CURRICULUM GUIDE FOR ADVANCE CARE PLANNING

OVERVIEW

What is an advance directive?

- An advance directive is a document that describes how healthcare decisions should be made for an individual if there is a situation in which they cannot make the decision themselves.
- The advance directive tells the medical team important information about the individual's healthcare wishes.
- Advance directives also name a specific trusted family member or close friend who makes decisions on behalf of the individual when they are unable.
- The process of creating an advance directive allows an individual to think ahead of time about their values and priorities for health so they can instruct their loved ones and health care providers if a time comes when they are unable to speak for themselves.
- Advance directives supply information about health care decisions only.
- Just as we plan for other important events like a wedding, birth of a child, or a ceremony, creating advance directives can be framed as planning ahead for a health event.

Why are advance directives important?

People who have advance directives ….

- have fewer hospital stays and spend less time in the ICU
- are more likely to die in locations that align with their personal values and wishes (for example, at home with hospice care).
- have less pain, depression, and insomnia.
- give important guidance for their families, which helps avoid conflicts at the end of life.

TIPS FOR USING THIS GUIDE

Confidentiality is a priority.

- Like any health information, conversations about end of life and advance directives are protected by HIPAA.
- Assure people that we adhere to the strictest confidentiality standards and that nothing they share will be associated with their name.
- Family involvement in these meetings should be invited and encouraged.

MOTIVATIONAL INTERVIEWING

- Each step has several strategies: **Ask, Listen, Inform**
  - Every strategy includes suggested guidance to aid the Support Star in meeting the Session Objective. It may be tempting to follow the Ask and Inform cues as a script, but it is best to try to make each step a natural conversation.
    - **Ask:** Invite the individual to explore issues by asking open-ended questions that lead to information needed to guide session.
    - **Listen:** Allow them time to respond to each question and for silences to help stretch the person's thinking. Supply facilitative responses and reflection statements.
    - **Inform:** Give them new information when they are ready. Ask for permission to supply information. Consider asking them about the experiences they have had with healthcare in the past. Reflect with them to ask for understanding.
    - **Plan**: Provide concrete ideas for next steps.

Motivational Interviewing strategies are highlighted throughout this manual with the following icon:

The guide will follow this format where appropriate:

1. Begin with *asking* skills
2. Follow up with *listening* skills
3. Offer *informing* skills when they are ready

- These strategies are based on techniques of **motivational interviewing**.[1]
- Compassion is essential when having serious conversations about healthcare decisions.
- Tribal members have expressed the need to feel that the Support Star cares about them, is personable and trustworthy.
- Resist the righting reflex. Resist the urge to persuade or tell the person what to do. Be non-judgmental and avoid blaming or being negative.
- Exercise silence, go slowly and be patient. Instead of offering advice, elicit the person's ideas and thoughts and use those to guide conversation.

To build confidence, **Role Playing** exercises are included throughout the guide. Role Playing exercises are indicated with this icon.

- Understand the person's motivations. Pay attention to the language they use to describe why they might want an advance directive or healthcare agent.
- Frame conversations in a positive tone, "This is a great way to support your family in the future." Listen to the person. Use empathetic statements to show understanding and concern.
- Listen for "change talk," including statements from the person such as, "I wish" or "I

[1] Rollnick, Miller, & Butler, 2008

want" or "I like."

- Empower the person. People are much more likely to stick to a plan that they created, rather than the one that is suggested by another person.

Motivational Interviewing Strategies

Use reflection, summary, or empathy statements:

- "Let me see if I have this right …" and summarize their concerns. [reflection and summary]
- "You care a great deal about your own health, and you have learned a great deal from your family's experience." [empathy]
- "You wonder if discussing this will really help you." [empathy]
- "I can tell that you are concerned about bringing this up with your family. If you did talk about it, what do you think would happen?" [reflection]
- "It sounds like you have already begun thinking about what you would like your healthcare to be like in the event that your health worsens." [reflection and empathy]

TIME REQUIRED

- People will have varying degrees of readiness to discuss their future healthcare. There might be times a Support Star can cover all content in 30 minutes, and there might be times that a Support Star cannot get halfway through the entire curriculum during time allotted. Go at the person's individual pace and practice active listening.
- Allow for a 1-hour discussion, recognizing that it will be essential to go at the person's own pace.
- Some people will have already completed an advance directive and not require a great deal of time while others may need to have more dialogue and engage with the teaching material.
- Flexibility is key. Although the guide is presented as a series of steps, this process of creating an advance directive is not always linear. Be prepared to follow the person in pace and process and tailor the meeting to the individual.

CULTURAL CONSIDERATIONS

- Whether the Support Stars are from the Eastern Band of Cherokee Indians (EBCI) community or are new to working with people in this community, a core component of this project is the attention to the cultural needs of the participants.
- Every person has some level of unconscious, or implicit biases that they carry with them. Implicit biases can affect how a person feels about religion, race, country of origin, class, and even characteristics like body size and disability or ability.
- Even though these biases are unconscious, it is important that Support Stars develop some awareness of their own stereotypes and biases. By examining personal biases, those implicit biases become recognizable and manageable.
- Within the EBCI community, people practice a range of religious/ spiritual beliefs, including Christian and traditional EBCI practices. There is wide variation in these practices, even within families. These beliefs may shape their medical decisions.

- As many as one-third of American Indians report being subject to microaggressions, less overt stereotypic assumptions that are subtly and repeatedly communicated to patients.[1]
- High levels of implicit bias can impact perceptions of discrimination, patient-provider interactions, treatment adherence, disparities in treatment recommendations, and pain management.[2] [3] [4]
- Microaggressions are correlated with increased heart attack, hospitalization, and worsening depressive symptoms.
- As many as 15% of American Indians delay healthcare because they feared or anticipated discrimination.[5]
- Providers that have been trained in cultural humility and implicit bias, have found that American Indians are just as likely to engage in

[1] Walls ML, Gonzales J, Gladney T, Onello E. Unconscious biases: Racial microaggressions in American Indian health care. *J Am Board Fam Med.* 2015; 28(2): 231-239 doi: 10.3122/jabfm.2015.02.140194

[2] Zestcott CA, Spece L, McDermott D, Stone J. Health care providers' negative implicit attitudes and stereotypes of American Indians. *J Racial Ethn Health Disparities*. 2021;8: 230-236.

[3] Findling MG, Casey LS, Fryberg SA, et al. Discrimination in the United States: Experiences of Native Americans. *Health Serv Res*. 2019;*54*:1431-1441. doi: 10.1111/1475-6773.13224

[4] Sequist TD, Cullen T, Acton KJ. Indian Health Service innovations have helped reduce health disparities affecting American Indian and Alaska Native people. *Health Aff*. 2011;*30*(10): 1965-1973.

[5] Marr L, Neale D, Wolfe V, Kitzes J. Confronting myths: The Native American experience in an academic inpatient palliative care consultation program. *J Palliat Med.* 2012;15(1):71-76. doi: 10.1089/jpm.2011.0197

end-of-life care conversations.[6] [1]

- Discussing death is highly personal in the EBCI community.
- Sometimes individuals have preferences regarding cultural rituals and activities that they would like to take place around the time of their death and burial. While they may not wish to write this information on their advance care plan, it is important that such preferences are known. The Support Star can help individuals indicate that these wishes exist and are included in the advance care plan.
- Additionally, tribal members have expressed concerns that their personal information will be shared with other community members. Maintaining confidentiality is extremely important throughout this process.
- When talking about someone who has died, it is respectful to speak of them in a positive light in the EBCI community.
- **Harvard Implicit Bias Test:** The Harvard Implicit Bias Test provides feedback on how one may be more prone to bias in certain categories such as gender, disability, and age. Go to **https://implicit.harvard.edu/implicit/takeatest.html**

[1] Colclough YY, Brown GM. Moving toward openness: Blackfeet Indians' perception changes regarding talking about end of life. *Am J Hosp Palliat Care*. 2019;36(4):282-289. doi: 10.1177/1049909118818255

HEALTHCARE AND FINANCIAL DECISIONS: FORMS, FORMS, FORMS!

- There is a lot of jargon surrounding end-of-life planning and forms. The terms can be very confusing.
- Clearly distinguish the difference between advance directive and financial planning or estate planning from the beginning.
- If the Support Star is unsure about a question, it is important that they do not add to the confusion. There are many resources available to answer questions, including Legal Assistance Office. Please reach out if something is not clear.

Do Not Resuscitate

For: People with serious health issues

Gives directions to health care providers during health emergencies

M O S T

For: People with serious health issues

Gives directions to health care providers during health emergencies

Advance Directives

For: All adults

Names a healthcare agent
Gives directions in case of an unplanned health event

Healthcare Power of Attorney & Healthcare Agent

For: All adults

Names a healthcare agent

Living Will

For: All adults

Gives directions in case of an unplanned health event

Will / Last Will and Testament

For: All adults

Names an executor (agent)
Tells family and others what to do with money and property after death

Power of Attorney

For: All adults

Names a person to make decisions about money and property if a person cannot speak for themselves

WELCOME AND STATEMENT OF PURPOSE (5 MIN)

Introductory statements should include:

- Your name and role on the team
- Overview of purpose of meeting
- Statements that reflect valuing their individual views
- Confidentiality statement
- Questions

STEP 1:
PICK SOMEONE YOU TRUST TO MAKE HEALTHCARE DECISIONS

Session Objectives:

- Assess their knowledge of healthcare agent and decision maker
- Offer education on healthcare agents/ decision maker
- Assess whether they have a healthcare agent/ decision maker
- Give information on how to establish healthcare agent/ decision maker
- Answer any questions or concerns about healthcare agents/ decision maker
- Help them in verbalizing understanding of healthcare agent/ decision maker

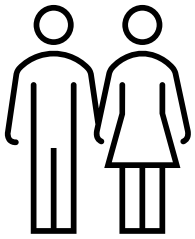
Rationale: Often people have ideas about what they would like to have done if their illness progresses but have not selected a decision maker.

MI Skills

Ask: Could you tell me a little bit about your experience with healthcare decision makers? [eliciting their thoughts/beliefs]

Inform:

- You can have control over your wishes by naming a healthcare agent who can make those decisions for you if you cannot.
- The healthcare agent has no authority in your healthcare unless you are unable to make decisions for yourself.
- A healthcare agent has no power over any other part of your life (finances, will, property). A healthcare agent only makes healthcare decisions.
- A healthcare agent can be any person you choose with some limited exceptions (healthcare provider, must be 18 or older).
- If you do not have a healthcare agent, the courts decide who will make your healthcare decisions, and usually this is the next of kin.



If they have a healthcare agent: You have been thinking ahead [empathetic response]. Would you be willing to share the details with me? [permission to inform] Who is your healthcare agent? Have you

filled out a form? Does your doctor have a copy of the form?

If they do NOT have healthcare agent: Considering all that we have discussed, I am wondering how you would feel about exploring this as a choice. [permission to inform]

Listen to their response. Allow time to process and respond with reflective and empathetic statements.

Role Play summarization, empathy and listening:

Sophia states, *I always thought that my husband had the final decision in my care if I could not speak for myself*.

John states, *I am worried that my husband would not be able to make difficult decisions for me.*

Plan

- Review North Carolina state form.

STEP 2:
THINK ABOUT WHAT YOU WOULD WANT IF YOU WERE NOT GOING TO GET BETTER

Session Objectives:

- Elicit their individual preferences about aggressive treatment in various scenarios
- Explore their experiences with chronic health issues
- Explore their concerns about how those experiences affect them

MI Skills

Ask: "Sometimes, after people learn about advance care planning, it brings up many questions and concerns about their own medical care in the future. What has been your experience with dealing with serious illness, either yourself or loved one? [open-ended question]

Listen: Allow for person to tell story without interruption. Offer reflective statements.

MI Skills

Ask: Elicit their own ideas and thoughts by asking exploratory questions and allow them plenty of time to think and answer. Probing questions include:

- What was your experience like?
- What went well?
- What was difficult?
- How does this compare to your health?
- Thinking about the future, how would you like things to be?
- What concerns or worries do you have about your own healthcare because of this experience?

Listen: Some examples you might hear:

- My family member had to rely on family.
- My family member was in a lot of pain.
- Why do we have to talk about this?
- This is out of my control; it is in Creator's/ God's hands.

- Discussing this makes me feel like you think I am going to die. Do you know something I do not know?

Inform, if appropriate. Ask for permission to give information and use examples of others.

- Spirituality is an important part of your healthcare decision. I have heard other people say it is helpful to talk to a spiritual or traditional leader.
- No one can predict our future. I want to make sure that every person I meet, regardless of age or illness, considers his or her healthcare wishes.
- This is a talk that we should have more than one time because many people change their minds about their healthcare throughout their lifetime. What we talk about today can change in the future.

Listen: Allow them time to reflect.

Case Studies: If the person does not have any personal experience, you can provide case studies to help illustrate why advance directives can be helpful for a person and their family.

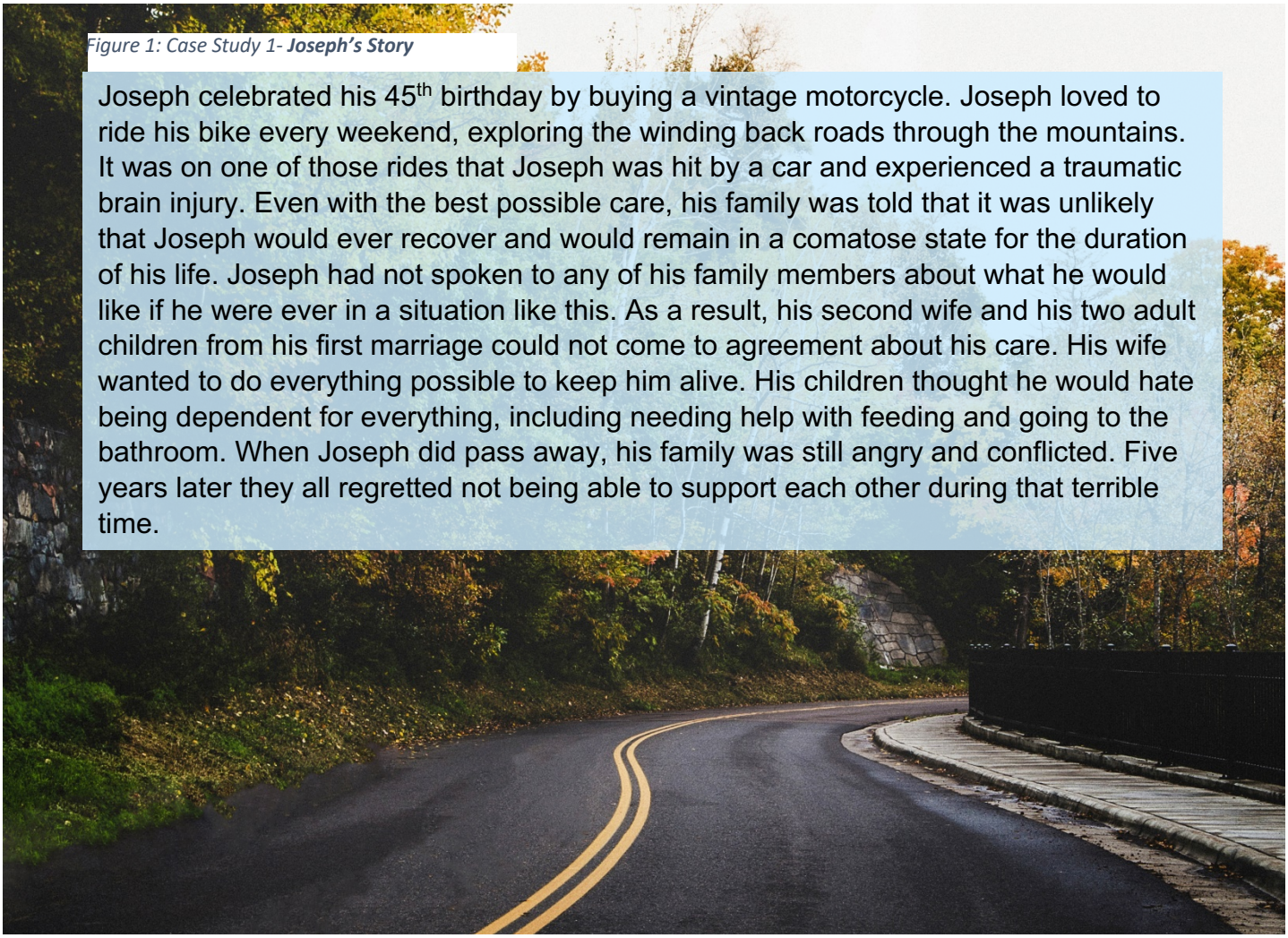


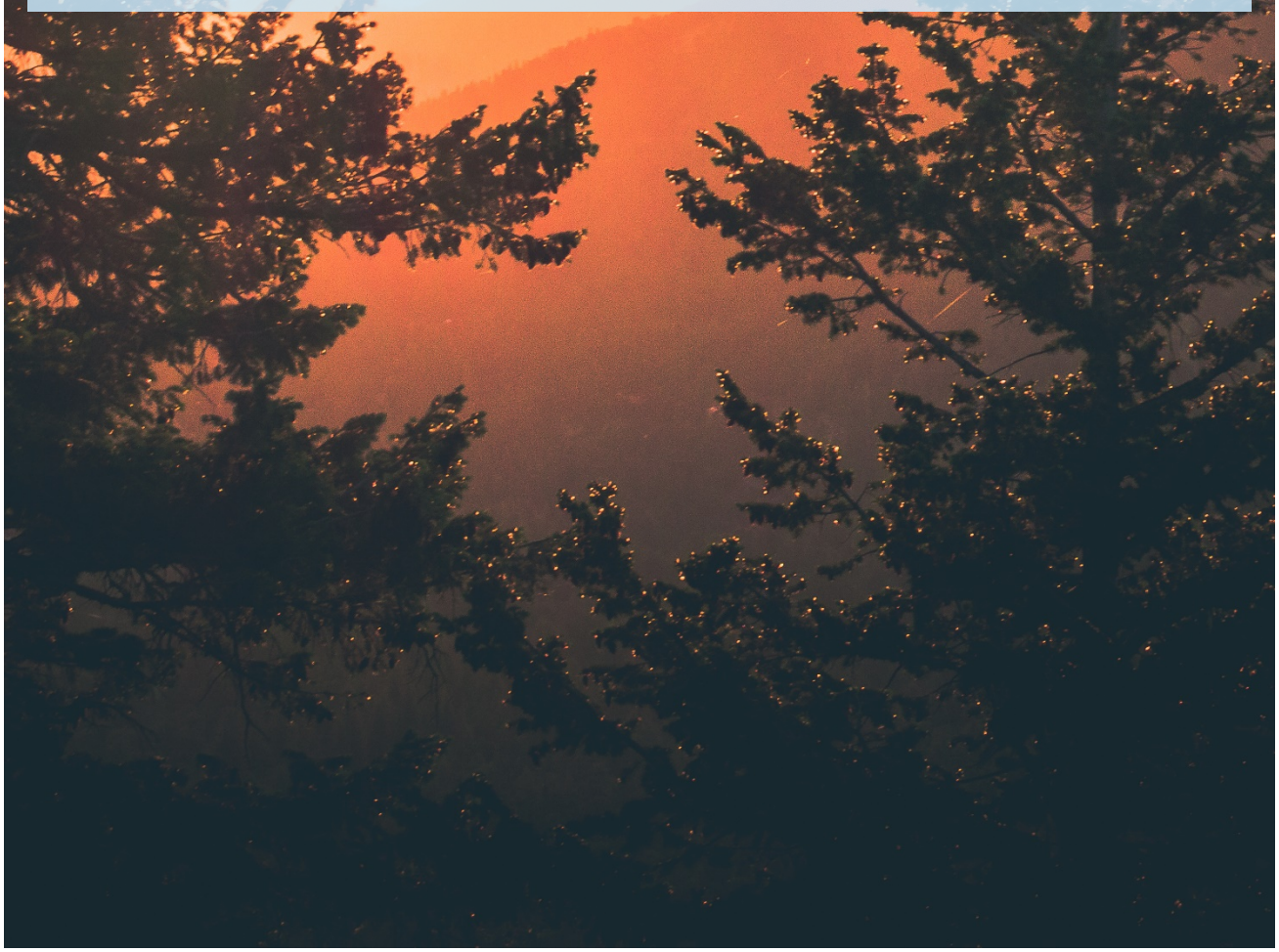
Figure 1: Case Study 1- ***Joseph's Story***

Joseph celebrated his 45th birthday by buying a vintage motorcycle. Joseph loved to ride his bike every weekend, exploring the winding back roads through the mountains. It was on one of those rides that Joseph was hit by a car and experienced a traumatic brain injury. Even with the best possible care, his family was told that it was unlikely that Joseph would ever recover and would remain in a comatose state for the duration of his life. Joseph had not spoken to any of his family members about what he would like if he were ever in a situation like this. As a result, his second wife and his two adult children from his first marriage could not come to agreement about his care. His wife wanted to do everything possible to keep him alive. His children thought he would hate being dependent for everything, including needing help with feeding and going to the bathroom. When Joseph did pass away, his family was still angry and conflicted. Five years later they all regretted not being able to support each other during that terrible time.

Figure 2: Case Study 2- ***Melissa's Story***

Melissa was disappointed when she learned that her breast cancer had come back, and the recurrence included tumors in her brain and lungs. She planned to receive treatment so she could live as long as possible, but she also knew she wanted to have a good quality of life while she was alive. After meeting with the palliative care team, Melissa had a family meeting and told them the news. She also told them that she had made some decisions about her care. She told her family that she had decided that her oldest daughter would be her official decision-maker if she could not speak for herself. She also told her family that she did not want to be kept alive if it meant she needed machines to feed her or help her breathe. Her lawyer helped her write up her wishes, and she had that document included in her medical chart at her next doctor's appointment.

A year later, Melissa was very weak from her cancer, and she became ill with pneumonia. Her daughter found the advance directive and medical power of attorney that Melissa had given her, and she was able to tell the medical team that her mother had specific wishes for her care. Her daughter spoke with the medical team about outcomes, and everyone agreed that Melissa had been very clear about her wishes. Melissa passed away a few days later. Melissa's family was sad, but they felt that Melissa's death was peaceful and just as she wished- at home and surrounded by her loved ones, with her beloved cat resting on her lap.

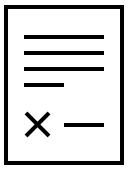


STEP 3:
WRITE YOUR HEALTHCARE WISHES DOWN

Session Objectives:

- Assess their knowledge of advance directives
- Offer education about advance directives, if needed
- Assess whether they have an advance directive or if they are ready to complete an advance directive
- Help them in verbalizing understanding of advance directives

Rationale: While most people have an idea about what they would like in a health crisis, people rarely complete the necessary documents to ensure they will receive the care they wish. Healthcare is so complex that it is not a yes/no decision, but one that includes complex tasks.



MI Skills

Ask: "Last week at the Community Information Session we covered a lot of information about advance directives. What questions or concerns do you have?"

Role play listening, reflection, empathy, and information giving using the following prompts:

"What happens to the Advanced Directive once I fill it out?"
"How do I know that what I put on this form is going to be confidential?"
"How is this different than 5 Wishes?"
"I am worried about what will happen to my property."
"I already did this form with my hospital social worker."

Listen: Allow them time to process by offering silence. Listen for statements such as "I want" and "I wish" and "I need." For people who are expressing readiness to change, use listening skills and ask if the person has already created an advance directive. For people who are not ready, reinforce their autonomy and respond to their emotion with empathetic statements.

Inform with permission, using examples:

- An advance directive is a tool for people to use so that they have a voice when medication or medical emergency prevents speaking.
    - This is a formal document that anyone over age 18 can fill out. Once signed and notarized, the document becomes legal.
    - They can change their advance directive at any time.
    - Healthcare providers should be asking about advanced care directives as soon as a person is old enough to make medical decisions and throughout a person's entire life. All people should evaluate their advanced care directives at the following points:
        - Before each annual health exam
        - After any major life change (birth, marriage, divorce, remarriage)
        - After any major healthcare change (a new diagnosis, hospitalization)
        - When a person cannot live by themselves due to health or safety reasons

MI Skills

Ask: "Do you have an advance directive?"

- *If Yes*: Ask about revisiting the document to see if anything has changed. Listen.
- *If No*: Reflect on any information you have learned about what motivates them to want to complete an advance directive. An example might be, "It sounds like you might have been wondering about whether this can help you." [Ask] Pause and allow them time to reflect. [Listen]. Ask if they would like to discuss what would put in the advance directive.
- Show table that outlines difference between advance care planning and will / last will and testament (page 7)

STEP 4:
SHARE YOUR ADVANCE DIRECTIVE WITH YOUR HEALTHCARE AGENT, HEALTHCARE PROVIDER, AND FAMILY

Session Objectives:

- Assess their readiness to start this conversation with family and healthcare team
- Decide a plan for them to have discussion with family and healthcare team
- Discuss potential barriers to having conversations and brainstorm solutions

Rationale: Advance directives and healthcare power-of-attorneys are *only effective when they are shared* with the necessary healthcare organizations or family members. Many people find it difficult to raise the topic with the healthcare team or family members.

MI Skills

Ask: Ask about experiencing having this conversation with family and healthcare team.

I am wondering if you can tell me about what kinds of conversations you have had with family or loved ones about advance directives or healthcare agents?

Role Play listening and empathy skills using the following prompt:

Sheila: I *was nervous talking about this with my family*.

If they have not had a conversation, ask what the barriers are, roll with resistance, and follow up with empathetic and affirmative statements.

- Pause and allow them to reflect. Elicit beliefs and thoughts by asking "what if?" questions.
- Ask family about someone else's healthcare experience or ask about cases such as the case studies provided.

MI Skills

Ask: “What is your plan for sharing this information with your doctor?”

Role play reflection, listening, and offering information.

Jason: *Dr. Ferguson has not asked me for my plan.*

Plan:

- Review any supportive material that you have available based on unique needs of the individual.
- Encourage the person to talk to their doctor who can provide them with answers to questions about healthcare treatments.

STEP 5:
TALK TO YOUR HEALTHCARE PROVIDER AND SUPPORT STAR ABOUT OTHER IMPORTANT FORMS, LIKE A MEDICAL ORDER FORM (MOST)

Session Objectives:
(For most people, this step will occur in a follow-up Support Star meeting or call, after they have completed an advance directive.)

- Assess their readiness to have their doctor to prepare a MOST form
- Inform them about the purpose of MOST and how it complements advance directive forms
- Decide a plan for having their doctor prepare a MOST form based on their wishes
- Discuss potential barriers to having a MOST form prepared

Rationale: Even when individuals have completed an advance directive, it may not be readily available in an emergency. The Medical Orders for Scope of Treatment (MOST) is a portable medical order form MOST that records the individual's treatment wishes. It is used across settings of care. Having a MOST form makes it more likely that they will receive the type of care they wish even if they are unable to speak for themselves in an emergency.

Ask: "I am wondering if you have heard about a MOST form before." [elicit their knowledge/experience]

Listen: If they have some knowledge, offer summary statements such as "You have heard of the MOST, but you aren't sure why you would need one now." If they do not know about MOST, offer information, with permission.

Inform:

- The MOST is a medical order form that states your healthcare wishes based on what is in your advance care plan. It is written by a physician or nurse practitioner or physician assistant.
- The MOST Form helps give you more control over receiving treatments you want and avoiding treatments you do not want; in the event you cannot speak during a medical crisis.
- A MOST Form always stays with the person, regardless of whether the

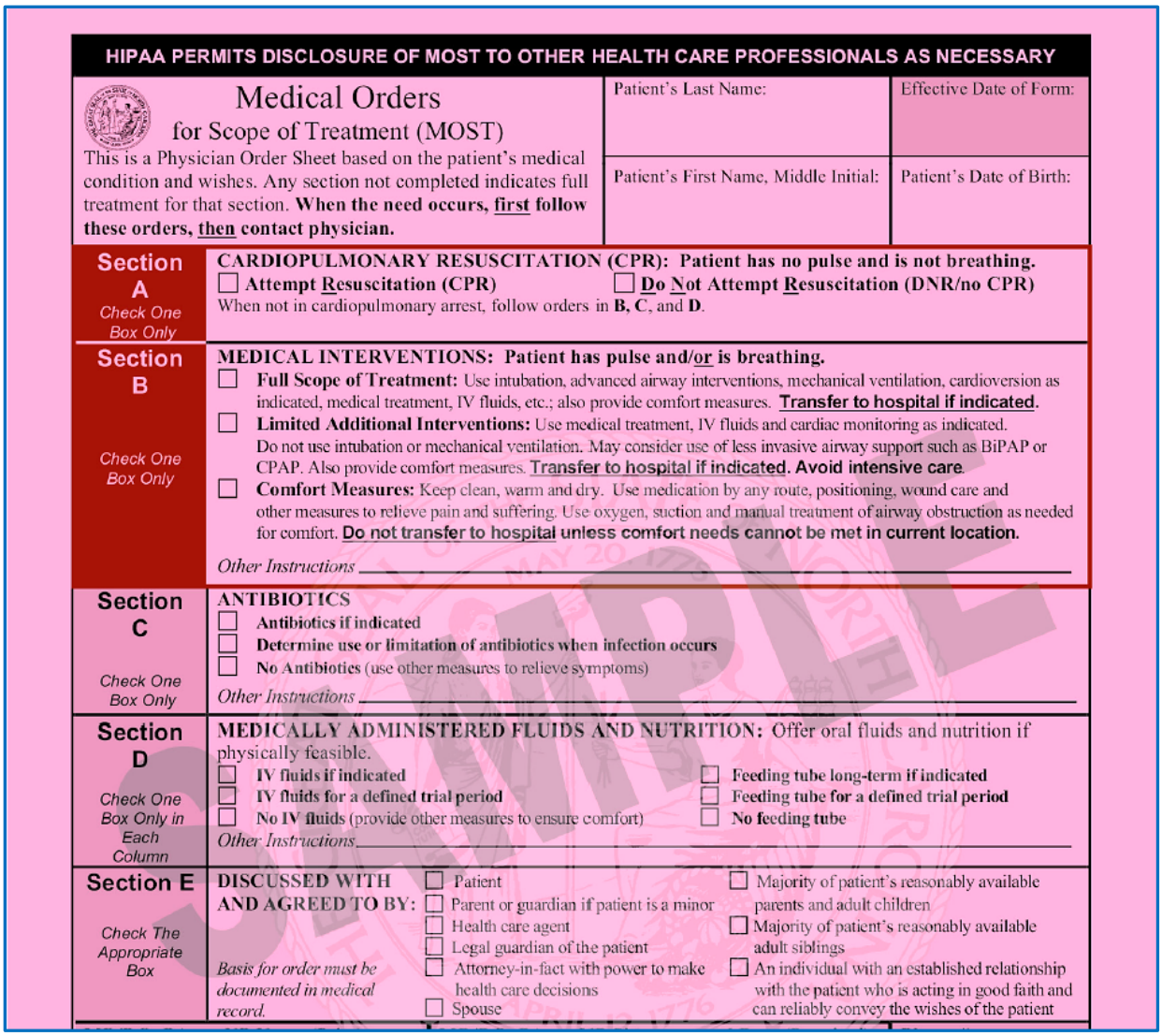
person is in the hospital, at home, or in a nursing home. They should put the form in a visible location recognized by emergency medical personnel (usually the front of the refrigerator or in a medicine cabinet). In a healthcare facility, a copy of the MOST form should be in the medical record.

- The MOST form is an extra layer of protection in addition to an advance care plan. Some people want to postpone a MOST form until their condition has progressed further.

Plan:

- Share a copy of the North Carolina MOST form (Figure 1).
- Plan for asking the doctor to prepare a MOST form. Decide with the person whether they will request the MOST at their next visit.

Figure 3: North Carolina MOST Form (sample)



HIPAA PERMITS DISCLOSURE OF MOST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

Medical Orders for Scope of Treatment (MOST)

This is a Physician Order Sheet based on the patient's medical condition and wishes. Any section not completed indicates full treatment for that section. **When the need occurs, first follow these orders, then contact physician.**

Patient's Last Name:	Effective Date of Form:
Patient's First Name, Middle Initial:	Patient's Date of Birth:

Section A *Check One Box Only*

CARDIOPULMONARY RESUSCITATION (CPR): Patient has no pulse and is not breathing.

☐ **Attempt Resuscitation (CPR)** ☐ **Do Not Attempt Resuscitation (DNR/no CPR)**

When not in cardiopulmonary arrest, follow orders in **B, C**, and **D**.

Section B *Check One Box Only*

MEDICAL INTERVENTIONS: Patient has pulse and/or is breathing.

☐ **Full Scope of Treatment:** Use intubation, advanced airway interventions, mechanical ventilation, cardioversion as indicated, medical treatment, IV fluids, etc.; also provide comfort measures. **Transfer to hospital if indicated.**

☐ **Limited Additional Interventions:** Use medical treatment, IV fluids and cardiac monitoring as indicated. Do not use intubation or mechanical ventilation. May consider use of less invasive airway support such as BiPAP or CPAP. Also provide comfort measures. **Transfer to hospital if indicated. Avoid intensive care.**

☐ **Comfort Measures:** Keep clean, warm and dry. Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. **Do not transfer to hospital unless comfort needs cannot be met in current location.**

Other Instructions _____

Section C *Check One Box Only*

ANTIBIOTICS

☐ **Antibiotics if indicated**

☐ **Determine use or limitation of antibiotics when infection occurs**

☐ **No Antibiotics** (use other measures to relieve symptoms)

Other Instructions _____

Section D *Check One Box Only in Each Column*

MEDICALLY ADMINISTERED FLUIDS AND NUTRITION: Offer oral fluids and nutrition if physically feasible.

☐ **IV fluids if indicated**	☐ **Feeding tube long-term if indicated**
☐ **IV fluids for a defined trial period**	☐ **Feeding tube for a defined trial period**
☐ **No IV fluids** (provide other measures to ensure comfort)	☐ **No feeding tube**

Other Instructions _____

Section E *Check The Appropriate Box*

DISCUSSED WITH AND AGREED TO BY:

☐ Patient	☐ Majority of patient's reasonably available parents and adult children
☐ Parent or guardian if patient is a minor	☐ Majority of patient's reasonably available adult siblings
☐ Health care agent	☐ An individual with an established relationship with the patient who is acting in good faith and can reliably convey the wishes of the patient
☐ Legal guardian of the patient	
☐ Attorney-in-fact with power to make health care decisions	
☐ Spouse	

Basis for order must be documented in medical record.

CONCLUSION AND WRAP UP

At this point, it is especially important for Support Stars to schedule a follow-up appointment or phone call within 2-3 weeks.

Reflective Statement: "We have covered so much difficult information in the last hour. It is time for our session to end, but we will have another opportunity to discuss this again."

MI Skills

Ask if they have any more questions.

Listen: Allow the person time to process and respond. Offer reflective and empathetic statements.

Inform: Explain to the person the purpose of the call is to make sure what was expressed here becomes a reality.

- The person should take time to review and reflect on conversations and resources with trusted family members or friends.
- Schedule a follow-up phone call or visit with them to review items addressed. For example, a follow up call or visit might include looking at the advance directive the person has begun working on, answering specific questions about healthcare treatment options, or notarizing the form.
    - If the person is ready to complete the form and has witnesses available, the Support Star can notarize the form.
- Encourage them to call or contact you with any questions or concerns during that timeframe.
- Remember that this is an organic process, and everyone will go at a different pace.

Follow up in person or by phone

The purpose of this call or visit is to check in with people about progress since first meeting. Often people need several meetings with a Support Star to complete the entire advance directive and healthcare agent forms. An example opening statements you can use is:

MI Skills

Ask: what questions do they have about the meeting and advance directives?

Listen: Remember, this is a fluid process. Go at their own pace. Use this meeting time to address what progress has been made and connect the person to necessary resources and complete necessary paperwork in the office.

Inform: It may be helpful to visit websites and show videos during the visit if internet is available.

Plan: Wrap up the visit or call by thanking them for taking part in the research project. Remind them that there will be follow up phone call by the Project Coordinator. Explain that his or her participation will be valuable in helping medical providers better communicate about their care. Allow time for questions and supply resources as needed.

SUPPORT STAR WORKSHEET

Participant ID_____ Date of follow-up _____

Date of meeting _____

STEP 1

Healthcare agent is:

They do not have healthcare agent but would like to name:

What are they willing to do to name healthcare agent?

STEP 2

Their experiences with loved ones with chronic health problems:

Their healthcare preferences:

Their concerns about healthcare:

STEP 3

Describe their understanding of advance directives:

What area do they need more information about advance directive?

STEP 4

They have discussed advance directive and healthcare agent with:

Their plan to address potential barriers:

They will share decisions with their medical team by this date:

STEP 5

Have they completed a MOST form? Yes No

Plan:

Person plans to speak to their doctor about MOST at next visit

Notes:

MYWAY Eastern Band of Cherokee Indians
Elder Services Guide Essential Phone Numbers

EMERGENCY AND 24-hour Crisis Lines			
District	Type of service	Title	Phone
National	EMS	EMS/Fire/Police	911
Tribal	Police	Cherokee Indian Police Department	828-359-6600
	24-hour hotline	Family Safety Program (FSP) Protective Services for Adults and Children 24-Hour Hotline	828-497-4131
Regional		Family Abuse Services 24-Hour Crisis Line	828-226-5985
Tribal		Eastern Band of Cherokee Indians DV / SA Program 24-Hour Crisis Line	828-359-6830
National		National 24-Hour Helpline for Substance Abuse	877-726-4727
		Alzheimer's Association 24-Hour Hotline	800-272-3900
		National Domestic Violence 24-Hour Hotline	800-799-7233
		National Suicide Prevention 24-Hour Hotline	800-273-8255

HEALTHCARE			
District	Type of service	Title	Phone
Tribal	Behavioral health	Analenisgi Mental Health Center	828-497-6892
Regional	Elder care	Southwestern Commission Area Agency on Aging Ombudsman Program	828-586-1962
Tribal		Tsali Care Nursing Facility	828-497-5048
		Tsali Manor Senior Citizens Program	828-359-6860 (Main Line) 828-359-6270 or 828-835-9741 John Welch Center in Cherokee, NC 828-497-9145 Snowbird Center
		Veteran Services for Elders/Disabled	828-359-6195
Regional	EOL Care	Harris Palliative Care and Hospice	828-586-7866
County	Healthcare	Cherokee County Clinic	828-837-4312
Regional		Davita Dialysis Center	828-497-6866
Tribal		Cherokee Hospital - Immediate Care Clinic	825-554-5555
		Cherokee Indian Hospital Authority	828-497-9163
		Kidney Smart	828-631-0430
		Lifeline Program	828-359-6886

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FAMILY/PATIENT SUPPORT AND SAFETY			
District	Type of service	Title	Phone
Tribal	DV support	Ernestine Walkingstick Domestic Violence Shelter	828-359-6830
	DV/SA support	Tribal DV / SA Program	828-359-6830
	Family support	1 st Family Services in Indian Country LLC (Rep. Payee)/ Cherokee Child Support Services & TANF	828-497-4317 Cherokee 828-497-1000 Snowbird
		Adult Protective Services - Family Safety Program	828-359-1520 After hours: 828-497-4131
		Home Health/ Caregiver Respite Program	828-359-6872
		Family Support Services	828-359-6092
		Tribal In-Home Care Services	828-359-6870 (828-497-9163 for emergencies)
Regional		Alzheimer's Support Group	828-359-6860
Tribal		Cherokee Cancer Support Group - Betty D's Place	828-497-0788

FINANCIAL SUPPORT			
District	Type of service	Title	Phone
Tribal	Finance	EBCI Finance (Accounting & Per Capita Distribution)	828-359-6000
		Tribal TANF	828-359-9751
	Food support	Tribal Food Distribution Program	828-359-9751
National	Social Security	Social Security Administration	1-800-722-1213 (National) 828-369-2972 (Franklin, NC)

HEALTH INSURANCE RESOURCES			
District	Type of service	Title	Phone
		Medicaid Eligibility	
County	Health insurance	Cherokee County	828-837-7455
		Clay County	828-389-6301
		Graham County	828-497-7911
		Jackson County	828-586-5546
		Swain County	828-488-6921
National		National Senior Health Insurance Information Program (SHIP)	855-408-1212
Tribal		Supplemental Health Insurance Program (SHIP)	828-359-6180 or 828-359-6183

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HOUSING			
District	Type of service	Title	Phone
Tribal	Housing	Housing and Community Development	828-359-6906
		Qualla Housing Authority	828-359-6351 OR 828-359-6330
		Tribal H.E.L.P.	828-359-6638

LEGAL RESOURCES AND CONTACTS			
District	Type of service	Title	Phone
State	Legal	NC Lawyer Referral Service	800-662-7660
Tribal		Attorney General	828-359-7434
		BIA Realty Main Line:	828-497 9131 828-497-6636 OR 828-497-3603
		Cherokee Clerk of Court	828-359-1060
		Cherokee Detention Center (Jail)	929-359-6691
		EBCI Legal Assistance Program	828-359-7400
		Tribal Court	828-359-1068
		Tribal Magistrate's Office	828-359-6657 or 828-359-6697
		Tribal Prosecutor's Office	828-359-6218

PUBLIC HEALTH			
District	Type of service	Title	Phone
		County Department of Social Services	
County	Public health	Cherokee County	828-837-7486
		Clay County	828-389-8052
		Graham County	828-497-7900
		Jackson County	828-586-8994
		Swain County	828-488-3198
		County Health Departments	
		Cherokee County	828-837-7486
		Clay County	828-389-8052
		Graham County	828-497-7900
		Jackson County	828-586-8994
		Swain County	828-488-3198
Regional		CIHA	828-497-9163
		PHHS/ FSP APS	828-359-1520
Tribal		Tsalagi Public Health	828-359-6240

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REGIONAL UTILITIES AND SERVICES			
District	Type of service	Title	Phone
Tribal	Transportation	Cherokee Transit	828-359-6740
	Tribal services	EBCI Enrollment	828-359-6467
			OR 828-359-6264
Regional	Utilities	Cablevision	828-497-4861
		Cherokee Broadband	828-359-1000
		Recycling	828-359-6141
		Sanitation	828-359-6140

VETERANS' SERVICES			
District	Type of service	Title	Phone
		Veterans' Services	
County	Veterans Services	Cherokee County	828-835-8663
		Clay County	828-389-3355
		Graham County	828-479-7966
		Jackson County	828-631-2231
		Swain County	828-488-9273

DISABILITY SERVICES			
District	Type of service	Title	Phone
		NC Division of Services for Persons who are Deaf / Hard of Hearing	
County	Disability Services	Cherokee County	828-837-7455
		Clay County	828-389-6301
		Graham County	828-497-7911
		Jackson County	828-586-5546
		Swain County	828-488-6921
		NC Division of Services for the Blind	
		Cherokee County	828-837-7455
		Clay County	828-389-6301
		Graham County	828-497-7911
		Jackson County	828-586-5546
		Swain County	828-488-6921

POST OFFICE			
District	Type of service	Title	Phone
Regional	Post Office	Post Office	828-497-3891

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WEBSITES
Prepare For Your Care helps people make specific medical decisions. This website has videos from other people making medical decisions: https://www.prepareforyourcare.org
The Mayo Clinic supplies information on different treatments you may want to consider: https://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/living-wills/art-20046303
The American Bar Association has a toolkit that each person can use to help with Advance Care Planning: https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning/
The North Carolina Medical Orders for Scope of Treatment (MOST) has information about MOST forms: https://info.ncdhhs.gov/dhsr/EMS/dnrmost.html
Home Health / Caregiver Respite Services: https://cherokee-phhs.com/in-home-care-services/index.html

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