



Aging Care Consultation Services

*Helping you
solve your puzzle
so all the pieces
fit into place*

Karin Taifour, MA LMHC GMHS
206.999.5934

Karin @ agingcareconsult.com

National Healthcare Decisions Day:

Helping your clients with advance care planning



Aging Care Consultation Services

*Helping you
solve your puzzle
so all the pieces
fit into place*

Karin Taifour, MA LMHC GMHS
206.999.5934

Karin @ agingcareconsult.com

I help older adults and families figure things out,
and I provide professionals with training and advice.

***You're always welcome to call or email me
for free information and resources!***

Today

- About National Healthcare Decisions Day
- About advance care planning
 - Why it's important
 - What's involved
- How to open the conversation with others about their wishes
- Tools for you to use

National Healthcare Decisions Day

- This year on April 16
- Collaborative effort of national, state and community organizations
- To inspire, educate and empower the public and providers about the importance of advance care planning.
- To encourage patients to express their wishes regarding healthcare and for providers and facilities to respect those wishes, whatever they may be.

Founded by Nathan Kottkamp in Virginia

- 2006: Virginia Advance Directives Day, went nationwide in 2008.
- “I was just 20 years old when I completed my own advance directive. I was in college, working for a healthcare decisions advocacy group... I was so young, but... the three most famous cases regarding health care decision-making involved women in their twenties: Karen Ann Quinlan, Nancy Cruzan, and Terri Schiavo.”
- “I hope that everyone will realize that advance care planning is a gift to loved ones.... Sometimes we just need a catalyst. National Healthcare Decisions Day is it.”

ACP: not just about old age

- At any age, at any time, a medical crisis could leave you too ill to make your own healthcare decisions.
- Even if you are okay now, making decisions and documenting your choices today can help make sure you get the medical care you would want if you are unable to speak for yourself.
- It also provides guidance and direction when doctors and family members are making the decisions for you.

We know what we want...

Nearly 80% of people say they would prefer to die at home.

- Almost **75%** of people **don't** die at home.
- People without ACP are **moved 3x** on average in the last few weeks of life.
- Having a Living Will is associated with decreased likelihood of dying in a hospital.

About 80% of people don't want their life extended by machines.

- Use of mechanical ventilation in 90 days prior to death has increased in the last 15 years.

We say... but...

82% of people say it's important to put their wishes in writing, but

- Only 23% have actually done it.

90% of people say that talking with their loved ones about end of life care is important, but

- Only 27% have actually done so.

60% of people say making sure their family is not burdened by tough decisions is "extremely important" but

- 56% have not communicated their end of life wishes.

When DO we talk? In a crisis

- 70% of family conversations about aging are prompted by an event such as a health crisis or other emergency
- Estate-planning attorneys recommend talking about aging and end of life issues before a parent is 70 and before an adult child is 40.
- 66% of families' court cases about aging or end of life issues could have been avoided if there had been discussion and documentation of wishes in advance.

In life we prepare for everything

College, marriage, a baby, retirement

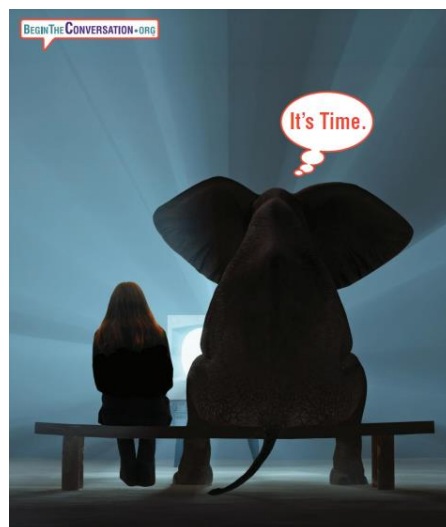
But we rarely begin the conversation about the end


Begin to **LEARN, PREPARE, ACT, CHOOSE, TAKE CONTROL**




Take the first step

EMPOWER - DON'T WAIT - IT'S TIME


BEGIN THE CONVERSATION.....It's a Gift.





(877) 473-4103   

BEGIN CONVERSATIONS RESOURCES ABOUT CONTACT



FACING THE ELEPHANT IN THE ROOM?

Learn how to take the first steps to Begin The Conversation.

You first! Model the way

- Think about your experiences with the end of loved ones' lives – and about what you do and don't want at end of life.
- Think about your values — what makes your life worth living and what you consider quality of life.
- Think about your own preferences and put your decisions in writing.
- When you communicate your wishes, you may realize you need to rethink who you chose as your proxy – that person needs to be able to carry out your directives. Some people may not be able to do what you would want.

Advance care planning – what's involved

- Thinking about your values
- Learning about options
- Talking about your decisions
- Documenting your wishes

Remember

- Best to decide before a crisis.
- Plans and directives can be changed as your situation or wishes change.
- This process is typically done over time, not in a single conversation.

Think about your values

- your religious or spiritual beliefs?
- your wish to have a dignified death?
- our wish to be spared pain?
- your wish to avoid burdening family and friends emotionally?
- your wish to avoid burdening others financially?
- your wish to avoid being dependent on others?
- the wishes of other family members regarding your care?
- your wish to live as long as possible?

*(adapted from Laraine Winter (2013). Journal of Palliative Medicine. 362-368.
<http://doi.org/10.1089/jpm.2012.0303>)*

Learn about treatment/care options

In general, there are various choices for care in different scenarios:

- CPR (cardiopulmonary resuscitation)
- Ventilator use
- Artificial nutrition (tube feeding)
- Artificial hydration (intravenous fluids)
- Comfort care
- Location of care

“The inevitability of death is one of the few certainties in medicine – but the trajectory toward dying has many surprises.”
-- Richard Stuart, UW

If you are facing an issue now

- You’ll need more specific information about your prognosis, treatment options, side effects, etc.
- Keep in mind:
 - HOPE is an emotion, EXPECTATION is a cognition.
 - Both matter, but radical acceptance is the basis of making good decisions.

Of course we are hoping for the best. Let’s plan for that. But let’s also make a plan for what you would want to happen if things don’t go as well as we’d hoped.

Talking About Your Decisions

- Valuable opportunity to reflect on what's important with loved ones
- Discussion needs to happen before a crisis
- Can provide comfort to your loved ones
- Is up to YOU to initiate the process!

Documenting Your Decisions

- Advance directives document your healthcare decisions regarding care or treatment, if you cannot communicate your wishes.
- These documents do not expire and can be updated as needed.

Two legal forms are available:

- Healthcare Power of Attorney
 - Living Will
- ... and also, the Dementia/Mental Health Advance Directive

Healthcare Power of Attorney

- Document designating who makes medical decisions about your healthcare if you are not able to do so.
- Can name a primary and a secondary, in case someone is unavailable with you need help.

May also be called a:

- "healthcare proxy or agent"
- "healthcare surrogate"
- "POA for healthcare"
- "attorney in fact"

Your Healthcare Agent

- Can be anyone over the age of 18* (19 in Nebraska)
- Can be a family member, loved one or close friend

Your agent should be someone who:

- You trust
- Knows you well
- Will advocate in your behalf
- Will honor your wishes

Living Will

- States what you want and do not want in terms of medical treatment at the end of life.

May also be called:

- Directive to physicians
- Healthcare declaration
- Medical directive
- Advance care directive

Dementia / Mental Health Directives

- 2002: WA created a Mental Health Advance Directive, which was tailored to create the Alzheimer's Disease/Dementia Mental Health Advance Directive.
- To create one, you must be an adult with capacity to understand the possible risks and benefits of your choices.
- **Because this document offers the option of permanently giving away your rights to make certain decisions**, it is very important that you read and fully understand these instructions and the entire Directive, before you complete and sign the Directive.

Dementia/MH Directive

- This Directive does not document your wishes for medical or end of life care – for that you need a Living Will / Healthcare Directive.
- Although WA law states your Directive should be followed to the “fullest extent possible,” it does not guarantee that all your choices can/will be honored by your family or health care providers.
- Because this Directive is based on Washington State law, it may not be legal or honored in other states. And although other states have enacted mental health advance directives, legal requirements differ from state to state.

After you’re done with YOU

- Then you’re ready to take the conversation to others.
- “Knock first” -- if they are not prepared for this type of conversation, it can be very difficult.
- Let them know you want to talk about your decisions and would like to hear their thoughts.
- Think about which would be best -- for them, and for you: a group/family talk or one-on-one.

Keep in mind

- It's better to prepare 10 years to early than 1 day too late.
- Don't rush. It's a process – not something to accomplish quickly.
- You and loved ones might disagree on things, and that's okay.
- You can't figure out every possible scenario. Stick to basics and guidelines.
- It doesn't have to be 100% serious – you can use humor. Don't make a simple process complicated.

Before you start

Make a safe space

- Ensure privacy
- Limit distractions
- Allow enough time
- Be supportive and non-judgmental

Use good communication skills.

- Avoid medical jargon
- Use empathetic listening skills
- Use positive language: *I want to ensure you receive the kind of treatment you want.*

Launching

- A trigger event can bring up the topic:
 - Death or funeral of another person,
 - A news story or article,
 - A book, TV episode, or film,
 - Sermons or faith services, or
 - Medical checkups.
- Open the conversation by sharing your own thoughts, rather than putting them on the spot.

*Did you see
that ____?*

*I found myself
thinking ____.*

Test the waters...

- Share what you thought about it, and ask them what they thought about it. See if this can lead to deeper conversations.
- Be prepared to have more than one conversation or that the subject may cause an emotional reaction.

This is ok.

*What did you
think?*

*How did you
feel about ____?*

Conversation starters: share your wishes

- *I need your help with something.*
- *Even though I'm okay right now, I'm worried about ____ and I want to be prepared.*
- *I've recently completed my advance care planning documents and I wanted to share them with you, so you would know what I want.*
- *If anything were to happen to me, I don't want you to stress over what to do for me, so I've written things down.*

Conversation starters: share your wishes

- *I know that this isn't easy to talk about, but if I get sick or have an accident, and can't make medical decisions for myself, I've thought about what would be important to me.*
- *I thought about what happened to ____ and it made me realize ____.*
- *If something happened to me, I would want ____.*
- *I would want ____ to make medical decisions on my behalf.*

Asking about their wishes

- After sharing your wishes:
 - *I've been wondering what would be most important to you, if you were not able to speak for yourself?*
- After a movie or news story:
 - *What would you want if you were in this situation?*

If it's too much right now

- *While I was in the doctor's office, I saw a brochure about advance care planning. I'd like to leave it for you to read so we could discuss it later?*
- *Thinking about getting sick can be scary. I understand if this is too much to talk about right now. Later on, could you think about what's important to you, so that we could discuss it together?*
- *It was hard for me to think about these things too. But I did it, and I feel better with some things decided. I can help you, or we can get someone else to help us through this.*

Asking about their wishes

- *Remember how ___ died? Was it a “good” death or a “hard” death? How would you want yours to be different?*
- *Do you have any particular concerns about your health? About the rest of your life?*
- *Are there any disagreements or family tensions that you’re worried about?*

Asking about their wishes - questions

- *What gives your life the most meaning?*
- *What do you want and not want at the end of life?*
- *Who should speak for you?*
- *What one thing do you want to be sure your doctors, family and friends know about your wishes?*

Asking about their wishes - questions

- *Would you want the doctors to try aggressive treatments, even if they wouldn't cure you, to give you more time?*
- *Or would you rather have doctors manage your pain or disease so you feel better but might not live as long?*
- *Would you rather be in a hospital or at home? Who would you want to be around you?*

Take notes – be on the same page

- Write down what you've discussed, and make a copy if possible.
- Be sure to clarify:
 - Who should / should not be informed of this conversation, as well as in the future, with regard to decision-making?
 - Are there people who should be present to hear things at the same time (like siblings who tend to disagree)?

Follow up afterward

- Review your notes to check:
 - Is there anything you don't understand, or need to clarify?
 - Is there something more you need to talk about?
- Call, email, or send a card to thank them for talking with you about this tough topic.

All done? Not quite...

- After you've done the hard work of thinking things through and creating your documents, now you have to make sure people know about them.
- Make copies and share them with your family members, significant others, doctors, attorney, clergy, etc.

*The single biggest problem in communication
is the illusion that it has taken place.*

-- George Bernard Shaw

A note about people not as close

- People who are not close by or not as closely involved may be the ones to cause conflict when it is time to make hard decisions and implement your wishes. This may happen because they feel guilty.
- By sharing your wishes with them, you have a chance to save your loved ones from that conflict.

Remember, these documents are a gift to those you care about.

What can you do?

- Talk to your loved ones
 - “Since today is National Healthcare Decisions Day, I want to take this opportunity to talk with you about my decisions for healthcare if I am ever in a situation that I can not speak for myself like Terri Schiavo [or ____].”
- Complete your advance directive
- Encourage others to do the same



When? NOW.

“The future depends on what we do in the present.”

– Mahatma Gandhi

“It’s always too soon until it’s too late.”

- unknown



Aging Care Consultation Services

*Helping you
solve your puzzle
so all the pieces
fit into place*

Karin Taifour, MA LMHC GMHS
206.999.5934

Karin @ agingcareconsult.com

This presentation and other resources are on my website for you to download – and please feel free to share.

Again, you’re always welcome to call or email me for free information and resources!