Calling PTH Volunteers
to work with our community

Train the trainer
for
advance care planning
community gathering

Tuesday, March 12
9 am - 2:30 pm *with lunch*
Congo church

Sherry Peirce Corbin, RN, MS

Vision

Folks in our community will feel comfortable enough to be able to tell others what matters to them when they reach end of life.

Why we're here today …

~ Feel comfortable discussing end of life issues

~ Explain or define terms related to ACP

~ Offer guidance in using advance directive forms

~ Offer guidance in "having the conversation"

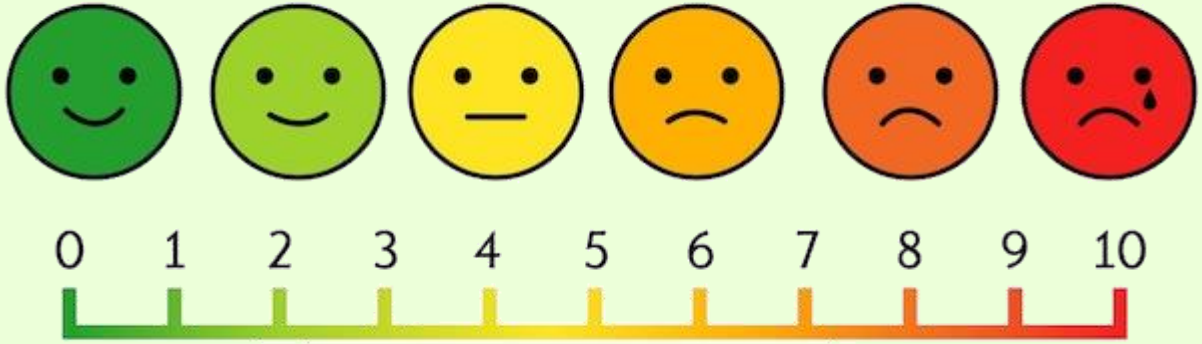
~ Provide resources for further information

~ Adhere to the schedule for the community session

***Jump* to the first slide listing all active web links in this presentation**

Feel comfortable discussing end of life issues

On a scale of 0-10, how comfortable are you **now** in discussing end of life issues?



0 = very comfortable

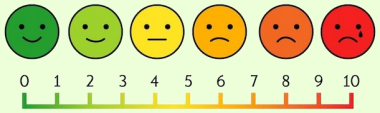
10 = don't even want to think about it

Is your comfort level the same when talking with…

- someone close to you about his/her end of life ?
- your hospice client about his/her end of life ?
- someone close to you about *your* end of life ?

Feel comfortable discussing end of life issues

Conversation Starters



Excellent resource for you:

❀ The Conversation Project: https://theconversationproject.org

An initiative of the Institute for Healthcare Improvement, a not-for-profit organization that is a leader in health and health care improvement worldwide

All in the approach

Shifting from	...to
Death and dying	Life and living
What's the matter **with** you	What matters **to** you
Clinical model	Values-based model
Telling	Listening

the **conversation** project

Five Consumer Segments

Worried Action Takers 10%

Younger, diverse, most educated. Nearly half identified as having a disability.

Highest trust and regard for the health care system. ~80% have been a caregiver for an incapacitated loved one.

Self-Assured Action Takers 24%

Oldest by far; most likely to be white and least likely to be low-income.

Confident about managing their health and navigating the health care system with fewer worries about a future serious illness.

Disengaged Worriers 34%

Youngest, most diverse, lowest education and income; poorest health and health care navigation and management skills.

Seen loved one's wishes not honored. Many worries about their health and future serious illness.

Confident Independents 18%

Older (mostly 45+), average education and racial composition. Fewer experiences with dying loved ones. Confident about managing their health and navigating the health care system with fewer worries about a future seriou illness.

Self-Reliant Skeptics 14%

Middle-aged, lower income and education.

Lowest trust of doctors and regard for the health care system. Poorer health care self-management and skills.

Approaches that worked for all groups

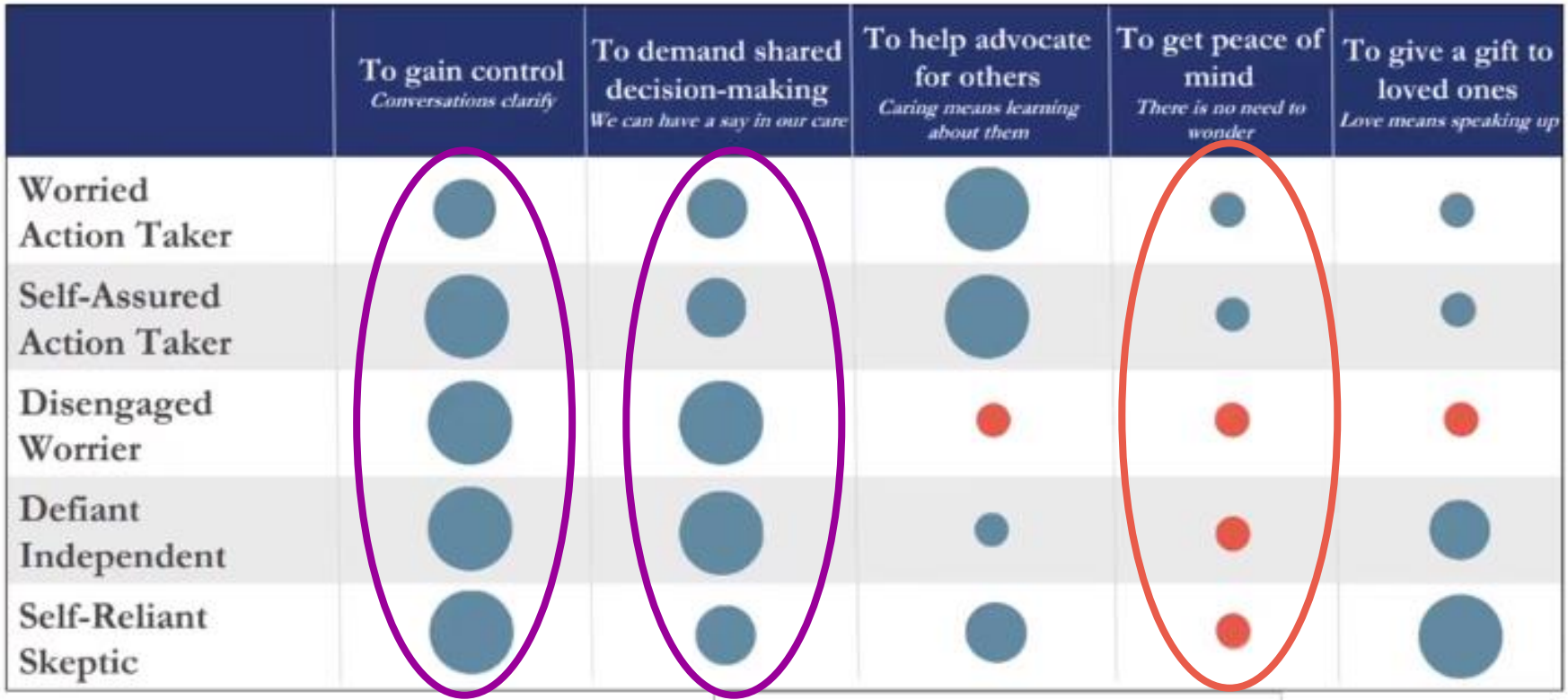
Gain Control

Shared Decision Making

Approach that didn't work well for any group

Get Peace of Mind

What messaging worked and didn't by segment



the conversation project

MA Coalition for Serious Illness Care

Steal These Messages – Advance Care Planning

You can have a say in your care

Treatments only work if they work for you

Talk to the people who matter most about the care you want

The more you speak up, the better your healthcare can be

Tell your doctors what matters most to you

You can get the care that's right for you

We'll figure this out together

Let's make a plan for your care

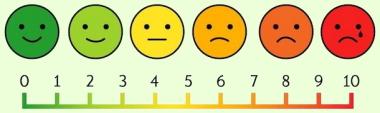
the **conversation** project

seriousillnessmessaging.org

https://seriousillnessmessaging.org

Feel comfortable discussing end of life issues

Conversation Starters



Excellent resource for you:

- The Conversation Project: https://theconversationproject.org
  An initiative of the Institute for Healthcare Improvement, a not-for-profit organization that is a leader in health and health care improvement worldwide

In the PTH office:

- Go Wish cards: https://codaalliance.org/go-wish
- Hello cards: https://commonpractice.com/products/hello-game

For the Community session:

- Sample starter questions
- "Prompts for Preferences" practice

The Go Wish Game

		not important to me	somewhat important to me	very important to me	
					I need support with this wish
1	To be free from pain				
2	To be free from anxiety				
3	Not being short of breath				
4	To be kept clean				
5	To have human touch				
6	To have my financial affairs in order				
7	To have my family prepared for my death				
8	To die at home				
9	To know how my body will change				
10	To feel that my life is complete				
11	To say goodbye to important people in my life				
12	To remember personal accomplishments				
13	To take care of unfinished business with family and friends				
14	To prevent arguments by making sure my family knows what I want				
15	To have an advocate who knows my value and priorities				
16	To be treated the way I want				
17	To maintain my dignity				
18	To keep my sense of humor				
19	To have a doctor who knows me as a whole person				
20	To have close friends near				
21	Not dying alone				
22	To have someone who will listen to me				
23	To trust my doctor				
24	To have a nurse I feel comfortable with				
25	To be mentally aware				
26	To have my funeral arrangements made				
27	Not being a burden to my family				
28	To be able to help others				
29	To be at peace with God				
30	To pray				
31	Not being connected to machines				
32	To be able to talk about what scares me				
33	To meet with clergy or a chaplain				
34	To be able to talk about what death means to me				

If it is very important, do you need support with this wish ?

If yes, how can we help?

Feel comfortable discussing end of life issues

Conversation Starters

How do I begin the conversation ?

“Have you thought about . . .

- … how you want us to treat you when you reach the end of your life ?
- … who should make decisions for you if you can’t tell us what you want ?
- … telling someone about how you want to be treated if you become unable to tell us ?
- … how you want to be treated if you were to suddenly become incapacitated?
- … what you want done with your belongings if you’re unable to tell us ?

Feel comfortable discussing end of life issues

Conversation Starters

What is an example of a “starter question” ?

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

I have a pamphlet with me called ‘Five Wishes’. You can use it to make it clear about how you want to be treated if you become unable to express your wishes for medical treatments and for comfort. 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 ?

Sometimes, when we reach the end of life, we aren’t able to share our wishes about how we want to be cared for. But we can make those wishes known ahead of time. May I help you write down your wishes ?

I notice you don’t have an advance directive. There are two really good reasons for having one: first, it gives you control by letting your caregivers and family 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 called ‘Five Wishes’ ?

Feel comfortable discussing end of life issues

Conversation Starters

What could I say if the person I am 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 matters to you. 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

Feel comfortable discussing end of life issues

Conversation Starters

"Prompts for Preferences"

A list to help the caregiver ***learn what matters to you*** at the end of life

If you were in bed and unable to tell us how to make you comfortable ...

- 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 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?
- 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?

Explain or define terms related to Advance Care Planning

What is …

Advance Care Planning

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

1) How you want to be treated when you reach the end of your life, and after your death
2) Who should make healthcare decisions for you
3) How you want to be remembered
4) Who should handle your money
5) How you want your possessions to be distributed after your death

Advance Directive

A legal written document that includes at least:

1) How you want to be treated when you reach the end of your life
2) Who should make healthcare decisions for you if you are unable to communicate

May also include how you want to be remembered
May also include your wishes about the care of your body after death

Does not address your money or your property

Five Wishes: https://www.fivewishes.org

Maine Health Care Advance Directive: : https://www.mainehealth.org/care-services/hospital-medicine-inpatient-care/advance-directives-l-advance-care-planning

Explain or define terms related to Advance Care Planning

What is …

Healthcare Power of Attorney

The person you have chosen and named in your advance directive to make healthcare decisions for you if you can not communicate

Also called: healthcare proxy, healthcare agent, medical power of attorney

Five Wishes calls this person a "healthcare agent"

Maine Advance Care Directive calls this person a "medical decision maker"

A healthcare power of attorney does not address your finances or your assets

A "healthcare power of attorney" is not the same as a "power of attorney"

A "power of attorney" is a "financial power of attorney" and is not related to healthcare

To avoid confusion, it may be best not to use the term "attorney" when referring to healthcare

What is …

Financial Power of Attorney
Part of "Advanced Care Planning" but NOT part of an "Advance Directive"

Someone who is legally authorized to act on your behalf with some or all of your assets such as bank accounts, income taxes, investments, real estate; you choose what power s/he has

You can choose to have your power of attorney be in effect only while you remain mentally capable (a general power of attorney); or remain in effect when you are incapacitated (a durable power of attorney)

You can terminate the authority of your financial power of attorney any time

The financial power of attorney cannot transfer power to another person

Power of all powers of attorney (healthcare power of attorney *and* financial power of attorney) end at the time of your death; the financial power of attorney does not manage your assets after your death

Explain or define terms related to Advance Care Planning

What is …

Living will

The part of an ADVANCE DIRECTIVE that identifies how you want to be treated if you are unable to communicate your needs and wishes

The word “will” (or “last will and testament”) refers to a legal document addressing assets and is not related to healthcare

To avoid confusion, it may be best to use the words “part of the advance directive”

Last Will and Testament

A legal document addressing distribution of your assets after your death; not related to healthcare

Names a personal representative (executor) to carry out the terms of your will; names beneficiary(s)

Must go through the probate process before your assets can be distributed; in Maine a judge is usually not involved unless there are irregularities or there is disagreement between heirs or involving creditors

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)

Explain or define terms related to Advance Care Planning

What is …

Financial Trust
A legal document granting ownership of your property to another person or institution, managed by a trustee, and which does not go through the probate process

Can be revocable or irrevocable

Beneficiary
A person you designate to receive money or property after your death

Any beneficiary(s) designated on a financial account trumps the will

Without a lawyer you can make a legally binding list of personal property indicating what goes to whom, as long as that property is not titled; your list must be handwritten in ink, signed, dated, and paper-clipped to your will

Property Title
Names the owner(s) of an asset; disposition is controlled by a will and goes through probate

There are different types of joint titles:

1) The entire asset may belong to the joint partner at the time of your death
2) You determine the beneficiary of your half of the asset (tenants in common)

Explain or define terms related to Advance Care Planning

What is …

Legacy
A written communication to others about your feelings and/or thoughts and/or knowledge and experiences

Sometimes called an "ethical will"; to *avoid confusion, it may be best to use the word "legacy"*

Life Sustaining Treatments
Medical interventions to maintain life, including: mechanical ventilation, renal dialysis, and nutritional support via tube feeding or intravenous infusion

Life sustaining medical interventions are usually uncomfortable, may cause complications, are expensive, may be distressing to loved ones; and may be ineffective in prolonging meaningful life for someone with a life-limiting illness

Do Not Resuscitate (DNR) and Allow Natural Death (AND) orders
A medical order to prevent interventions to restore breathing and heartbeat after they have stopped

The DNR or AND order is signed by a licensed healthcare provider (medical doctor, certified nurse practitioner, physician's assistant)

An advance directive form may provide space for a DNR request, but it can not legally be honored unless there is a separate DNR or AND order

What is …

Portable Medical Order (POLST = Physician Orders for Life-Sustaining Treatment)
A portable medical order intended for seriously ill or frail individuals nearing end of life which provides direction for medical treatment, including resuscitation

The POLST form accompanies the individual when transporting to/from locations such as extended care to/from acute care facility

A POLST is not an advance directive: it does not name a healthcare proxy and it does not address the individual's wishes for care

Explain or define terms related to Advance Care Planning

What is …

Alternative Funerals

You have choices about the disposition of your body after death

- Burial
  - Under ground in a cemetery or in a family cemetery
  - In a green cemetery with no embalming
- Cremation
  - Direct in a crematorium with no embalming
  - Alkaline hydrolysis
- Organ or full body donation

Costs vary from $0 to under $1000 to more than $10,000

No matter where your body goes, you can have a funeral, memorial service or celebration of life gathering

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 self administered, will hasten the end of their life

Requires the participation of a Maine licensed physician

The signed request can be rescinded at any time

Explain or define terms related to Advance Care Planning

What is …

The "Red Book"

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

- Location of advance directive and will
- Password list: phone, tablet, computer, email, social media, etc
- Your social security number
- Location of cash and of bank account information for paying bills
- List of current outstanding debts
- Location of financial account(s) information
- List and location of valuables
- Location of keys: house, car, safe deposit box, etc
- 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
- ???

PS… the book is meant to be READ
but it does not have to be RED!

Web links

THE CONVERSATION

The Conversation Project: https://theconversationproject.org

Go Wish cards: www.codaalliance.org/go-wish

Hello cards: www.commonpractice.com/products/hello-game

Life Planning Conversations Seminar sponsored by Maine Council on Aging and Tri-State Learning Collaborative on Aging, January 16, 2024: https://vimeo.com/903530678?share=copy

Serious Illness Messaging: www.seriousillnessmessaging.org

Web links

ADVANCE DIRECTIVE

Five Wishes: www.fivewishes.org

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

Maine Death with Dignity Act: www.mainedeathwithdignity.org

ALTERNATE FUNERAL ARRANGEMENTS

Funeral Consumers Alliance of Maine: www.fcamaine.net

Last Things: www.lastthings.net

Die Well Death Education: www.diewelldeatheducation.com

More Web links

CaringInfo, a program of the National Hospice and Palliative Care Organization: www.caringinfo.org

Maine State Bar Association to find a Maine attorney to assist in writing a will: www.mainebar.community.lawyer

Maine POLST: www.mainehospicecouncil.org/about-us/polst-maine-physician-orders-for-life-sustaining-treatment

Maine DNR form: www.maine.gov/ems/protocols-resources/comfort-care-dnr-program

Death with Dignity Life Files to download: www.deathwithdignity.org/resources/?p-type=the-life-file (*you can unsubscribe)*

[day], [,month, date]
9:00 am to 12:00 noon
[Location]

Planning now for later

You *DO* have choices for living well

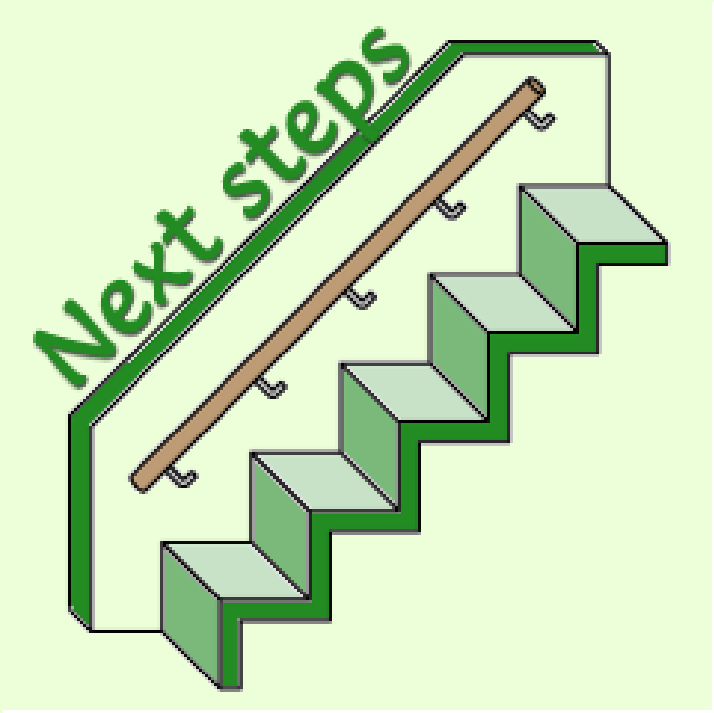
Join us to learn what *you* can do

A *free* Pine Tree Hospice Community Gathering

Folks in our community will feel comfortable enough to be able to tell others what matters to them when they reach end of life.

By the end of the session, community participants will:

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 living at the end of life issues



Share with the community

How do we make that happen ???

For the community gathering

Handouts for attendees (*the same packet you have now*):

1) Outcomes; Agenda; How to Reach Us
2) Some Definitions and Some Web Links
3) Five Wishes Advance Directive Form
4) Prompts for Preferences List
5) List of Important Information for the "Red Book"
6) Evaluation form

Activities:

~ Introductions; explanation of information in packet of handouts

~ Random questions about advance care planning, divided by topic, will be addressed

~ Each attendee will have about 15" to begin to fill in the Five Wishes advance directive form

~ With another person, each attendee will have about a half hour to practice starting the conversation with the "Prompts for Preferences" list

~ Peruse resource table

~ Distribute answers to all discussion questions at end of gathering

Basket Questions for the community gathering

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

Questions are divided into 4 topics:

Advance Directive questions are coded blue
Finance and Asset questions are coded green
Funeral Arrangement questions are coded yellow
Conversation questions are coded pink

Adherence to schedule is important

- ❀ Distributes attention to topics appropriately
  For example, time allotted to financial issues is limited to 15 minutes
- ❀ Within topic's time allotment, leaders are free to be engaging
  For example, soliciting questions, providing examples, sharing anecdotes, clarifying confusion, offering suggestions for finding further information

Planning now for later You *DO* have choices for living well	
¼ hr *or less*	Greeting; introduction; rest rooms Explain handout information in packets and basket question format State that answers to ALL questions will be distributed
1 hr	**Basket questions:** **Advance directive** 
¼ hr with break	With pencil, begin to complete the Five Wishes advance directive
¼ hr	**Basket questions:** **Disposition of finances and other assets** 
¼ hr	**Basket questions:** **Funeral arrangements and memorials** 
½ hr	**Basket questions:** **Starting "the conversation"** 
½ hr with break	With another person, practice starting the conversation using the "Prompts for Preference List"
¼ hr *or less*	Q&A Peruse resource table Distribute handout: basket question answers

Some tips for the community gathering

Watch the clock

- Keep the promise… start and end on time
- Stick to the schedule… address topics as planned

Field questions

- It's OK if you can not answer someone's question … we're not supposed to know everything !
- "I don't know, but I'll find out and let you know *(tell them how)*_____"
- *or* "I don't know but you can find that information *(tell them where)*_____"

} are fine answers

- Write down the question… maybe it should be included as part of the presentation next time

Engage attendees

- Make gentle, brief eye contact with each one
- Notice if someone appears uncomfortable… approach them at break time or afterwards
- Offer the basket to folks who don't volunteer (but only once ☺)
- Circulate, offer guidance, during practice sessions

Where do we go from here ???

- You can choose to work alone or with another facilitator

- PTH will coordinate with you to establish a date, time and place for your community gathering

- Facilitator will need to pick up from the PTH office:
  1) Basket with laminated questions, divided by topic
  2) Packets of handouts for the participants
  3) Answers to basket questions to be given to participants at the end
  4) Copies of the Five Wishes Advance Directive form
  5) Pencils for participants
  6) Box of items for the resource table
  7) Refreshments

- Facilitator will need to return to the PTH office: basket with questions, box of resource table items, extra copies of the handouts, and the evaluations