South Dakota State University Extension

NDSU | EXTENSION

# Conversations that Matter:
## Advance Care Planning for Rural Families

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# Introduction and Welcome Letter

Thank you for your interest in teaching others about advance care planning. This is an important topic for individuals and their families. *Conversations That Matter: Advance Care Planning for Rural Families* is the result of a collaboration between North Dakota State University Extension, the College of Nursing at South Dakota State University, and SDSU Extension. This booklet is designed to be used to facilitate community education events in a variety of settings, including churches, lunch and learn events, community centers, and many more. These materials are designed to be used with adults of all ages. The materials in this booklet were piloted with sociology students at South Dakota State University. Based on the results of the evaluation, the materials were refined to clarify some aspects of advance care planning. It is our hope to continue to improve the content of these materials. If you have questions or comments, please contact Leacey E. Brown, SDSU Extension Gerontology Field Specialist at either leacey.brown@sdstate.edu or 605-394-1722. We offer a special thank you to Monica Herrera, 2018-2019 AmeriCorps VISTA Volunteer and Paige Madsen, 2019-2020 AmeriCorps VISTA Volunteer.

### Objectives

1. Increase understanding of the purpose of advance care planning
2. Describe the difference between long term care planning and advance care planning
3. Increase knowledge about the role of healthcare agent/proxy

**Time requirements:** 60 to 75 minutes

**Target Audience:** Adults age 18 and older

**Number of participants:** 15 to 20

# How to Run a Conversations That Matter Program

Advance Care Planning is an important topic and is often discussed in small group settings. We have provided the tools to help you successfully lead a small group event in this booklet. Included in the tools are:

- Advance Healthcare Planning video: https://youtu.be/aP4GDwLLSqI
- Overview and checklist
- In-person planning checklist and agenda
- Virtual planning checklist and agenda
- Event Script
- Marketing and promotion examples
- Case studies
- Samples responses to case studies
- Key content and main idea review
- Evaluation
- How to get started with advance care planning handout
- Helpful resources handout
- Myths and realities of advance care planning handout
- Common advance care planning terms handout

### Overview and Checklist

The purpose of Conversations that Matter small group events is to help adults understand the aspects of advance care planning and understand how difficult these conversations can be. Small group events allow people to share their thoughts and ask questions to clarify their understanding of advance care planning. The event is easy to run because everything you need is available within the Conversations that Matter booklet. The session can be hosted in-person or virtually. The following materials will describe the materials needed for both the in-person and virtual meeting.

## Overview of What to Expect

- Prior to facilitating an event, review the Conversations that Matter booklet.
- Select a day and time to host the event.
    - Reserve a room large enough to comfortably hold the number of participants; OR
    - Host a virtual session ("Zoom" is a commonly used platform. More information can be found here: https://zoom.us/).
- Promote the event so people know it is happening.
- If you are showing the Advance Healthcare Planning video at the beginning of the session you will need:
    - Computer, projector, screen, speakers, and internet access.
    - You may also choose to ask participants to view the video prior to the session.

# In-Person Session

## Items You Need:

- ❑ A meeting room large enough to host a group of up to 20 people
- ❑ Presentation screen/blank wall (if showing video during session)
- ❑ Projector and speaker (if showing video during session)
- ❑ A computer with internet connection (to use for showing video)
- ❑ Pens or pencils and blank paper
- ❑ A copy of the Conversations that Matter booklet
- ❑ Copies of the handouts from the Conversations that Matter booklet
- ❑ Copies of the Conversations that Matter case studies
- ❑ Copies of the evaluation form

## Preparing for the Event:

- ❑ Review the Conversations that matter booklet
- ❑ Ensure the room is set up
    - Computer
    - Speakers
    - Internet access
    - Projector and speakers (if showing the video)
    - Screen or blank wall (if showing the video)
    - Flip chart/chalk board/dry erase board
    - Markers/chalk
    - Enough tables and chairs for the group
    - Handouts for participants
        - Advance care planning case studies
        - Advance care planning lesson evaluation
        - How to get started with advance care planning
        - Myths and realities of advance care planning
        - Common advance care planning terms
    - A clock or watch to keep time
- ❑ Have pens/pencils and blank paper available at each table. Ensure there is enough for each participant
- ❑ Create a time schedule for the event. Participants will work in small groups to complete one case study per group. It is reasonable to plan for 15 minutes for completion of the case study discussion portion of the session.
- ❑ If showing the video, be sure to check the internet access, video, and sound prior to the start of the event.

## Event Agenda

1. Welcome and introductions
   a. Ice breaker: ask each attendee to introduce themselves and share why they decided to attend this class
   b. Description of lesson purpose: increase knowledge about advance care planning and identify strategies to ensure their healthcare preferences are honored.
   c. Overview of lesson structure
      i. Watch video
      ii. Small group discussion using case studies
      iii. Report back to larger group
      iv. Review key content and main ideas
      v. Complete evaluation

2. Watch Advance Healthcare Planning video (if watching as a group)

3. Break larger group into 4 groups.

4. Give each group one case study and allow 5-10 minutes to read case study and answer questions. Ask one member of each group to volunteer to report to the larger group about the small group discussion.

5. Ask for a volunteer to record responses to questions on chalkboard, flip chart, or dry erase board.
   a. Identify which case study they had and provide a brief summary.
   b. Describe key issues/problems.
   c. What were the main theme(s) of the group discussion?

6. Review of Advance Care Planning: Key Content and Main Ideas Review

7. Conclusion
   a. Thank the audience for their attendance and participation.
   b. Distribute and collect the evaluation form.

## Event Reminders:

- Give each participant a copy of the handouts
- Ensure that all participants can view, hear, and understand the video.

# Virtual Session

## Items You Need:

- ❑ Virtual meeting room created (Zoom, Google Hangouts, etc.)
- ❑ A computer with internet connection, video and audio capability
- ❑ A copy of the Conversations that Matter booklet
- ❑ Select which case study will be reviewed by the group during the virtual session.
- ❑ Copies of the handouts from the Conversations that Matter booklet available in electronic form
- ❑ Copies of the Conversations that Matter case studies available in electronic form
- ❑ Copy of the evaluation form or evaluation link to send to participants after the session.

## Preparing for the Event:

- ❑ Review the Conversations that matter booklet
- ❑ Ensure the virtual room is set up
    - Computer
    - Speakers
    - Internet access
    - A blank word document on your computer which can be shared with participants
    - Handouts for participants
        - Advance care planning case studies
        - Advance care planning lesson evaluation
        - How to get started with advance care planning
        - Myths and realities of advance care planning
        - Common advance care planning terms
    - A clock or watch to keep time

## Event Agenda

1. Welcome and introductions
    a. Ice breaker: ask each attendee to introduce themselves and share why they decided to attend this class.
    b. Description of lesson purpose: increase knowledge about advance care planning and identify strategies to ensure their healthcare preferences are honored.
    c. Overview of lesson structure
        i. Watch video
        ii. Group discussion using case studies
        iii. Review key content and main ideas

2. Watch Advance Healthcare Planning video (if watching as a group)

3. Display the case study so participants can read the story and the questions. Allow 3 to 5 minutes for attendees to read and consider the situation described.

4. Within the group, have a volunteer, or volunteers, respond to the following questions:
    a. What are your initial thoughts about the circumstances described in this case study?
    b. What issues or problems do you see here? How does this impact decision making?
    c. How would the healthcare proxy/agent ensure the patient's preferences are honored?
    d. How could advance care planning make this difficult situation easier?

5. Review of Advance Care Planning: Key Content and Main Ideas Review

6. Conclusion
    a. Thank the audience for their attendance and participation.
    b. Remind participants they will receive an evaluation via e-mail. Encourage participants to complete the evaluation.

### Event Reminders:

- Give each participant a copy of the handouts. This can be done by e-mailing a copy to each participant.
- Ensure that all participants can view, hear, and understand the video.

# Event Script

This information is provided as an example of what you might want to say when hosting this event. This is only a guide. You can say what you are most the most comfortable saying.

### Introductions:

- Introduce yourself and welcome participants:
  - "Hi, my name is ________________ and we are happy you are here today to learn more about advance care planning. I would like to take a minute to give everyone the opportunity to introduce themselves and, if they would like, why they chose to attend today's session."

### Program Summary:

- "Let's get started. First, I will share a little bit about the 'Conversations that Matter: Advance Care Planning for Rural Families' booklet. This booklet was designed to help community members of any age gain a better understanding of advance care planning and encourage these behaviors. These materials are available free online to everyone."

### Logistics (In-Person Session):

- "Today we will watch the Advance Healthcare Planning video as a group (if appropriate). After we watch this video, you will work in groups and review a case study that relates to advance care planning. As a group, you will review the case that is presented and talk through the questions. After you work in small groups, we will come back as a large group to discuss the case studies. After reviewing the case studies, we will talk more about advance care planning."

### Logistics (Virtual Session):

- "Today we will watch the Advance Healthcare Planning video as a group (if appropriate). After we watch this video, you will work as a group and review a case study that relates to advance care planning. As a group, you will review the case that is presented and talk through the questions. We will review the case study as a group. After reviewing the case studies, we will talk more about advance care planning."

### Video (if applicable):

- "We will now watch the Advance Healthcare Planning video. This video gives you an introduction to what we will be discussing today. At the end of the video we will take a moment to answer any questions."

### Case Studies (In-Person Session):

- "Now we will complete the case studies. I will assign one of the case studies to each group. In your group, please read the case study, talk about the events, and answer the questions related to the case study. You will have about 15 minutes to complete this part, but you may have extra time if needed. I will let you know when you have about 5 minutes left."
- "Now that you have had a chance to review the case studies in your small groups, we will review the case studies as a group. Each group should choose one group member to represent your group. The group member will provide a brief overview of the case study, describe key issues/ problems, and identify the main theme or themes from your group discussion."

### Case Studies (Virtual Session):

- "Now we will complete the case studies. Please read the case study, talk about the events, and answer the questions related to the case study. You will have about 15 minutes to complete this part, but you may have extra time if needed. I will let you know when you have about 5 minutes left."
- "Now that you have had a chance to review the case studies, we will review the case studies as a group. A volunteer, or volunteers from the group will provide a brief overview of the case study, describe key issues/problems, and identify the main theme or themes from your group discussion."

### Review of Advance Healthcare Planning (In-Person Session):

- "Next we will review information on advance healthcare planning. I will ask a few questions and I would like you to do your best to answer the questions. If you feel more comfortable writing down your answers and putting them on your table for me to pick up, you can do that."

### Review of Advance Healthcare Planning (Virtual Session):

- "Next we will review information on advance healthcare planning. I will ask a few questions and I would like you to do your best to answer the questions. If you feel more comfortable writing down your answers you can use the 'chat' feature and type in your answers"

### Evaluation Form (In-Person Session):

- "Thank you for your attendance today. Before you leave today, please complete the evaluation form. This will help to make this program better."

### Evaluation Form (Virtual Session):

- "Thank you for your attendance today. I will be sending you an e-mail which includes an evaluation form for today's session. Please complete the evaluation form."

# Promoting Your Event

To encourage people to attend your event, it might be helpful to use the promotional materials provided.

**Newsletter Blurb:**

- We are hosting an event: Conversations that Matter: Advance Care Planning for Rural Families at (Include Location) that can help you understand advance healthcare planning.
- At this event we will watch a video about advance care planning and discuss cases related to advance care planning.
- We are hosting this event on (Date, Time, Location). Please RSVP to (name/contact). This event is free.

**E-mail:**

Dear (potential participant's name),

- We are hosting an event: Conversations that Matter: Advance Care Planning for Rural Families at (Include Location) that can help you understand advance healthcare planning.
- At this event we will watch a video about advance care planning and discuss cases related to advance care planning.
- Everyone is welcome and the event is free.

(Date and Time)
(Exact Location)
RSVP (how) by (date)

**Submission to a community calendar, local paper, etc.**

Conversations that Matter: Advance Care Planning for Rural Families: (Location/Group) is hosting a free event to help people understand how to prepare for medical decision making. A short video and case studies will show people the importance of knowing how to make medical decisions and how to do so. (Date, Time, RSVP Info)

# Advance Care Planning:
# Key Content & Main Ideas Review

### Instructions

After the group has discussed the case studies and reported to the larger group, the material below will revisit some of the content covered in the video and clear up common misconceptions. Ask for a volunteer from the audience to answer the following questions. Notes provide key elements that often require clarification.

**Question 1:** Describe the similarities and differences between a financial power of attorney and a medical power of attorney.

a. Both designate someone to make decisions and act on your behalf.

b. A financial power of attorney is typically active immediately, unless it includes specific language stating that it does not become active unless you become incapacitated.

c. Medical power of attorney typically do not become active until a person is unable to communicate and make decisions for themselves. These typically become active when the patient does not have decision making capacity (e.g., unconscious after a serious accident).

**Question 2:** What is the difference between a Medical Power of Attorney and a Living Will?

a. Medical Power of Attorney may be completed with the aid of an attorney and designates a person to speak on your behalf if you become incapacitated.

b. A living will is a document typically provided by health care providers that allows you to write down the type of care you would like to receive in specific circumstances, if you are terminally ill and are unable to speak for yourself.

c. A living will does not require the assistance of an attorney to complete. However, many states require living wills to be signed before two witnesses and before a public notary.

**Question 3:** What is the difference between long term care planning and advance care planning?

a. Long term care refers to options for people who are not able to provide routine, daily care for themselves (bathing, cooking, medication management, cleaning, etc.).

b. Long term care planning refers to making decisions about where you want to receive daily care (e.g., assisted living or at home) and how you will pay for this care.

c. Many individuals who require daily assistance are often able to communicate their

preferences and make decisions for themselves.

d. Advance care planning is for situations when a person cannot communicate or make decisions, often due to an accident or sudden medical incident (e.g., stroke).

e. Advance care planning may also be relevant for routine medical procedures (e.g., surgery), if complications take place.

**Question 4:** When does the health care proxy or agent make medical decisions on your behalf?

a. The healthcare agent or proxy ensures your preferences for healthcare are honored when it is determined you are not able to make healthcare decisions.

b. Incapacitation refers to situations when a person is either physically or mentally unable to communicate their preferences, make decisions, or act on their own behalf.
   i. Incapacitation can be a temporary situation such as being injured during an accident.

c. The agent or proxy can only make decisions when it is determined you are not able to make healthcare decisions. You will not lose control of your medical care, if you develop an advance care plan and name an agent or proxy.

**Question 5:** What is the role of the health care proxy/agent?

a. The duty of a proxy or agent is to make medical decisions for you that you would make for yourself, if you were not able to communicate your preferences and wishes.

b. This is a person that you have discussed your preferences with and has agreed to follow your wishes.

c. If you have not identified a healthcare agent or proxy, your closest family member will be asked to make decisions (spouse, adult children, parents, siblings, etc.)

**Question 6:** What documents should I have in place if I am at the end-of-life?

a. For patients that have been diagnosed with a terminal condition by their provider, 2 additional documents may be helpful. Medical providers define “terminal conditions” as a condition a patient has and the medical provider would not be surprised if the patient passed away within a year.

b. In South Dakota, patients may request a Comfort One and/or a SD MOST Form.
   i. Comfort One: A medical order telling emergency medical service (EMS) personnel to not start emergency rescue techniques (CPR) if a breathing or cardiac failure happens. This is a signed medical order and is appropriate for persons living in the community setting. If a person does not have a Comfort One, EMS personnel, by law, are to start CPR.
   ii. SD MOST (“Medical Orders for Scope of Treatment”): A transportable medical order sheet that is executed by a patient through conversations with the medical provider. This document is entered into the patient’s medical record and provides direction to healthcare providers about the goals and preferences of the patient. This document should be used as a complement to the patient’s advance directive(s). This document translates the patient’s wishes in the advance directive into actionable medical orders.

c. In North Dakota, patients may create a POLST document. POLST stands for Physician Order for Life Sustaining Treatment. It is a signed medical order that communicates the patient's wishes for emergency treatment when a person faces serious illness, frailty or end of life. (Note, the term patient is also intended to include the patient's healthcare agent or surrogate decision maker. The term, provider includes those with prescriptive practice- physician, nurse practitioner, clinical nurse specialist or physician assistant).

## Sample Responses to Case Study Discussion Questions

**Case Study 1** – Ranch Accident

1. What are your initial thoughts about the circumstances described in the case study?
   - Anna is very emotional.
   - The doctor is throwing a lot of information at Anna all at once.
   - Anna is trying to manage two situations: injured husband, children at home, and the family business (e.g., ranch).
   - Multiple people need to talk to Anna (doctor and nurse)
   - Anna is tired.
   - Anna is alone taking in the information with no support (hour from home).
   - Anna is uncertain about where she will sleep overnight.
2. What issues or problems do you see here? How does this impact decision making?
   - Bill and Anna live far away from medical services.
   - Bill was injured in a ranch accident.
   - Bill could have significant brain damage.
   - It helps to identify what might be important to Bill (e.g., the ability to work on his ranch).
   - Bill's decision maker is available to make decisions.
   - Bill's decision makers is in a difficult place (e.g., a lot of incoming information about Bill's condition, completed hour long drive after being awake since early morning, etc.).
   - Anna is alone in terms of having to take in the information. Even though she is the one to make decisions, it helps to have someone else there to also listen or take notes
   - If Anna is not a rancher/farmer, how will she know what decisions to make?
   - How will she handle taking care of things while Bill recovers? Will she have to hire someone?
3. How would the health care proxy/agent ensure Bill's preferences are honored?
   - Bill's health care proxy/agent is present. She is available to say what to do and not what to do.
   - Follow what Bill would want, even if that is different than what Anna would want.
   - Some decisions would already be made for Anna – taking some stress and decision making off Anna in an already difficult situation
4. How could advance care planning make this difficult situation easier?
   - If Bill and Anna have talked about advance care planning, then Anna will be more confident in the decisions that she makes for Bill's medical care.
   - Having these conversations before a crisis has been shown to decrease anxiety and guilt for the decision maker.

**Case study 2** – Thanksgiving Accident

1. What are your initial thoughts about the circumstances described in the case study?
    - Everyone needs medical attention.
    - The father's condition is the most serious.
    - Father is separated from wife and children.
    - Uncertain about how far the distance is between the father and the rest of his family.
    - Potential that decision makers are unable to make decisions (husband/wife unable to make decisions for each other. Can wife make decisions about children's care)
    - How will the hospital know the Father's wishes – depending on his condition?
    - Who else knows the Father's wishes? More than one person should know.
    - Is another family member able to help who knows parents' wishes?
2. What issues or problems do you see here? How does this impact decision making?
    - The wife and husband both appear to have head injuries.
    - They have small children who will need care.
    - We do not know if they have an alternate person to make medical decisions, since both husband and wife are injured.
    - Is someone able to take care of kids and make child-rearing decisions if both parents have head injuries?
3. How would the health care proxy/agent ensure Smith's family preferences are honored?
    - Depending on the severity of the injury, their current health, and preferences for medical care, the health care proxy/agent will make decisions that they would make for themselves.
4. How could advance care planning make this difficult situation easier?
    - It would allow them to identify someone to make medical decisions on their behalf, since both the husband and wife were injured.
    - This is an important thing to address. While many people choose a spouse to be their decision maker, it is good to have an alternate for situations such as this.

**Case Study 3** – Unexpected Lump

1. What are your initial thoughts about the circumstances described in the case study?
    - Nancy is an older woman.
    - There are many steps (i.e., check for cancer then decide on treatment).
    - There are many options (chemotherapy, surgery, or nothing at all).
    - Nancy is able to make decisions for herself.
    - What is Nancy's overall health besides this?
    - Nancy is upset by this news and needs time to think, whereas other people may not feel that same way.
    - Glad that Melanie is present to help her mother and be someone for her to talk to.

2. What issues or problems do you see here? How does this impact decision making?
    - We do not have any other information about Nancy's current health (other than the bleeding).
    - What would the treatment look like?
    - How would treatment affect quality of life during and after?
    - Is Nancy otherwise healthy or would potential cancer treatment be dangerous?
    - We do not know Nancy's exact age.
3. How would the health care proxy/agent ensure Nancy's preferences are honored?
    - The health care proxy/agent would know current information about Nancy's current health, even though Nancy still had decisional capacity.
    - Could be an important time for Nancy and her daughter to revisit her wishes (since ACP is a process and should be re-evaluated)
    - Nancy has help with her decision-making.
4. How could advance care planning make this difficult situation easier?
    - It will not be the first time the family has discussed end-of-life topics.
    - It is a conversation starter for a difficult topic for some families
    - If they have not previously discussed these types of things it could help with other similar issues that may arise.

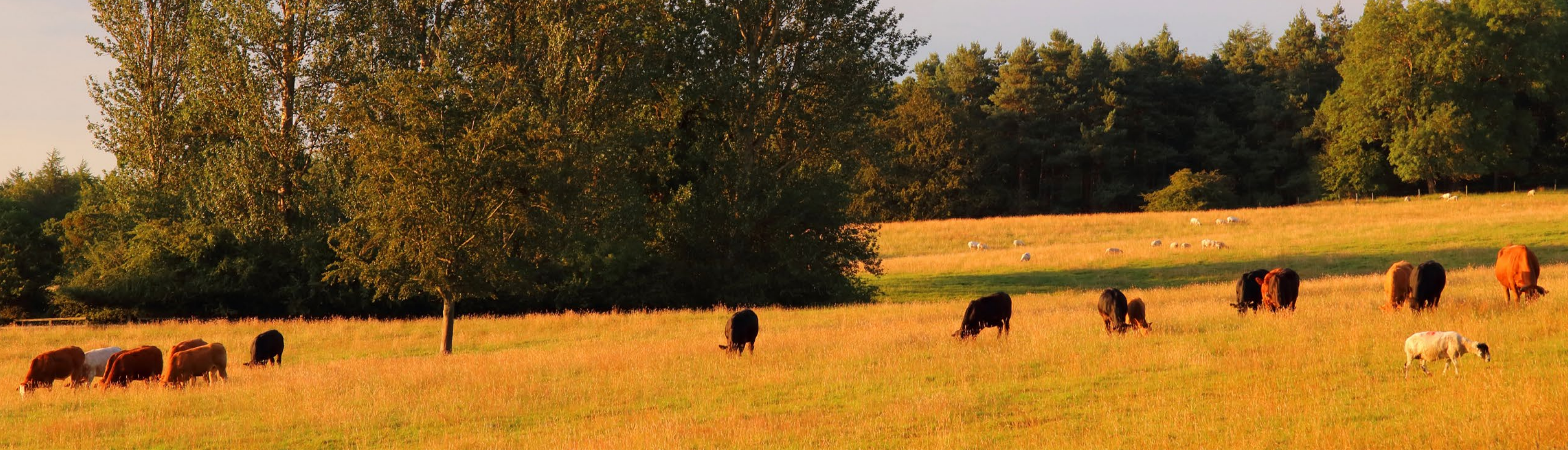
**Case Study 4** – The Stroke

1. What are your initial thoughts about the circumstances described in the case study?
    - We do not know who to call.
    - Her children might be old enough to provide appropriate contact information (e.g., dad, grandparent, godparent, etc.) for emergency purposes.
    - Frightening but could be eye-opening for some. No matter our age, we should have such conversations with our loved ones. Many don't worry about advanced care planning until they are older or have a health concern.
    - This was likely very scary for her boys, we do not know what they will do while she is taken to the hospital.
    - We need to have these conversations at all ages, just in case
2. What issues or problems do you see here? How does this impact decision making?
    - We do not know if Janet engages in advance care planning.
    - We do not know how to contact her health care proxy/agent (i.e., the legal code has established the order of priority for speaking on behalf of a person who is incapacitated).
    - Janet's preferences for health care proxy/agent may be different from who the legal code would support, especially if ever challenged in the legal system.
    - Sometimes people choose a friend over a spouse or even a living parent depending on their age.

- We do not know her contact, or if she even has one. Is she married? Does she have family close by? How will doctors know what to do?

3. How would the health care proxy/agent ensure Janet's preferences are honored?
    - They would have conversations with medical provider's about Janet's condition.
    - They would consider her diagnosis, treatment options, and likely outcomes as they decide which course of action aligns with Janet's wishes.
4. How could advance care planning make this difficult situation easier?
    - Janet's children are able to provide emergency professionals with contact information for her health care proxy/agent.
    - Depending on severity and location of the stroke, many things could be done to help with quality of life and recovery. But it could also depend on what else is going on in Janet's health and her desires.

# HANDOUTS



# Advance Care Planning:
# Case Studies

### Case study 1 – Ranch Accident

It was early fall on the ranch. It was time to bring the cattle in to winter pasture. While loading up the horses in the trailer, Bill was kicked in the head. He immediately lost consciousness. His crew tried to bring him around with no luck. Emergency services were called and he was medevacked to a larger community to receive care. Bill's wife, Anna, had to drive an hour to get to the hospital. When Anna arrived, Bill was stable, but the doctor was concerned about intracranial hematomas and hemorrhages along with skull, facial, and spine fractures. The nurse was asking Anna questions about Bill's medical history to complete Bill's hospital admission. Anna was so upset; she just wanted to know if Bill was going to be okay. While Anna waited for the CAT scan to be performed, she was calling to make arrangements for someone to care for the kids for the evening. Hours later the doctor came to talk to Anna. He said Bill had hematomas that required surgery to relieve the pressure on the brain. Fortunately, there were no broken bones. They were calling in a neurosurgeon to perform the procedure. In the meantime, the doctor needed to go over information about the surgery (time, risks, etc.) and receive Anna's consent to perform the procedure. Anna was so tired she could barely process what she was being told about the procedure.

### Discussion Questions

1. What are your initial thoughts about the circumstances described in the case study?

2. What issues or problems do you see here? How does this impact decision making?

3. How would the health care proxy/agent ensure Bill's preferences for care are honored?

4. How could advance care planning make this difficult situation easier?

### Case study 2 – Thanksgiving Accident

November is a beautiful time in the Midwest. It was Thanksgiving week and the Smith family was planning to travel a few hours to spend the holiday with family. On Thanksgiving Day, they woke up to a beautiful white landscape. It had snowed overnight. It was only a few inches so the family decided to make the trip. While on the way an unfortunate event occurred, a deer darted out of the ditch in front of the car. The driver did everything right, but the roads were snow covered and the car went sliding off the road and barreled into a tree. The mother and father were both unconscious and pinned in their seat. The children in the back seat were scared but okay. Fortunately, a family in a different car traveling behind the Smith family saw what happened. They arrived at the scene and dialed 911. While waiting for help to arrive, the good Samaritan talked calmingly to the children trying to make them feel better. They looked okay but he didn't want to risk moving them in case they had injuries that could not be seen. When help arrived, emergency services had to use the Jaws of Life to free the mother and father from the car. By the time the mother was freed from the car, she was beginning to regain consciousness. She was disoriented but seemed to only have a minor head injury. Unfortunately, the steering wheel had been wedged against the father's chest and the emergency professionals were concerned about internal bleeding and other injuries. Because of the difference in severity of injuries, the mother and children were taken to the nearest hospital and the father was medevacked to an urban community with more specialists available to treat him.

### Discussion Questions

1. What are your initial thoughts about the circumstances described in the case study?

2. What issues or problems do you see here? How does this impact decision making?

3. How would the health care proxy/agent ensure the Smith's family preferences for care are honored?

4. How could advance care planning make this difficult situation easier?

### Case study 3 – Unexpected Lump

Nancy was healthy overall, but she had recently noticed some bleeding. Since she went through menopause 35 years ago, she knew she needed to see her doctor. After not finding anything during the physical exam, the doctor recommended an ultrasound. Nancy attended the appointment for the ultrasound and then waited to hear the results. A week later the doctor called her in to review the results. Nancy decided to bring her daughter, Melanie, with her. During the appointment, the doctor reported that a mass had been found on Nancy's uterus. It was about the size of a quarter. The doctor explained that the ultrasound could not tell us if the mass was cancer or not. A biopsy was needed. Once that test was completed, then the doctor would be able to talk about next steps which might include chemotherapy, surgery, or nothing at all. Nancy was upset. She told the doctor she needed some time to think about what was best for her.

### Discussion Questions

1. What are your initial thoughts about the circumstances described in the case study?

2. What issues or problems do you see here? How does this impact decision making?

3. How would the health care proxy/agent ensure Nancy's preferences for care are honored?

4. How could advance care planning make this difficult situation easier?

## Case study 4 – The stroke

Summer time is full of family fun! Janet enjoyed the extra time with her boys, Caleb and Ben. Both boys were involved in 4-H shooting sports. While at one of the competitions, Janet noticed that her leg was feeling numb. She figured she had been sitting for too long so she decided to stand up and stretch her legs a bit. Suddenly she became very dizzy and had a sharp headache. As she looked around, she felt disoriented and uncertain where she was. Janet was having a stroke. She crumpled to the ground. Bystanders saw her fall and came to her aid. They called 911 and she was rushed to the local hospital.

## Discussion Questions

1. What are your initial thoughts about the circumstances described in the case study?

2. What issues or problems do you see here? How does this impact decision making?

3. How would the health care proxy/agent ensure Janet's preferences for care are honored?

4. How could advance care planning make this difficult situation easier?

# Advance Care Planning:
# Lesson Evaluation

**Instructions:** Please rate your level of agreement with the following statements.

1. As a result of this session, I have more knowledge about advance care planning.
   - ❑ Strongly disagree
   - ❑ Disagree
   - ❑ Somewhat disagree
   - ❑ Somewhat agree
   - ❑ Agree
   - ❑ Strongly agree
2. As a result of this session, I understand the difference between advance care planning and long term care planning.
   - ❑ Strongly disagree
   - ❑ Disagree
   - ❑ Somewhat disagree
   - ❑ Somewhat agree
   - ❑ Agree
   - ❑ Strongly agree
3. As a result of this session, I plan to create, review, or update my advance care plan.
   - ❑ Strongly disagree
   - ❑ Disagree
   - ❑ Somewhat disagree
   - ❑ Somewhat agree
   - ❑ Agree
   - ❑ Strongly agree
4. Comments or additional feedback:

# How to get started with advance care planning

1. Discuss your preferences
    a. Starter questions by Atul Gawande (Source - Being Mortal: Medicine and What Matters in the End):
        i. What do I understand about my health today and likely outcomes?
        ii. What questions do I have for my provider about my health?
        iii. What are my fears and worries?
        iv. What are my goals and priorities?
        v. What tradeoffs am I willing/not willing to make?
        vi. How would a good day look?
    b. Include family and loved ones in the conversation.
    c. Include clergy or other spiritual/religious adviser in the conversation.
    d. Trained volunteers are available to help you have the conversation between you and your healthcare proxy or agent:
        i. Honoring Choices North Dakota – 701-989-6228
            1. Website: https://www.honoringchoicesnd.org/
        ii. South Dakota Quality Conversations Program
            1. Website: https://www.advancedcareplanningsd.com/
    e. Most important: give yourself and your loved ones time to process this discussion. It may be the most difficult conversation of your life. You and your loved ones will take comfort in knowing they are making decisions that honor you, if needed.
2. Put it in writing
    a. Request an advance directive form from your medical provider. Some medical providers have made their advance directive forms available for download from their website.
    b. Identify one person to serve as your healthcare agent or proxy.
    c. If you have a chronic health condition, it may be helpful to visit with your medical providers about your health care wishes
    d. Review and complete the form carefully.

e. Sign the form before a Notary Public.

3. Give copies of the advance healthcare directive to:
   a. Your healthcare agent or proxy.
   b. Your healthcare provider.
   c. Store a copy with other important paperwork in a place that is easily accessible to others, including your proxy or agent.
4. Review Regularly
   a. Marriage, divorce, loss of a loved one, medical diagnosis, or end-of-life decline impact your healthcare planning preferences so review the document at least every year.

# Helpful Resources

**Disclaimer:** The following is presented for informational purposes only. Neither NDSU Extension or SDSU Extension endorse the services, methods or products described herein, and makes no representations or warranties of any kind regarding them.

### Comfort One (Do not resuscitate) South Dakota

An order that tells emergency medical service personnel to not start emergency rescue techniques (CPR) if a breathing or cardiac failure happens. It is a signed medical order. It is signed by or on the behalf of a person and a medical provider. This document is appropriate for persons living in the community setting. Emergency service personnel identify if a person has a Comfort One from the Comfort One form, or if the person is wearing a Comfort One bracelet. If a person does not have a Comfort One, emergency medical service personnel, by law, are to start CPR. For more information, please visit the South Dakota Department of Health website: https://doh.sd.gov/providers/ruralhealth/ems/advanced-directives.aspx.

### Conversation Starter Kit

The Conversation Starter Kit is a useful tool to help you have the conversation with a family member, friend, or other loved one about wishes regarding end-of-life care. It is available in several languages. All of the Starter Kits are available to download and print for free. Visit The Conversation Project website to download the kits: https://theconversationproject.org/starter-kits/

### Hello Game by My Gift of Grace

My Gift of Grace is a conversation game. In the box, you'll find an instruction sheet, 47 Question Cards, and 32 Thank You chips. During each turn, all the players have a chance to share their answers to the same question, trading chips as part of the game play. Questions in the game cover a wide variety of topics about living and dying well, and games can last anywhere from 20 minutes to three hours or more. The game can be played by families, co-workers, teams, strangers, or a mix of any of these. There are no age restrictions or experiences you need to have before you play. The game adjusts itself to the level of comfort of the players and to how long a group wishes to play. To learn more, please visit the My Gift of Grace website: http://www.mygiftofgrace.com/

### National Healthcare Decisions Day (NHDD) website

National Healthcare Decisions Day (NHDD) exists to inspire, educate, and empower the public and providers about the importance of advance care planning. NHDD is an initiative to encourage patients to express their wishes regarding healthcare and for providers and facilities to respect those wishes, whatever they may be. This website has many tools available to help individuals and families explore the topic of advance care planning. To learn more, please visit the NHDD website: https://www.nhdd.org/

### Medical Orders for Scope of Treatment (MOST) - South Dakota

Available in South Dakota. It is a medical provider's order that outlines a plan of care respecting the patient's wishes concerning care at end of life. MOST is not a legal document. It is a transportable medical order signed by a health care provider for individuals with a terminal illness. The goal of the MOST initiative is to inform and empower patients to clearly state their end-of-life care wishes, and to authorize health care providers to carry out those wishes. This form is valid across all care settings and in all facilities, including the home. MOST is a medical order, not an advance directive. An advance directive is a legal document and a way to name a durable power of attorney for healthcare (a healthcare agent) and/or a living will (providing general treatment wishes). Patients diagnosed with a terminal condition should have both documents as a part of their advance care plan. To learn more, please visit https://doh.sd.gov/providers/most/

### Physicians Orders for Life-Sustaining Treatment (POLST) – North Dakota

Available in North Dakota. It is a signed medical order that communicates a patient's wishes for emergency treatment when the person is seriously ill, frail, or at the end of life. This document lists a patient's wishes for cardiopulmonary resuscitation (CPR), breathing support (ventilators), treatments for life-threatening problems, and being taken or admitted to the hospital. This form is valid across all care settings and in all facilities, including the home. The patient keeps a copy of the form in case emergency responders need to know their choices. To learn more, please visit https://www.honoringchoicesnd.org/polst/.

### The Go Wish Game

Go Wish gives you an easy, even entertaining way to talk about what is most important to you. The cards help you find words to talk about what is important if you were to be living a life that may be shortened by serious illness. To learn more, please visit the Go Wish website: http://www.gowish.org/index.php.

### Tool Kit for Health Care Advance Planning by the American Bar Association

This tool kit contains a variety of self-help worksheets, suggestions, and resources. There are currently 9 tools in all, each clearly labeled and user-friendly. The Tool Kit does not create a formal advance directive for you. Instead, it helps you do the much harder job of discovering, clarifying, and communicating what is important to you in the face of serious illness. To access this tool kit, please visit the American Bar Association website: https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning/.

### PREPARE for Your Care

PREPARE for Your Care is an easy-to-use website that provides video stories to help people engage in advance care planning. These videos are divided into 5 steps: choosing a medical decision maker, deciding what matters most in life, choosing flexibility for your decision maker, telling others about your medical wishes, and asking doctors the right questions. To access this resource please visit: https://prepareforyourcare.org/welcome.

# Myths and Realities of Advance Care Planning

**MYTH 1:** There is only one type of power of attorney.

**REALITY 1:** Many patients (and their families) think if they have power of attorney for financial matters, they also have power of attorney for health care. These are typically separate legal documents, but can be combined into one comprehensive document prepared by an attorney.

**MYTH 2:** Advance care planning should not begin on an outpatient basis.

**REALITY 2:** Many studies have shown that patients want their doctors to talk about advance care planning with them before they become ill. Many patients have a positive response when advance care planning discussions are held during outpatient visits.

**MYTH 3:** An advance directive means "don't provide medical care".

**REALITY 3:** Advance directives do not say "don't give me medical care". They say, "give me the medical care I would ask for, if I could not speak for myself".

**MYTH 4:** Once a person names a proxy or agent in an advance directive they lose control of their own care.

**REALITY 4:** As long as a person has decision making capacity, he/she has control of their medical care. A doctor determines if a person has decision-making capacity.

**MYTH 5:** A lawyer is required to complete an advance directive.

**REALITY 5:** A lawyer may be helpful, but is not required. Again, check your own state requirements for the number of witnesses or the need for a notary public seal.

**MYTH 6:** Doctors and other health care providers (doctors, nurses, specialist, etc.) are not legally required to follow advance directives.

**REALITY 6:** Doctors and other health care providers (doctors, nurses, specialist, etc.) are required to follow advance directives.

**MYTH 7:** My doctor can be my proxy or agent while caring for me as a patient.

**REALITY 7:** If a doctor is named as your agent or proxy, they can no longer be your doctor.

**MYTH 8:** Only older people need advance directives.

**REALITY 8:** Tragedies can happen at any age, so every adult should have advance care planning in place. Family members and health care providers (doctors, nurses, specialist, etc.) should be made aware of those plans.

**MYTH 9:** Once advance directives are signed, they cannot be changed.

**REALITY 9:** Advance directives can be changed at any time; they should be reviewed at least every year and updated whenever major life changes occur. A lawyer does not need to be involved to create initial directives or to revise them.

**MYTH 10:** If I am living at home and my advance directive states that I do not want CPR, I will not be resuscitated by Emergency Medical Service (EMS) responders.

**REALITY 10:** Your advanced directive cannot usually be followed in this situation. When 911 is called, EMS responders must provide life-sustaining treatment, UNLESS you have an Out-of-Hospital Do-Not-Resuscitate (DNR) order, such as Comfort One South Dakota (https://doh.sd.gov/providers/ruralhealth/ems/advanced-directives.aspx) or North Dakota POLST (https://www.honoringchoicesnd.org/polst/).

**MYTH 11:** My doctor is the only one who needs a copy of my advance directive.

**REALITY 11:** It is important to have your advance directive available when needed in an emergency. For this reason, the following people and places are recommended for having a copy of your advance directive.

- Physician
- Hospital(s) most likely to treat you
- Each of your healthcare agents or proxies
- Family members close to you
- Your lawyer
- Keep a copy in your glovebox of your vehicle
- Keep a copy in your home where it can be easily found

# Common Advance Care Planning Terms

- **Advance care planning (ACP)** – A process for setting goals and plans with respect to medical care and treatments. It requires conversations between the individual and his or her family, key health care providers, and anyone else who may be involved in decision-making. It can begin at any point in a person's life, regardless of his or her current health state and, ideally, is documented in an advance directive or recorded in your medical record, revisited periodically, and becomes more specific as your health status changes.

- **Advance directive** – The general term for any document in which you provide instructions about your health care wishes or appoint someone to make medical treatment decisions for you when you are no longer able to make them for yourself. Living wills and durable powers of attorney for health care are both types of advanced directives.

- **Antibiotics or antiviral medications** can be used to treat many infections. If you were near the end of life, would you want infections to be treated aggressively or would you rather let infections run their course?

- **Capacity** means a patient's ability to make medical decisions. Does he or she have the ability to understand the medical problem? Does he or she understand the risks and benefits of the treatment options? The word does not mean the same as competency. Competency is a legal status ordered by the court.

- **Cardiopulmonary resuscitation (CPR)** attempts to restart the heart when it has stopped beating. Determine if and when you would want to be resuscitated by CPR or by a device that delivers an electric shock to stimulate the heart.

- **Comfort care** includes any number of interventions that may be used to keep you comfortable and manage pain while abiding by your other treatment wishes. This may include being allowed to die at home, getting pain medications, being fed ice chips to soothe mouth dryness, and avoiding invasive tests or treatments (medical procedures that break the skin and likely require follow up medical care).

- **Dialysis** removes waste from your blood and manages fluid levels if your kidneys no longer function. Determine if, when, and for how long you would want to receive this treatment.

- **Donating your body** for scientific study also can be specified. Contact a local medical school, university, or donation program for information on how to register for a planned donation for research.

- **Durable power of attorney for healthcare (or Healthcare Proxy)** – A type of advance directive in which you appoint someone else to make all medical treatment decisions for you, if you cannot make them for yourself. The person you name is called your agent, proxy, representative, or surrogate. You can also include instructions or guidelines for decision-making.

- **DNR** – Do not resuscitate; allow natural death. Written or verbal medical order.
- **Emergency medical services (EMS)** refers to a group of agencies that provide emergency care. This care is usually to persons outside of healthcare facilities. EMS personnel generally include paramedics, first responders and other ambulance crew.
- **Hospice** is for a person that a doctor says may die within the next six months. Hospice supports the patient and family. Hospice is made up of a team of people with special training. The team helps with pain and symptom control, spiritual needs, money, and legal issues. They help with other needs as well. Care may be provided at home or in the hospital, nursing home, or other settings.
- **Intubation** refers to "endotracheal intubation." A tube is inserted through the mouth or nose into the trachea (windpipe). It is used to create and maintain an open airway to help the patient breathe.
- **Life-sustaining treatments** replace or support a vital body function (also called life support treatments). This can include CPR, breathing tubes, nutrition and hydration through tubes and IV's, kidney dialysis, and other treatments.
- **Living will** – A type of advance directive in which you state your wishes about care and treatment you want or don't want if you are no longer able to speak for yourself. Normally, living wills address one's preferences about end-of-life medical treatments, but they can also communicate your wishes, values, or goals about any other aspect of your care and treatment. These documents are signed and notarized.
- **Mechanical ventilation** is also known as a 'breathing machine'. A machine forces air into the lungs through a tube that is inserted into the nose or throat. The machine does the breathing work for the lungs to keep oxygen moving that is necessary for life.
- **Natural death** - Death by natural causes, as recorded by coroners and on death certificates and associated documents, is death resulting of an illness or an internal malfunction of the body not directly caused by external forces, typically due to old age, but not always.
- **Organ and tissue donations** for transplantation can be specified in your living will. If your organs are removed for donation, you will be kept on life-sustaining treatment temporarily until the procedure is complete. To help your health care agent avoid any confusion, you may want to state in your living will that you understand the need for this temporary intervention.
- **Palliative care** is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially trained team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient's prognosis. This care is appropriate at any age and at any stage in a serious illness.

- **POLST/MOLST/POST** – "Physician Orders for Life-Sustaining Treatment" (also referred to by other terms, such as "Medical Orders for Life-Sustaining Treatment" or "Provider Orders for Scope of Treatment") Is a set of medical orders in a standardized format. These orders address key critical care decisions consistent with the patient's goals for care and results from a clinical process. A key goal is to facilitate shared, informed medical decision making and also communicate care goals of patients with health care providers (doctors, nurses, specialist, etc.).
- **Tube feeding (artificial hydration and nutrition)** supplies the body with nutrients and fluids intravenously or via a tube in the stomach. Decide if, when, and for how long you would want to be fed in this manner.
- **Ventilator (respirator)** is a machine that pushes air into the lungs. To do this, a tube placed in the trachea (breathing tube). Ventilators are used when a person cannot breathe on his or her own; cannot breathe well enough to get oxygen to the cells of the body; or rid the body of carbon dioxide, which is vital for life.
- **Withholding or withdrawing treatment** means to stop life-sustaining treatments. It can also mean to stop treatments after they have been used for a certain amount of time. This is generally done when treatments are no longer helping to improve a patient's health or the treatment is causing more symptoms.

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