Advance Care Planning
Facing Alzheimer's with Dignity: Empowered Choices for a Hopeful Future

Advance Care Planning Program (ACP) Coordinators
Mary Arbuckle, CISW
Parini Tolat, LCSW

UW Health's Advance Care Planning Program Coordinators

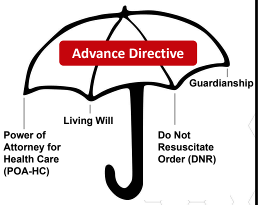
Mary Arbuckle	Parini Tolat
MSW, CISW, CCM	MSW, LCSW
2012 graduate of UW-Madison School of Social Work	2007 graduate of Portland State University School of Social Work
10+ years with UW Health	13+ years with UW Health
Areas of expertise: ACP, guardianship, case consultation, complex discharge planning, long-term care placement	*Areas of expertise:* ACP, case consultation, palliative care, neurological care coordination, member of hospital ethics committee

---

What is Advance Care Planning (ACP)?

Planning ahead for future health care decisions if a sudden, unexpected event (like a car accident or sudden illness) left you unable to communicate and make your own healthcare decisions and others would need to make decisions for you.

The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.



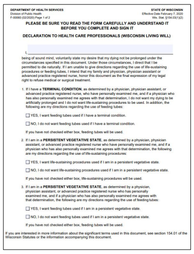
Sudore R, et al. Defining advance care planning for adults: A consensus definition from a multidisciplinary Delphi panel. Journal of Pain and Symptom Management. 2017. 53(5):821-832.

Why is ACP Important?

1. Dementia is the most common reason people lose the ability to guide their own care, so expressing and documenting your wishes in advance is very important*
2. It can help people feel more in control of their life and their health care
3. It can help reduce stress and conflict for loved ones if a person is unable to make health care decisions for themself
4. It can help ensure people receive the care that is most important to them
5. Health Care Agents have legally recognized status as a health care decision maker

*Source: Dementia Action Alliance

Living Will (Declaration to Physicians)



DEPARTMENT OF HEALTH SERVICES
Division of Public Health
F-00060 (02/2020) Page 1 of 2

STATE OF WISCONSIN
Effective Date February 7, 2020
Wis. Stat. §154.03(1)(2)

PLEASE BE SURE YOU READ THE FORM CAREFULLY AND UNDERSTAND IT BEFORE YOU COMPLETE AND SIGN IT

DECLARATION TO HEALTH CARE PROFESSIONALS (WISCONSIN LIVING WILL)

I, ______________________________

being of sound mind, voluntarily state my desire that my dying not be prolonged under the circumstances specified in this document. Under those circumstances, I direct that I be permitted to die naturally. If I am unable to give directions regarding the use of life-sustaining procedures or feeding tubes, I intend that my family and physician, physician assistant or advanced practice registered nurse, honor this document as the final expression of my legal right to refuse medical or surgical treatment.

1. If I have a **TERMINAL CONDITION**, as determined by a physician, physician assistant, or advanced practice registered nurse, who have personally examined me, and if a physician who has also personally examined me agrees with that determination, I do not want my dying to be artificially prolonged and I do not want life-sustaining procedures to be used. In addition, the following are my directions regarding the use of feeding tubes:

   ☐ YES, I want feeding tubes used if I have a terminal condition.

   ☐ NO, I do not want feeding tubes used if I have a terminal condition.

   If you have not checked either box, feeding tubes will be used.

2. If I am in a **PERSISTENT VEGETATIVE STATE**, as determined by a physician, physician assistant, or advanced practice registered nurse who have personally examined me, and if a physician who has also personally examined me agrees with that determination, the following are my directions regarding the use of life-sustaining procedures:

   ☐ YES, I want life-sustaining procedures used if I am in a persistent vegetative state.

   ☐ NO, I do not want life-sustaining procedures used if I am in a persistent vegetative state.

   If you have not checked either box, life-sustaining procedures will be used.

3. If I am in a **PERSISTENT VEGETATIVE STATE**, as determined by a physician, physician assistant, or advanced practice registered nurse who has personally examined me, and if a physician who has also personally examined me agrees with that determination, the following are my directions regarding the use of feeding tubes:

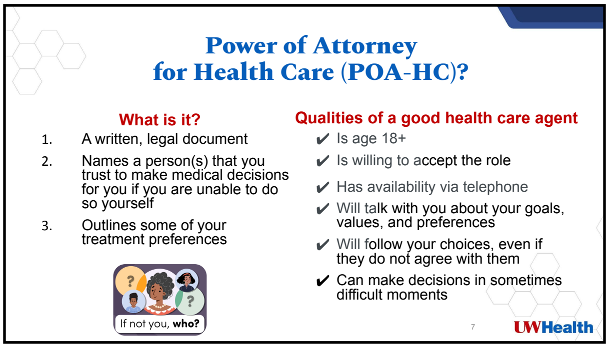
   ☐ YES, I want feeding tubes used if I am in a persistent vegetative state.

   ☐ NO, I do not want feeding tubes used if I am in a persistent vegetative state.

   If you have not checked either box, feeding tubes will be used.

If you are interested in more information about the significant terms used in this document, see section 154.01 of the Wisconsin Statutes or the information accompanying this document.

- Documents health care wishes regarding life-sustaining procedures and feeding tubes
- Used only if the patient has a terminal condition or is in a persistent vegetative state
- Does not designate a decision maker



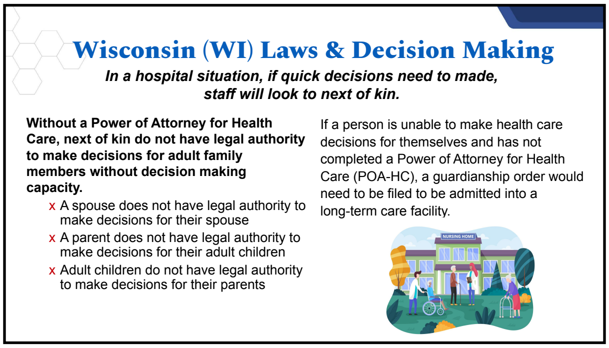
Power of Attorney for Health Care (POA-HC)?

What is it?

1. A written, legal document
2. Names a person(s) that you trust to make medical decisions for you if you are unable to do so yourself
3. Outlines some of your treatment preferences

Qualities of a good health care agent

- ✔ Is age 18+
- ✔ Is willing to accept the role
- ✔ Has availability via telephone
- ✔ Will talk with you about your goals, values, and preferences
- ✔ Will follow your choices, even if they do not agree with them
- ✔ Can make decisions in sometimes difficult moments



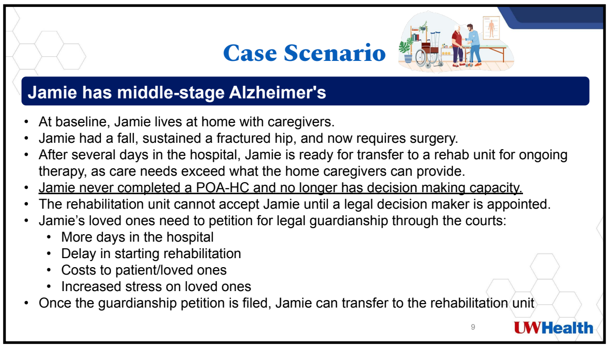
Wisconsin (WI) Laws & Decision Making

In a hospital situation, if quick decisions need to made, staff will look to next of kin.

Without a Power of Attorney for Health Care, next of kin do not have legal authority to make decisions for adult family members without decision making capacity.

- x A spouse does not have legal authority to make decisions for their spouse
- x A parent does not have legal authority to make decisions for their adult children
- x Adult children do not have legal authority to make decisions for their parents

If a person is unable to make health care decisions for themselves and has not completed a Power of Attorney for Health Care (POA-HC), a guardianship order would need to be filed to be admitted into a long-term care facility.

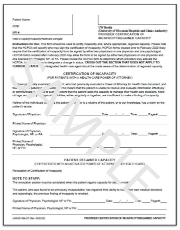


Case Scenario

Jamie has middle-stage Alzheimer's

- At baseline, Jamie lives at home with caregivers.
- Jamie had a fall, sustained a fractured hip, and now requires surgery.
- After several days in the hospital, Jamie is ready for transfer to a rehab unit for ongoing therapy, as care needs exceed what the home caregivers can provide.
- <u>Jamie never completed a POA-HC and no longer has decision making capacity.</u>
- The rehabilitation unit cannot accept Jamie until a legal decision maker is appointed.
- Jamie's loved ones need to petition for legal guardianship through the courts:
  - More days in the hospital
  - Delay in starting rehabilitation
  - Costs to patient/loved ones
  - Increased stress on loved ones
- Once the guardianship petition is filed, Jamie can transfer to the rehabilitation unit

When Does a Health Care Agent's Authority Begin?



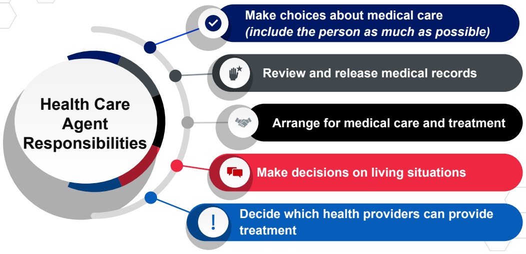
The POA must be activated

Two providers (MD, DO, NP, PA, or Psychologist) must:

- ✔ Examine the individual AND
- ✔ Sign a statement certifying the person is incapacitated

UWHealth

What is the Role of a Health Care Agent?



Health Care Agent Responsibilities

- Make choices about medical care *(include the person as much as possible)*
- Review and release medical records
- Arrange for medical care and treatment
- Make decisions on living situations
- Decide which health providers can provide treatment

UWHealth

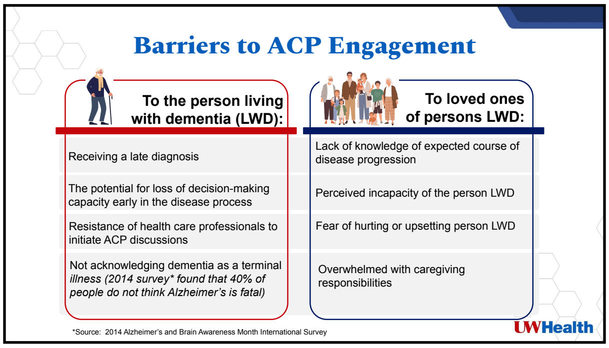
When is the "Right Time" for ACP?

Every adult over the age of 18, regardless of their health, should complete a Power of Attorney for Health Care.

Once signs of cognitive impairment appear, it can be difficult for someone to think about future health care decisions for the first time.

ACP is a process, not a one-time event. It's best to review your wishes and POA-HC on the 5Ds.

UWHealth

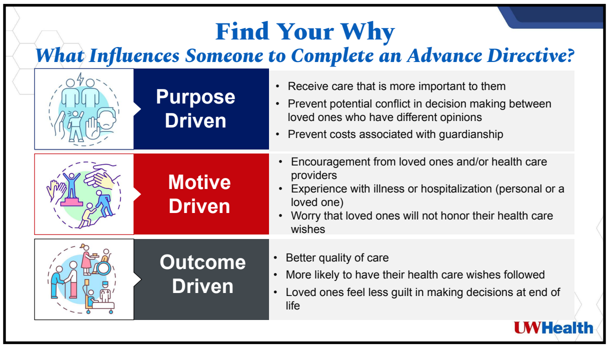


Barriers to ACP Engagement

To the person living with dementia (LWD):	To loved ones of persons LWD:
Receiving a late diagnosis	Lack of knowledge of expected course of disease progression
The potential for loss of decision-making capacity early in the disease process	Perceived incapacity of the person LWD
Resistance of health care professionals to initiate ACP discussions	Fear of hurting or upsetting person LWD
Not acknowledging dementia as a terminal *illness (2014 survey* found that 40% of people do not think Alzheimer's is fatal)*	Overwhelmed with caregiving responsibilities

*Source: 2014 Alzheimer's and Brain Awareness Month International Survey

UWHealth

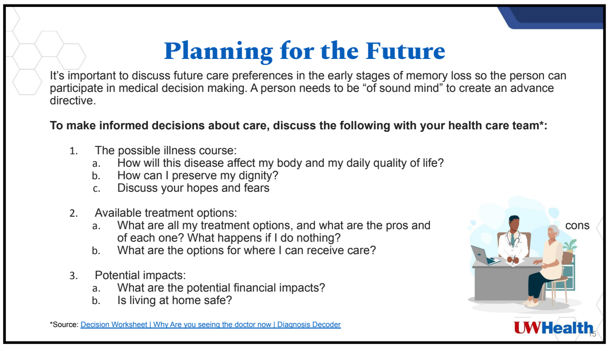


Find Your Why

What Influences Someone to Complete an Advance Directive?

Purpose Driven	Receive care that is more important to them Prevent potential conflict in decision making between loved ones who have different opinions Prevent costs associated with guardianship
Motive Driven	Encouragement from loved ones and/or health care providers Experience with illness or hospitalization (personal or a loved one) Worry that loved ones will not honor their health care wishes
Outcome Driven	Better quality of care More likely to have their health care wishes followed Loved ones feel less guilt in making decisions at end of life

UWHealth



Planning for the Future

It's important to discuss future care preferences in the early stages of memory loss so the person can participate in medical decision making. A person needs to be "of sound mind" to create an advance directive.

To make informed decisions about care, discuss the following with your health care team*:

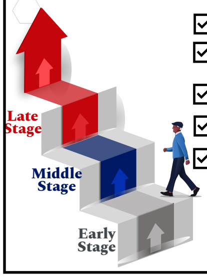
1. The possible illness course:
   a. How will this disease affect my body and my daily quality of life?
   b. How can I preserve my dignity?
   c. Discuss your hopes and fears
2. Available treatment options:
   a. What are all my treatment options, and what are the pros and cons of each one? What happens if I do nothing?
   b. What are the options for where I can receive care?
3. Potential impacts:
   a. What are the potential financial impacts?
   b. Is living at home safe?

*Source: Decision Worksheet | Why Are you seeing the doctor now | Diagnosis Decoder

UWHealth

Dementia Across the Stages

ACP Guidance: Early-Stage Diagnosis



☑ **Identify a surrogate decision maker**

☑ **Review goals, values, and what matters most to you.** Completing a dementia specific addendum can help guide you through this step.

☑ **Consider any spiritual, cultural, or religious beliefs**

☑ **Think about code status preferences**

☑ **Complete a Power of Attorney for Health Care**
Recommended free forms:
1) WI Medical Society Advance Directive including POA-HC *(expanded form allowing you to choose up to 3 health care agents and document additional health care wishes)*
2) State of WI POA-HC *(short form allowing you to choose up to 2 health care agents and document brief statements of desires, special provisions, and limitations.)*

UWHealth

Dementia Specific Addendums

A Dementia Specific POA-HC Addendum advises loved ones and medical providers of the wishes of a person with dementia.

It can include preferences about:

- Quality of life preferences across the stages of dementia
- Activities of daily living (bathing, toileting, eating, dressing, etc.)
- Cognition
- Communication
- Ambulation
- Mood and behavior
- Out of home care
- Oral eating and drinking/artificial nutrition and hydration

For those who want to provide specific guidance, there are several options they can use:

- Dementia-directive.org
- Compassionandchoices.org
- Write a simple letter outlining wishes

IMPORTANT!

You must also complete a POA-HC. Once the dementia specific addendum is completed, signed, and witnessed (follow the same witnessing requirements as their POA-HC), attach it to the POA-HC.

UWHealth

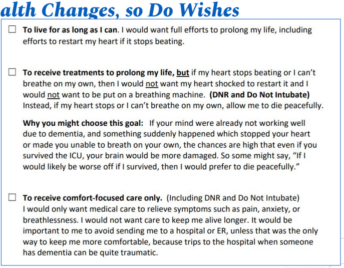
Example: Dementia Specific Addendum:

Just as Health Changes, so Do Wishes

Complete for each stage of dementia *(early, middle and late)*

If I have

____________ stage dementia, I would want the main goal for my care to be:



☐ **To live for as long as I can.** I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.

☐ **To receive treatments to prolong my life, but** if my heart stops beating or I can't breathe on my own, then I would not want my heart shocked to restart it and I would not want to be put on a breathing machine. **(DNR and Do Not Intubate)** Instead, if my heart stops or I can't breathe on my own, allow me to die peacefully.

Why you might choose this goal: If your mind were already not working well due to dementia, and something suddenly happened which stopped your heart or made you unable to breath on your own, the chances are high that even if you survived the ICU, your brain would be more damaged. So some might say, "If I would likely be worse off if I survived, then I would prefer to die peacefully."

☐ **To receive comfort-focused care only.** (Including DNR and Do Not Intubate) I would only want medical care to relieve symptoms such as pain, anxiety, or breathlessness. I would not want care to keep me alive longer. It would be important to me to avoid sending me to a hospital or ER, unless that was the only way to keep me more comfortable, because trips to the hospital when someone has dementia can be quite traumatic.

Source: Dementia-directive.org

UWHealth

Example: Dementia Specific Addendum

Thinking Through Values & Priorities

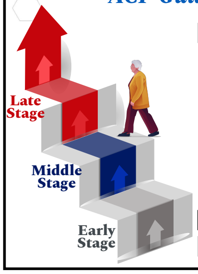
If I am unable to walk or move safely without assistance from a caregiver then I want	Live as Long as Possible ○	Treat me but Not Aggressively ○	Allow a Natural Death ○
If I am unable to bathe and clean myself without assistance from a caregiver, then I want	Live as Long as Possible ○	Treat me but Not Aggressively ○	Allow a Natural Death ○
If I am unable to remain at home and have to live in a nursing facility, then I want	Live as Long as Possible ○	Treat me but Not Aggressively ○	Allow a Natural Death ○
If I no longer have control of my bladder (urinary incontinence) or bowels (bowel or fecal incontinence), then I want	Live as Long as Possible ○	Treat me but Not Aggressively ○	Allow a Natural Death ○
If I am no longer aware of my surroundings (where I am, the date/year, who is with me), then I want	Live as Long as Possible ○	Treat me but Not Aggressively ○	Allow a Natural Death ○
If I am unable to clearly communicate my thoughts or needs (words and phrases do not make sense), then I want	Live as Long as Possible ○	Treat me but Not Aggressively ○	Allow a Natural Death ○

- **Live as Long as Possible** - My goal is to live as long as possible and receive aggressive medical care and life-saving treatments. This could include calling 911, going to the hospital, CPR, nutrition support, artificial hydration or breathing assistance if needed.
- **Treat me but not Aggressively** - I want to continue medication for chronic health conditions and treatment for illness. I want to avoid surgery, long-term feeding tubes, aggressive treatment and other life-prolonging care.
- **Allow a Natural Death** – Focus on comfort care, avoiding medications and treatments that prolong life. This could include stopping dialysis or blood transfusions, avoiding surgery, turning off a pacemaker or withdrawing treatment for heart disease, diabase and other health conditions.

Source: compassionandchoices.org (Dementia Advance Directive)

Dementia Across the Stages

ACP Guidance: Middle-Stage Diagnosis



☑ **Assess their capacity to review or complete a POA-HC.** Take breaks and do the document in sections. Recommended free form: State of WI POA-HC
(short form allowing you to choose up to 2 health care agents and document brief statements of desires, special provisions, and limitations.)

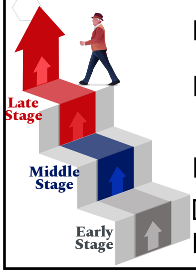
☑ **Remind the person with memory loss about their experiences with someone at the end of life (i.e. remember when grandma died?)** Explore how they felt about it, and their previously expressed views. What went well? What didn't go well?
Storytelling can be powerful.

☑ **Consider any spiritual, cultural, or religious beliefs**

☑ **Review code status preference**

Dementia Across the Stages

ACP Guidance: Late-Stage Diagnosis



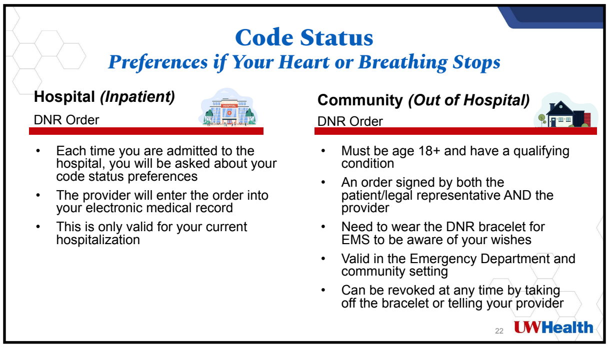
☑ **Consider if guardianship is needed if no POA-HC exists**
Recommended resource: Guardianship Support Center

☑ **When making decisions for the person LWD, it can be helpful to think about how the person lived their life. Think about what values and wishes they expressed in the past.**

☑ **What can be done to promote quality of life? How can you best advocate to ensure wishes are honored?**

☑ **Consider any spiritual, cultural, or religious beliefs**

☑ **Review code status preference**



Code Status

Preferences if Your Heart or Breathing Stops

Hospital *(Inpatient)*

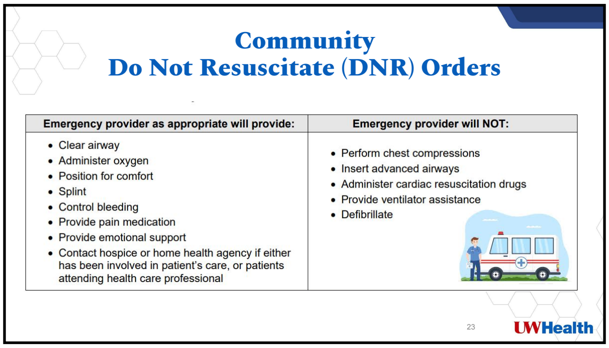
DNR Order

- Each time you are admitted to the hospital, you will be asked about your code status preferences
- The provider will enter the order into your electronic medical record
- This is only valid for your current hospitalization

Community *(Out of Hospital)*

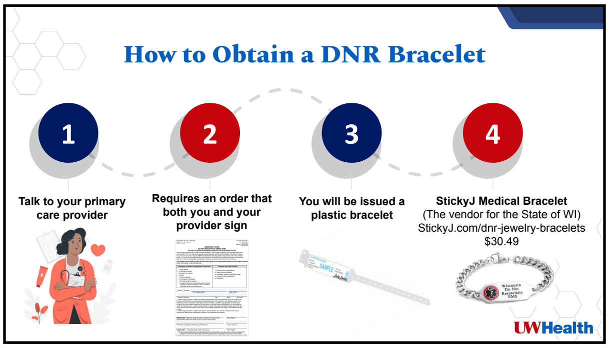
DNR Order

- Must be age 18+ and have a qualifying condition
- An order signed by both the patient/legal representative AND the provider
- Need to wear the DNR bracelet for EMS to be aware of your wishes
- Valid in the Emergency Department and community setting
- Can be revoked at any time by taking off the bracelet or telling your provider



Community
Do Not Resuscitate (DNR) Orders

Emergency provider as appropriate will provide:	Emergency provider will NOT:
• Clear airway • Administer oxygen • Position for comfort • Splint • Control bleeding • Provide pain medication • Provide emotional support • Contact hospice or home health agency if either has been involved in patient's care, or patients attending health care professional	• Perform chest compressions • Insert advanced airways • Administer cardiac resuscitation drugs • Provide ventilator assistance • Defibrillate



How to Obtain a DNR Bracelet

1. **Talk to your primary care provider**
2. **Requires an order that both you and your provider sign**
3. **You will be issued a plastic bracelet**
4. **StickyJ Medical Bracelet**
(The vendor for the State of WI)
StickyJ.com/dnr-jewelry-bracelets
$30.49

Tips for Loved Ones

1

Prepare
Get ready to talk with someone you care for about wishes for their care through the end of life. Think about what questions you want to ask and how they might respond. Start with a story.

Start Simple
Talking about specific medical decisions can be scary and overwhelming. Instead, try asking about any concerns they may have and who they might trust to make decisions for them.

2

3

Advocate
Ensure health care teams know what is important to the person LWD and advocate to ensure wishes are honored. Share who the person is. They are more than just a patient. Include them in decision making to the extent they can participate.

Source: https://theconversationproject.org/wp-content/uploads/2020/12/DementiaGuide.pdf

UWHealth

Tips for Healthcare Providers

Become an ACP Champion
Gain skills to confidently facilitate ACP. Create your own POA-HC to be an example for patients and staff.

1

2

"Nothing about me, without me"
Assume patient capability and promote their active engagement in decision making. Focus on exploring their goals of living and values.

Make ACP Routine
Initiate ACP discussions early. Revisit ACP with patients and families on a regular basis, especially following any significant change in health condition.

3

UWHealth

When the Document is Complete

Running Toward
a Hopeful Future

✓ **Give copies to:**
- Health Care Agents
- Primary Care Clinic
- Any health care organization where care is received

✓ **Talk to loved ones about document and wishes**

✓ **Keep original POA where it can be easily found**

UWHealth

Resources

UW Health

- Free fillable POA-HC forms in several languages
  - Advance Care Planning & Advance Directive by the Wisconsin Medical Society
  - State of WI POA-HC

The Conversation Project

- Theconversationproject.org
- Conversation Starter Guide for Caregivers of People with Alzheimer's or Other Forms of Dementia

GWAAR-Guardianship Support Center

Dementia Specific POA-HC Addendums

- Dementia-directive.org
- Compassionandchoices.org
- katybutler.com (example of a letter)

Dementia Action Alliance

Compassion and Choices/Diagnosis Decoder

THANK YOU

Questions & Contact Info

Ambulatory Social Work
(608) 821-4144

Mary Arbuckle, CISW
Advance Care Planning
Program Coordinator
marbuckle@uwhealth.org

Parini Tolat, LCSW
Advance Care Planning
Program Coordinator
ptolat@uwhealth.org