of attorney: (also called **healthcare proxy, healthcare agent, medical power of attorney; durable power of attorney for healthcare**)

- The person you designate to make healthcare decisions for you if you are unable to communicate; named in your advance directive
- A healthcare power of attorney does not handle finances
- A healthcare power of attorney begins making decisions for you when your doctor and another health professional agree that you can no longer communicate choices
- Select someone who will carry out your wishes even if s/he does not agree with you; and who can make difficult decisions (not necessarily a spouse or best friend)
- Select only one healthcare power of attorney, but do select a backup in case the “one” is unavailable when needed
- You can change your power of attorney any time...record, date, sign and have witnessed, the change in your advance directive



Advance care planning

Legacy (sometimes called **Ethical will**)

- A communication to others; not a legal document, for example:
 - A story of your life
 - A letter to your loved ones
 - A way to communicate your beliefs and values
 - A way to communicate your knowledge and experiences
 - A means to offer forgiveness, when words cannot be said
- You can share your legacy before you die

Living will:

- The part of the advance directive that describes how you want to be treated at the end of life
- The living will does not address distribution of belongings



Advance care planning

Life support treatment:

- Wishes for life sustaining treatments can be included as part of your advance directive
- Includes intubation with mechanical ventilation, renal dialysis, and nutritional support via tube feeding or intravenous infusion
- There are complications with life-support treatment which can be uncomfortable and can cause physical damage
- Given a health condition from which you are not expected to recover, life support is unlikely to restore quality of life
- Prolonged life support can be unacceptably costly, and can become a hardship for loved ones
- Comfort measures are always instituted when under the care of a healthcare professional



Advance care planning

CPR (cardiopulmonary resuscitation) and DNR (do not resuscitate):

- Treatment is instituted only after your heartbeat and breathing have stopped
- Healthcare providers will automatically give CPR unless there is a separate written authorized DNR (also called AND, allow natural death) order
- The DNR or AND order must be an addition to the advance directive
- CPR is not expected to significantly prolong the life of someone with a terminal illness
- Brain function may be diminished after CPR
- Severe injury is likely if CPR is done on a frail person
- CPR is usually followed by intubation and mechanical ventilation



Advance care planning

Maine Death with Dignity Act:

- Provides eligible Maine residents who have a terminal illness and a probable death within 6 months, the option to be prescribed a dose of medication that, if taken, will hasten the end of his or her life
- Requires the participation of a Maine licensed physician
- The request can be rescinded at any time
- Life insurance companies are prohibited from denying benefits
- The information is confidential, not a public record and not open to public inspection
- The eligible resident must be capable of making a voluntary, informed health care decision, and must be able to self-administer the prescribed dose



Advance care planning

POLST (physician orders for life-sustaining treatment):

- A medical order typically used in facilities such as nursing homes which goes with a person to/from other locations such as a hospital
- Intended for seriously ill or frail individuals nearing end of life
- Provides direction for resuscitation, medical treatments (full, selected, or comfort only), and nutrition
- Not an advance directive; does not name a health care proxy



Advance care planning

Funeral and Burial choices:

- No matter your choice of where your body goes, you can have a funeral, memorial service, or celebration of life gathering; you can plan them in detail, or you can simply put your wishes in your advance directive
- You can write your own obituary...a biographical sketch of who you are
- You can specify your wishes in your advance directive for your body to be
 - embalmed or not
 - buried in a traditional cemetery, a green cemetery, a family cemetery
- You can choose cremation without embalming
- Cremains can be put almost anywhere
- You can donate your entire body, or you can choose which organs to donate to medical science
- Funeral Consumers Alliance of Maine (www.fcmaine.net)



Advance care planning

Financial Power of attorney; usually called “power of attorney”:

- The person who is legally authorized to act on your behalf with some or all of your finances and your possessions
- Your power of attorney does not make healthcare decisions for you
- You decide the extent of the authority of your power of attorney: such as all finances, specified finances such as bank accounts, income taxes or investments, managing real estate
- You can choose to manage your finances until you are no longer able to do so; the power of the power of attorney begins when you decide it should
- If you are able, you can terminate the authority of your power of attorney at any time
- The power of the power of attorney ends at the time of your death



Advance care planning

- There is more than one kind of financial power of attorney; some take effect only while you are mentally capable, some remain in effect when you become incapacitated
- You can have a joint bank account instead of a power of attorney
 - the co-owner is limited to using only that account to manage financial transactions for you
 - the co-owner will have full ownership of the account after your death
- The Power of Attorney does not grant permission to deal with social security on your behalf; you must call social security and add the person's name to the authority list
- Seek legal counsel to decide which type of financial power of attorney is right for you



Advance care planning

Last will and testament, usually called a “will”:

- A legal document stating how you want your finances and belongings to be distributed after your death
- The will is not related to healthcare
- You appoint a “personal representative” to carry out terms of your will (an executor of your estate)
- When applicable, a will names a guardian for minor children and addresses care for minor children and adult family members with special needs
- Seek legal counsel to prepare a will that is right for you



Advance care planning

- A will names the beneficiary(s)
 - The person you designate to receive money or property after your death; this is typically chosen when the account is set up, but you can change your beneficiary at any time
 - Accounts with beneficiaries include investments, retirement accounts, and life insurance as well as checking and savings
 - Assets with a beneficiary do not need to be included in a last will and testament
 - Any beneficiary(s) designated on a financial account *trumps the will*
 - If all assets owned by the individual name a beneficiary, then a lawyer and a last will and testament are not needed
 - Check your beneficiary(s) from time to time to make sure the person(s) listed is/are still what you want



Advance care planning

- A will goes through the probate process before distributing assets named in the will
- If an asset goes through probate without a will, the process can be long and there is no personal control over who ends up with the asset
- Without a lawyer you can make a legally binding distribution of your belongings that are not titled
 - your list must be handwritten in ink, signed, dated, and attached to your will
 - Anything that is titled that does not have a beneficiary, or titled jointly with those assets belonging to co-owner upon death, must be distributed through a will and/or go through probate.



Advance care planning

- A property title names the owner of an asset, such as real estate or vehicles
 - Disposition is controlled by a will and goes through probate
 - The title may be in your name only or it may be joint. There are different types of joint titles: the entire asset may belong to the joint partner at the time of your death, *or* you determine the beneficiary of your half of the asset (tenants in common)
- A trust is a legal document that grants ownership of your property to another person or institution
 - Does not go through probate
 - Trustee is appointed to manage the property for the benefit of the person or institution
 - A revocable trust allows you to maintain control of your property during your life, and decide how the property is distributed after death, without needing to go through probate court; your trust can include your home and any other assets you have
- Seek legal counsel to decide which type of title and/or trust is right for you

ADVANCE CARE PLANNING ... how you want to live

Planning that **PUTS YOU IN CONTROL**

by letting your wishes be known if you become unable to communicate



- ♥ How you want to be treated when you reach the end of your life
- ♥ Who should make healthcare decisions for you if you can't make them yourself
- ♥ How you want to be remembered
- ♥ Who should handle your money if you are unable
- ♥ How you want your possessions to be distributed after your death

Pine Tree Hospice www.pinetreehospice.org

An **ADVANCE DIRECTIVE** is a legal document that includes:

♥ How you want to be treated if you cannot communicate your wishes ... sometimes called a “**living will**”

♥ **Healthcare power of attorney** (also called healthcare proxy, healthcare agent) ... is the person you name to make healthcare decisions for you if you cannot communicate
Power ends at your death

♥ May include how you want to be remembered; may include care of your body after death

♥ **Financial power of attorney:** is the person you name to handle some or all of your assets if you are unable; s/he does not make healthcare decisions for you

You decide how much power s/he has
You decide when the power takes effect
Power ends at your death

♥ **Last will and testament:** is a legal document that includes:

The person you name to be your personal representative (executor) to handle your possessions after your death

How you want your possessions to be distributed; names your beneficiary(s)



Become familiar with various advance directive forms, including “The Five Wishes”

We have choices for how we want to live at the end of life

- ? What if I become unable to make decisions for myself ?
 - ? Who will do that for me ?

- ? How will doctors and nurses treat me before I die ?
 - ? Would I agree with everything they want to do ?

- ? Will my last days be comfortable ?
 - ? If I want pain medication, will I get it ?
 - ? If I want to be awake and aware until the last moment...even if I have pain,
 - ? will they let me ?

- ? When I’m dying, will people treat me the way I want them to ?

There are things I want my loved ones to know... how can I tell them ?



Become familiar with various advance directive forms, including “The Five Wishes”

An advance directive helps you share your choices with others

The Five Wishes Advance Directive www.fivewishes.org

- 1) The person I want to make health care decisions for me when I can't make them for myself
- 2) My wish for the kind of medical treatment I want or don't want
- 3) My wish for how comfortable I want to be
- 4) My wish for how I want people to treat me
- 5) My wish for what I want my loved ones and health care team to know



Become familiar with various advance directive forms, including “The Five Wishes”

The Five Wishes is a legal document in Maine

- You do not need a lawyer
- You do not need a signature from a doctor, or nurse practitioner or physician assistant
- Your signature needs to be witnessed by two people, and signed by the witnesses
 - Must be over 18 and cannot be: your healthcare proxy, your healthcare provider or employee of healthcare provider; financially responsible for your health care; an employee of your insurance provider; related to you by blood, marriage or adoption; your creditor or your beneficiary
 - Witnesses do not need to read your advance directive, they only need to witness your signature
- It does not need to be notarized, but a notarized copy is a good idea if you spend time in a state where the Five Wishes is not a legal document, you should attach the Five Wishes to the advance directive of that state



Become familiar with various advance directive forms, including “The Five Wishes”

You make changes in the Five Wishes advance directive

- You can change your advance directive any time
- You can change all of it, or just part of it
- You can add anything to the form... for example, organ donation, disposition of your body after death, type of funeral you want, your obituary
- You can attach additional papers to the form or write in the margins
- You can cross out anything you disagree with or don't want
- Sign, date, and have your signature witnessed on any changes; be sure to inform loved ones and healthcare providers of any changes
- If you update your advance directive, be sure ALL copies are updated



Become familiar with various advance directive forms, including “The Five Wishes”

If you have already filled out an advance directive but want to use the Five Wishes instead...

- Fill out the Five Wishes, sign it, date it, and have your signature witnessed; then destroy ALL previous copy(s) of an advance directive, or clearly indicate “revoked”
- If you have completed a state of Maine advance directive and your wishes for medical treatment have not changed, you can simply attach the Five Wishes to the state advance directive
- Inform your health care proxy, health care provider, and family of any change



Become familiar with various advance directive forms, including “The Five Wishes”

Can I put a “Do Not Resuscitate” request in my advance directive ?

- You can, but it *will not be honored unless* you have a “Maine Emergency Medical Services Comfort Care/Do Not Resuscitate Directive” or a written medical order
- If EMS (911) is called, they WILL intubate AND initiate CPR even if you have stated your wishes in an advance directive...unless they can see a properly signed DNR order(usually on the bedroom or refrigerator door)
- It is scary to ask for a DNR order, but we all need to ask the question, when is life no longer valuable ? PTH library has a helpful book, Hard Choices for Loving People by Hank Dunn (also available on Amazon)
 - Honors inevitable and impending death with dignity
 - Discusses the implications of unpleasant life prolonging treatments
 - Offers compassionate help for people faced with these issues



Become familiar with various advance directive forms, including “The Five Wishes”

Your advance directive must be readily accessible to your healthcare provider (doctor, nurse practitioner, physician assistant, hospital) AND to your healthcare proxy (the person who you want to make healthcare decisions for you)

- Put your advance directive in an easily accessible place at home such as the refrigerator, your nightstand drawer, unlocked fire box
- Make sure your healthcare provider and your healthcare proxy know the location of your advance directive
- You can give a paper and/or electronic copy to your healthcare provider and to your healthcare proxy
- Do not keep your advance directive in a location accessible only to you, such as a safe deposit box
- You can carry a wallet card stating the location of your advance directive



Become familiar with various advance directive forms, including “The Five Wishes”

Do I have to use the Five Wishes as my advance directive ?

- No, there are many different forms available, such as
 - Maine Advance Directive Form
www.mainehealth.org/care-services/hospital-medicine-inpatient-care/advance-directives-l-advance-care-planning
 - Prepare for your care
www.prepareforyourcare.org/en/welcome
- The Five Wishes is gentle and easy to understand; and you can alter it any way you wish...it is still valid



Become familiar with various advance directive forms, including “The Five Wishes”

Do I still need an advance directive if...

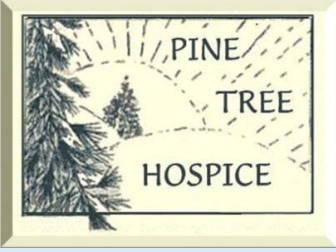
How I am treated is not important to me *or*

I have no awareness and I am not expected to recover awareness *or*

I’m not concerned about what happens to my body after I die

An advance directive spares your loved ones from making hard decisions

during what will be a difficult time for them



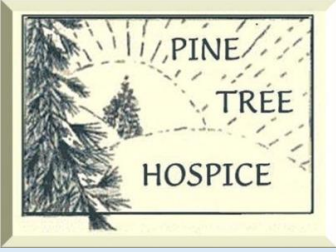
Advance care planning



Wishes and Living Wills

Community gatherings to help folks feel comfortable enough to be able to tell others what matters when they reach end of life

1. Begin to feel comfortable thinking about and discussing end of life issues
2. Understand the difference between an advance directive and a will (last will and testament)
3. Understand the difference between a healthcare power of attorney (also called medical power of attorney or healthcare proxy) and a financial power of attorney
4. Be prepared to complete the 5 Wishes advance directive form
5. With at least one other person, practice “starting the conversation” using the Pine Tree Hospice “Prompts for Preference List”
6. Understand that advance care wishes can be changed any time
7. Begin a list of important information for others such as your passwords, financial information, location of advance directive, location of will, etc.
8. Know about choices: various advance directive forms, life sustaining treatments, do not resuscitate orders, long term care resources, alternative funeral arrangements
9. Know where to find more information about end of life issues



Advance care planning



Wishes and Living Wills

Community gatherings to help folks feel comfortable enough to be able to tell others what matters when they reach end of life

- 1) Advance directives
- 2) Disposition of finances and other assets
- 3) Funeral arrangements and memorials
- 4) Having “the conversation” with someone who is at the end of life

Basket question format for Pine Tree Hospice “Wishes and Living Wills” facilitators

Random Question / Answer format

- ✿ Engages participants comfortably
- ✿ Eases presentation for leaders
- ✿ Provides continuity for community gatherings
- ✿ All questions will not be addressed,

but all answers will be distributed at end of gathering

