


# NACR "Native American Palliative Care" Curriculum – Objectives 1-5




## Native American Palliative Care and End-of-Life Curriculum

Linda Burhansstipanov, MSPH, DrPH (Cherokee Nation of OK)  
Lisa Castro, Grants Manager  
Lisa Harjo, MA (Choctaw Nation)  
Rose Lee (Navajo Nation)  
Terri Rattler (Oglala Lakota)  
Native American Cancer Research  
3022 South Nova Road  
Pine, CO 80470-7830  
Phone: 303-838-9359; Fax: 303-838-7629  
Native Cancer Survivor's Support Network: 1-800-537-8295  
Web Page: <http://www.NatAmCancer.org>

Native American Cancer Research (303-838-9359) EOL "Intro slides"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

1



## End-of-Life Nursing Education Consortium (ELNEC)

This objective is #5 out of 5 that evolved from cultural modifications of ELNEC Module #4. Special acknowledgements to the authors and team leaders from the ELNEC Consortium:


Special thank you to key members of the Consortium:  
Geraldine Bednash, PhD, FAAN      Betty Ferrell, PhD, FAAN  
Executive Director, AACN      Research Scientist, City of Hope  
Principal Investigator      Principal Investigator

Anne Rhome, MPH, RN      Marcia Grant, DNSc, FAAN  
Deputy Executive Director, AACN      Research Scientist, City of Hope  
Co-Investigator      Co-Investigator

Barbara Penn, PhD, RN, C Rose Virani, RN, MHA  
Project Director, AACN      Project Director, City of Hope

Native American Cancer Research (303-838-9359) EOL "Intro slides"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

2



## NACR EOL Objectives 1-5 An excerpt of the cultural modification of ELNEC Module #4

Modified by Linda Burhansstipanov, DrPH (Cherokee)  
Jody Pelusi, FNP, PhD, AOCN  
Caren Trujillo, Consultant, BSW (Yaqui)  
Linda U. Krebs, RN, PhD, AOCN  
NACR staff: Lisa Castro, Lisa Harjo (Choctaw), Rose Lee (Navajo), and Terri Rattler (Oglala Lakota)

*Thank you,  
Linda Burhansstipanov, MSPH, DrPH  
Executive Director, NACR*

Native American Cancer Research (303-838-9359) EOL "Intro slides"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

3



## Supported by

The Denver Affiliate of the Susan G. Komen Breast Cancer Foundation through the 2002-3 community grants to NACR.

Native American Cancer Research (303-838-9359) EOL "Intro slides"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

4




## supported by

Mayo Clinic's, "Spirit of E.A.G.L.E.S."  
U01 CA86098 (2002)  
200 First Street S.W.  
Rochester, MN 55905  
Toll-free: 877-372-1617  
Fax: 507-538-0504  
E-mail: [nativecircle@mayo.edu](mailto:nativecircle@mayo.edu)  
Web Page:  
<http://www.mayo.edu/nativecircle>  
<http://www.mayo.edu/leadershipinitiative>

Native American Cancer Research (303-838-9359) EOL "Intro slides"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

5



## The Medicine Wheel / Circle of Life

This curriculum uses the concept of the Medicine Wheel and/or the Circle of Life to help explain how chronic or end-of-life care needs to focus on the whole person.

Native American Cancer Research (303-838-9359) EOL "Intro slides"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

6



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5

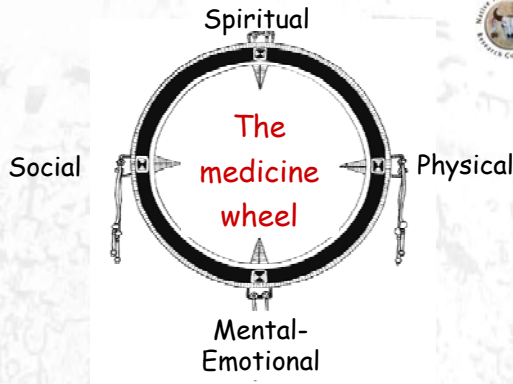
**The Medicine Wheel / Circle of Life**

The medicine wheel or Circle of Life are not used by all tribes.

Interpretation of the Medicine Wheel or Circle of Life varies among tribes.

Native American Cancer Research (303-838-9359) EOL "Intro slides"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

7



**The medicine wheel**

Modified from Phil Lane Jr., *The Sacred Tree*, Four Worlds Development Press, Lethbridge, Alberta, Canada, 1984 p. 29

8

The medicine wheel is a sacred symbol used by Northern Plains and others. It is related to balance in all life and all living things. Its universal knowledge is looked to for healing, wisdom, and direction.

Native American Cancer Research (303-838-9359) EOL "Intro slides"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

9

Some, but not all, tribal Nations use a medicine wheel.

The use of the wheel evolved for their own perspectives.

Native American Cancer Research (303-838-9359) EOL "Intro slides"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

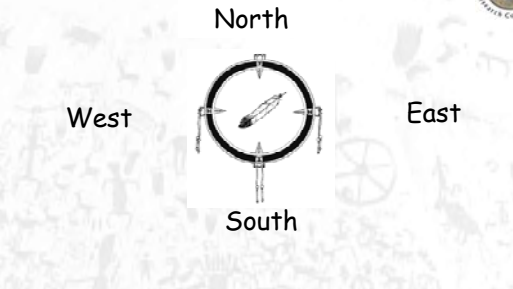
10

**Examples of uses:**

- elements (water, fire, air, earth)
- seasons (fall, winter, spring, summer)
- ages of life cycle (birth, childhood, adult, elder)
- sacred colors (red, white, yellow, black)
- aspects of human being (spiritual, physical, mental, emotional)

Native American Cancer Research (303-838-9359) EOL "Intro slides"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

11




**Four Directions**

Native American Cancer Research (303-838-9359) EOL "Intro slides"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

12



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5




A central diagram consisting of a circle with a feather in the center. Four lines extend from the circle to the words: Mental (top), Physical (left), Spiritual (right), and Emotional (bottom).

Mental  
Physical Spiritual  
Emotional

Aspects of a human being

Native American Cancer Research (303-838-9359) EOL "Intro slides"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

13




A central diagram consisting of a circle with a feather in the center. Four lines extend from the circle to the words: Fire (top), Water (left), Earth (right), and Air (bottom).

Fire  
Water Earth  
Air

Elements of life

Native American Cancer Research (303-838-9359) EOL "Intro slides"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

14




A central diagram consisting of a circle with a feather in the center. Four lines extend from the circle to the words: Fruits (top), Vegetables (left), Meat (right), and Wheat / grains (bottom).

Fruits  
Vegetables Meat  
Wheat / grains

Basic Foods

Native American Cancer Research (303-838-9359) EOL "Intro slides"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

15




A central diagram consisting of a circle with a feather in the center. Four lines extend from the circle to the words: Elders (top), Adults (left), Beginnings (right), and Youth (bottom).

Elders  
Adults Beginnings  
Youth

Stages of Life

Native American Cancer Research (303-838-9359) EOL "Intro slides"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

16



A central diagram consisting of a circle with a feather in the center. Four lines extend from the circle to the words: White (top), Black (left), Red (right), and Yellow (bottom).

White  
Black Red  
Yellow

Sacred Colors

Native American Cancer Research (303-838-9359) EOL "Intro slides"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

17

## Objective #1

### Roles and Responsibilities of the Caregiver Providing End of Life (EOL) Care

Lisa Castro, Grants Manager, NACR

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

18



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5

## Objective #1

By the end of this workshop, the learner will be able to:

1. define "caregiver"
2. identify roles and responsibilities of the caregiver providing end of life care to a loved one

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

19

What does it mean to be a caregiver?

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

20

## Definition of a Caregiver

**Primary Caregiver** - The main person who provides care for the patient's daily needs. This is usually a family member or close friend of the patient.

**Supporting Caregivers** - The people who assist the primary caregiver (family, friends, neighbors, volunteers, etc.)

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

21

## An Example:

Mary Looking Elk is a 65 year old Lakota woman who was recently diagnosed with terminal breast cancer. Her eldest daughter that lives close to her mother has now become her "primary care giver". But her younger daughter who is a single mother does help occasionally with grocery shopping and other errands as needed. She is considered a "supporting caregiver".

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

22

## Characteristics of a Successful Primary Caregiver

- Good communication skills
- Flexible with their schedule
- Can multi-task well
- Has their own transportation
- Being in good health  
(physically able to care for someone who may be unable to assist themselves)
- Remaining positive during a difficult time
- Willingness to make the commitment

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

23


What are some roles and responsibilities of a caregiver?

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

24



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5




## Caregiver Roles

The overall *role* of the caregiver is to find ways to successfully meet the daily and long term needs of the family member near the end of life.

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

25




## Caregiver Roles (cont.)

The primary caregiver becomes the advocate. The caregiver thinks and acts in the best interest of the family member.

The primary caregiver may need to decide if EOL care will be given in the home of the patient or their own home (this may determine who the primary caregiver will be).

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

26




## Caregiver Responsibilities

The *responsibilities* of the Caregiver are the specific tasks and actions that are done on a daily or regular basis.

For example, the caregiver may need to make schedules for doctor appointments (who is going to transport the patient to/from which appointment.)

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

27



## Caregiver Responsibilities

The Caregiver may need training to learn how to give shots and medications, help the family member with limited mobility and other physical needs.

If the Caregiver is unable to perform any of the above tasks, they may need to seek help from other family members or health care providers.

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

28



## Specific Responsibilities

- Daily care of loved one (providing meals, medications, bathing, etc.)
- Care of their home (housekeeping, shopping, etc.)
- Managing the patient's financial issues (mortgage, household bills, medical bills, medications)
- Helping your family member fulfill other responsibilities (care of children, elders or pets)

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

29

### Example of what may be included in a caregivers' schedule

<input checked="" type="checkbox"/>	What	When	Who
<input type="checkbox"/>	bathing	~noon	Mary
<input type="checkbox"/>	Doctor appt.	2:00 p.m.	Lisa
<input type="checkbox"/>	preparing meals and feeding	breakfast and lunch	Rose
<input type="checkbox"/>	cleaning house	MWF	Lee
<input type="checkbox"/>	administering medications	10:00 a.m. Bedtime 2:00 a.m.	Rose Lisa Lisa



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5

## NOTICE!!

In reality, most people feel so overwhelmed that they do not have the time to update schedules. Simple daily checklists can be very helpful.

Don't assume that you can remember everything yourself or do everything yourself.

Be realistic. Use the schedule to problem solve and get others involved.

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

31

## Caregiver's Notebook

Organization is key for the caregiver and with so many details to remember we suggest starting a "caregiver's notebook" to keep track of things.

This notebook can be as simple as a three ring binder.

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

32

## Caregiver's Notebook (cont.)

The Caregiver Notebook is a central place where patient schedules, activities, and a daily log can be kept.

- Daily notes
- Daily schedules
- Doctor Contact Information
- Medication log
- Visitor notes

It should be kept with the patient at all times.

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

33

## EOL Caregiving

Remember that caring for someone who is thought close to passing may turn out to be for several months or even longer.

This will be a very emotional time made more difficult by the feeling of burden to your own schedule and responsibilities. You may feel guilty about these feelings, but they are completely normal.

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

34

## Caregiver Guilt. Why guilt?

- Feeling somehow responsible for the family member getting the cancer

*"My mom got cancer because my brother was beating his wife and the Creator wanted to help our family find balance again. I should have done something to help."*

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

35

## Caregiver Guilt (cont.)

- Feeling resentful about the burden of fitting in the time with all of their other responsibilities
- Wondering "Why them and not me?"
- Giving up school or even a job to care for their loved one

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

36



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5

## Caregiver Burnout

Many times the patient wants one person to do it all, but you need help.

Talk to the family and find a way to spread the responsibilities among more than just yourself.

Remember you can't help anyone if you become sick yourself. Be an advocate for yourself too.

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

37

## Delegate!!

Look to:

*Family, friends, neighbors, church, spiritual healers, CHRs (Community Health Representative), volunteer organizations*

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

38

## EOL Care

**How is End of Life (EOL) care different from standard caregiving?**

*When the goal of treatment shifts from curing the illness to providing "comfort care".*

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

39

## In Conclusion

**Being the Primary Caregiver is:**

- A challenging responsibility
- A very important role with a mixture of guilt and duty
- Hard!
- An honor!

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

40

## Interactive Activity

Break into small groups and answer the following questions. When finished, write your groups answers on the paper provided and share with the larger group.

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

41

## Interactive Activity

1. List of four benefits a caregiver receives from the caregiving.
2. List of four benefits the sick family member receives from being cared for by a person who is close to them.
3. Predict at least three issues that might arise in the process of caregiving for a family member.

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's, "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

42



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5

## Resources for the Caregiver:

National Family Caregiver Association  
www.nfcacares.org / 1-800-896-3650

National Cancer Institute  
www.nci.nih.gov / 1-800-4-CANCER

Colorado Cancer Resource Guide  
www.ccronline.org

Cancer Care Counseling Line  
www.cancer-care.org / 1-800-813-HOPE

Today's Caregiver Magazine  
www.caregiver.com

Colorado Hospice Organization  
www.coloradohospice.org

EOL – NACR objective 1: Roles of Caregiver  
Mayo Clinic's "Spirit of E.A.G.L.E.S." Native American Cancer Survivors' Support Network 800-537-8295

43

## Objective #2

By the end of this session, the learner will be able to:

1. Describe what may be included in "quality" end-of life care.
2. Identify ways to provide quality end of life care for your family member.

Native American Cancer Research EOL obj #2: Quality EOL care 303-838-9359

44

## What is quality end-of-life care?

How would you define quality end of life care for you or for your loved ones?

Native American Cancer Research EOL obj #2: Quality EOL care 303-838-9359

45

## Possible answers

Being at home surrounded by loved ones and the things that make you feel comfortable (feathers, drum, totem)

Being with your partner, children, grandchildren, nieces, nephews, friends

Being able to do physical activities without discomfort

**continued on next page**

Native American Cancer Research EOL obj #2: Quality EOL care 303-838-9359

46

## Possible answers

Being able to pray and feel spiritual comfort and love from the Creator

Being pain-free

Being able to do physical activities without discomfort

Being able to think clearly

Being able to remember all of the good things that have happened in your life

Native American Cancer Research EOL obj #2: Quality EOL care 303-838-9359

47

## Quality end-of-life care needs to:

- Focus on the whole being of the person

- Address all four aspects of their life: physical, mental, emotional and spiritual.

Native American Cancer Research EOL obj #2: Quality EOL care 303-838-9359

48



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5

## The Medicine Wheel

The End Of Life modules focus on the whole being of the person.

The medicine wheel is a reflection of what the person needs to be comfortable in end-of-life care.

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

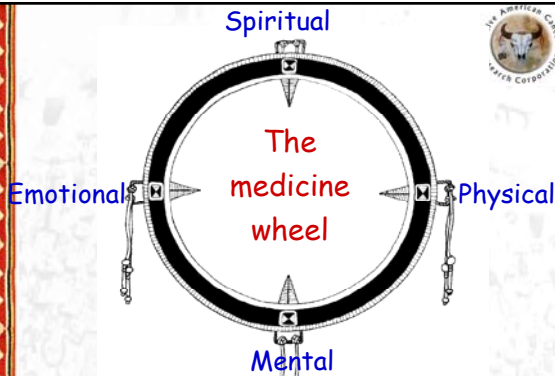
49

## The Medicine Wheel

- Can be used as a symbolic expression of what a person needs to be comfortable in end of life care.
- Is not used by all American Indian tribes however it is universally accepted as a cultural expression of life in balance.

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

50



Modified from Phil Lane Jr., *The Sacred Tree*, Four Worlds Development Press, Lethbridge, Alberta, Canada, 1984 p. 11

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

51

## Physical Area

- Inform the patient about *choices* of care such as home care and/or hospice
- Your physical surroundings
- Safety of physical surroundings
- Medications

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

52

## Physical Area

- Pain management
- Nutritious foods
- Physical activity
- Appearance of self (make-up, nails, hair, clothing, etc.)
- Water and other beverages (feeding tubes)

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

53

## Mental Area

- Thoughts of self, one's life and death
- Worries about how the family will thrive
- Mood swings (happy <-> depressed)
- Contentment about one's life and family
- Ability to think clearly

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

54



## NACR "Native American Palliative Care" Curriculum – Objectives 1-5

### Mental Area

- Creating a schedule of tasks, visitors, spiritual healers visits &/or ceremonies (see obj. #1)
- Keeping track of how medications or other situations affect the sick person's ability to concentrate or remember things.
- Creating an opportunity for the sick person to discuss Living Will and Final Will with family members

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

55

### Emotional Area

- Socializing with family members and friends
- Doing ceremonies
- Having some "alone" time
- Having good communication among loved ones, caregivers and doctors

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

56

### Emotional Area

- Organizing relaxing, healing activities such as reading, writing, listening to music and doing crafts.
- Sending out cards and letters and keep track of special occasions of loved ones (e.g., relatives birthdays) so that they are not forgotten.
- Providing a comfortable and welcoming setting that encourages others to sit and listen to stories or visit.

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

57

### Spiritual Area

The spiritual area includes:

- prayer
- traditional ceremonies
- religious ceremonies
- burial requests
- prayer items (e.g., Bibles, totem bags).

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

58

### Spiritual Area

- Creating a setting and opportunity for the patient to discuss spiritual issues, needs and /or desires.
- Working with the head spiritual authority/elders to make certain things are done properly.
- Getting permission from the hospital to burn sage, cedar, sweetgrass, etc.

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

59

### Spiritual Area

- Last rites and related tribal ceremonies/body preparation
- Acknowledge intertribal customs and beliefs between families and loved one.
- Respect your loved one requests in all areas of life.

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

60



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5

## Interactive Activity - Small Group

1. Please form groups of 3-5 individuals each and choose a person to record answers for the group.
2. Please read the following story and come up with ways you could provide care and comfort for the person for the chosen area given to you by the facilitator.

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

61

## Story

- A Blackfeet/Cherokee female, 68 years old and lives at home on a reservation with many relatives.
- She has been told by both her doctor and the medicine man that she is unlikely to live through another winter.
- She is taking pain medications that interfere with her memory and her ability to concentrate.

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

62

## Story

- She has five children. This woman practices Blackfeet traditional ways but her children practice Cherokee traditional ways.
- She is worried about her home, finances, pain and medications.

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

63

## Questions

1. In what ways can this elder be cared for to improve her
  - physical life
  - spiritual life
  - social life
2. In what ways can this person be cared for to reduce her
  - emotional concerns
  - mental concerns

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

64

## Summary of Quality End of Life Care

Quality End of Life care supports the family member in finding balance within the four areas of the medicine wheel during the final journey of their life.

Native American Cancer Research EOL obj #2- Quality EOL care 303-838-9359

65

## Objective #3

By the end of the workshop, the participant will be able to:

1. discuss examples of cultural, legal, and ethical issues that may arise in end of life care
2. identify three strategies to address the issues.

Native American Cancer Research (303-838-9359) EOL Obj #3, "Issues"  
Part of NACR's Cultural Modification to EOL/NEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

66



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5

## Issues during End of Life Care

- When individuals face end of life, many issues may arise that impact themselves, their caregivers, and family members.
- While these issues vary from family to family and tribe to tribe, the same strategies for working through them can be used in many situations.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

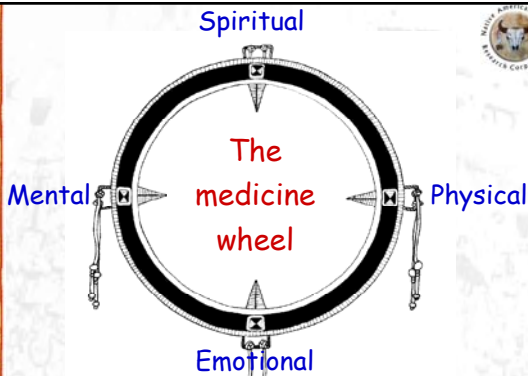
67

Let's look at a few of these issues through the lens of the Medicine Wheel of quality care.

Issues can impact an individual in more than one area. The issues are also categorized as cultural, legal and ethical.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

68



Modified from Phil Lane Jr., *The Sacred Tree*, Four Worlds Development Press, Lethbridge, Alberta, Canada, 1984 p. 11

69

## The Medicine Wheel

- Physical Area - This area relates to the physical body and its care.
- Emotional Area - This area relates to human feelings and emotions.
- Mental Area - This area relates to the thinking process and memory.
- Spiritual Area - This area relates to the beliefs about life and religion.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

70

## Physical Area Issues

- Language and cultural differences between patient and health care providers can cause misdiagnosis, misunderstandings, and errors in treatment. **(Cultural Issue)**
- Cultural and religious differences between the patient and their family can cause inadequate care. **(Cultural Issue)**

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

71

## Physical Area continued

- When a dying family member has no living will and has not assigned a durable power of attorney, other family members and medical providers can disagree on the level of care. **(Legal and ethical Issue)**

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

72



## NACR "Native American Palliative Care" Curriculum – Objectives 1-5

### Physical Area continued

- Ill family member may want to, and not be able to use traditional herbal remedies instead of, or in addition to, western medicine due to hospital and/or doctor restrictions. (Cultural Issue)

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

73

### Emotional Area

- When family members are very ill or close to death they are emotional, and can be more easily coerced into making or changing a will. (Legal and Ethical Issue)
- Family members may not express their real needs due to fear, mistrust, or other emotional issues. (Ethical Issue)

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

74

### Emotional Area continued

- Ill family members can become very upset worrying about how to pay for their funeral costs. (Legal Issue)
- Ill family member can worry about bills and other financial matters creating added stress. (Legal Issue)

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

75

### Emotional Area continued

- Family members who remove items from the home or hospital/nursing home room that they want before ill family member passes with or without their knowledge cause much grief and sadness. (Legal and Ethical Issue)

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

76

### Mental Area

- Ill family members can gradually lose their memory of details and their short term memory.

When family members are receiving chemo therapy, they often experience "chemo brain" or a lack of memory.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

77

### Mental Area continued

- Medications and illness can cause ill family members to lose ability to think and reason as they normally could so they can't manage their own medications and other schedules without help. They can be "forced" into things easily. (Can become a Legal Issue)

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

78



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5

## Mental Area continued

- Time management and relationship to time changes which can cause confusion and improper treatment. (Can lead to Ethical and Legal Issues)

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

79

## Spiritual Area

- When an American Indian patient's funeral and burial beliefs differ from the dominant society, they are often not honored and allowed. (Cultural Issue)
- Doctors who don't respect or respond to patient's wishes to use traditional medicine. (Cultural Issue)

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

80

## Spiritual Area

Ill family member is concerned about who they want to get their spiritual and religious items. (Cultural Issue)

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

81

## What strategies can caregivers utilize to address these issues?

- While the issues may differ due to the unique family and community situations and the stage of the illness, a few basic strategies are useful to the caregiver to help them meet the needs of the ill family member.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

82

## Communication

Good communication skills are a key to success in all human interactions.

All interactions between the ill family member and others will be improved with clear communication.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

83

## Communication continued

- Listen
- Clarify
- Be patient
- Repeat when necessary
- Don't get mad or upset

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

84



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5

## Communication continued

- Among caregivers
- Between the ill family member, the other family members
- Between the ill family member and the hospital, hospice, and doctors.
- Between the family caregiver and family members.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

85

## Communication continued

- Among family members regarding the patient.
- Between the patient and the caregiver.
- Between the patient and spiritual leader.
- Between the family and burial home.
- Between the family and hospital.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

86

## Mediation

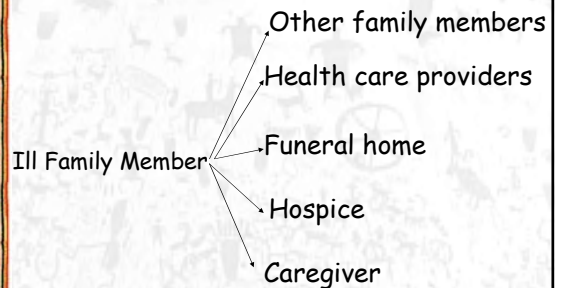
Mediation is a method of problem solving between two or more parties that promotes a win-win situation for everyone involved. All sides of the situation are considered.

Often a person outside the family or situation is needed to facilitate the mediation process.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

87

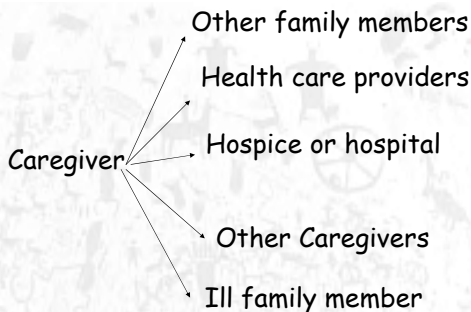
## Mediation continued



Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

88

## Mediation continued



Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

89

## Write everything down

- All "verbal agreements" should be written down in front of witnesses and signed by the parties involved.
- Wills and Living Wills should be in writing.
- Any and all instructions from the patient regarding burial preparations and burial should be written down.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

90



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5

## Maintain a Good Sense of Humor

A good sense of humor about all things will help the caregiver, ill family member, and other family members and loved ones. While end of life is a serious time, laughter and smiles play a big part in addressing issues and working out solutions.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

91

## Get Outside Help When Necessary

When facing issues that arise in end of life care, it may become necessary to call on an attorney, an outside mediator, a nurse, or other individual or group to help get information, conduct a ceremony, write a legal document, or inform family members about rights or medical explanations.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

92

## Get Outside Help When Necessary continued


It may even be necessary to contact the tribe or local social services agency to seek help for financial costs of funeral and burial.

You may also want to get legal advice about the bills and other financial issues.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

93


## Interactive Activity - Small Group

 Please form groups of 3-5 individuals each and read the following case study. Take about ten minutes to decide on a respectful way to respond to the questions.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

94


## Interactive Activity - Small Group

 **Case Study:** Sara Mae is a traditional elder woman who is dying of melanoma. Her son, John, is the family member providing all of her care at home. She owns sheep, her home, her land, many ceremonial objects, and beautiful jewelry. She has no saving account. She has no will.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

95

## Interactive Activity - Small Group

 **Case Study:** She has no money set aside for burial ceremonies. In addition to her son John, his wife, and their five children, Sara Mae has four other children, none of whom live in the local area.

1. How can the family decide how her burial and burial ceremony should be paid for?

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

96



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5

## Interactive Activity - Small Group



Questions Continued..

2. How will it be determined who receives her personal property?

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

97

## Small group activity

Please take 15 minutes to share your answers with one another in your groups.

After 15 minutes, we will ask for volunteers who are willing to share something they learned from their group.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

98

## Summary



This session provided some examples of cultural, legal and ethical issues that may arise in end of life care.



The suggested strategies seem simple, but are very successful when used.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

99

## Summary



Mediation helps resolve many of the issues



These are very challenging issues.



We personally are making all of our team work on wills and other actions related to end of life and we encourage you to do the same.

Native American Cancer Research (303-838-9359) EOL Obj. #3, "Issues"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

100

## Objective 4

By the end of the session, the participant will be able to describe the parts that should be included in a will and advance directive (living will).

Native American Cancer Research (303-838-9359) EOL Obj. #4, "Living wills and wills"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

101

## Overview

What is a:

Will  
Advance Directive  
Living Will  
and

Who Needs a Them?

Native American Cancer Research (303-838-9359) EOL Obj. #4, "Living wills and wills"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

102



## NACR “Native American Palliative Care” Curriculum – Objectives 1-5

### What is a Will?

- A will is a document you can use to control:
1. who gets your property,
  2. who will be guardian of your children and their property, and
  3. who will manage your estate upon your death.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

103

### Estate

- Property
- Money
- Personal Belongings
- Everything you own
- Some bills may be included

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

104

### What is an Advance Directive?

An Advance Directive is a written decision about what kind of care you want when you are sick and dying, that you make ahead of time. Three examples of Advance Directives are:

- Living Will
- Medical Durable Power of Attorney
- CPR Directive

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

105

### What is a Living Will?

- A Living Will is a document by which a person declares that he or she does or does not want artificial life support systems used if he or she becomes terminally ill.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

106

### What is medical durable power of attorney?

- Medical durable power of attorney is a document you sign naming someone to make your health care decisions when you are unable to make them yourself.

Let's first learn about wills. Then we will come back to the advance directives.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

107

### What is a Will?

The maker of a will decides who will get their property, responsibility for their children, if any, and who will make certain their wishes are followed.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

108



## NACR “Native American Palliative Care” Curriculum – Objectives 1-5

### Beneficiaries

These are the people (relatives and/or friends) or organizations who receive specific personal items, property, and/or money according to your will.

You can specify who gets what in your will.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

109

### What about my children?

You can appoint a guardian for your minor children in your will.

You can also appoint someone to take care of the property or money that you leave to your children.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

110

### What is a guardian?

- Guardian

A Guardian is a person who will care for your minor children when you are gone.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

111

### Who makes sure my wishes are followed?

The executor is the person who will be in charge of handling your estate. This may include filing taxes and other forms, gathering your assets and distributing them to your beneficiaries as your will states, and hiring of attorneys or accountants to assist with the implementation of your will.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

112

### What if I have no Will?

- If you have no will, the laws of the state you live and die in will determine who receives the property that you own and your children.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

113

### What if I have no Will?

- In most states, if money (bank accounts) and or real estate is jointly held, it will pass to the joint owner with or without a will.
- Any property in your name alone would go to the persons named by the state law.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

114



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5

## Typical Sequence

1. Spouse if legally married.
  2. Children
  3. Parents
  4. Brothers and Sisters
  5. Grandparents
  6. Aunts and Uncles
  7. Nieces and Nephews
- All blood relatives

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

115

## What if I have no Will?

Every state has different laws but they typically provide for the following:

- If you have a spouse and children, the property is divided among them.
- If you have a spouse and parents or siblings but no children, some states give it all to your spouse while others also give a share to your parents and siblings.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

116

## What if I have no Will?

Every state has different laws but they typically provide for the following:

- If you have children and no spouse, everything is divided between the children.
- If you have no children or spouse, your parents would get your property, unless a share was given to your siblings.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

117

## What if I have no Will?

- Every state has different laws but they typically provide for the following:

If you have no spouse, children, or parents, your brothers and sisters would share your property.  
If you have no spouse, children, parents, brothers, or sisters, your property would go to your grandparents, aunts and uncles, or nieces or nephews in that order.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

118

## How do I make a Will?

- Anyone over the age of 18 years of age and who is of sound mind may make a will.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

119

## What do I do first?


Make a list of your real personal property, real estate, and bank accounts etc. Be very specific in your descriptions.  
Decide who you want to receive each item, or how the item is to be divided among your beneficiaries.  
Identify the people you need to help you as Executor and Guardians and witnesses.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

120



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5




**You CAN leave someone out of your Will.**

When making your will you can included a section where you name a person(s) and leave them completely and forever from receiving anything from your estate.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELSHC Module #4 "Ethical/Legal Issues in End-of-Life Care"

121



**What if someone contests my will?**

- When making your will you can complete a "Self-Proved Will Affidavit" which is signed by a notary and two witnesses. This document is attached to the will and helps to prove that you stated your wishes in your will and that witnesses can attest to its validity.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELSHC Module #4 "Ethical/Legal Issues in End-of-Life Care"

122

**Assets**

	Value	Joint or Marital Property	Husband's Separate Property	Wife's Separate Property
Home				
Other Real Estate				
Checking Accounts				
Savings Accounts and Certificates				
Credit Union Accounts				
Annuities				
Oil, Gas or Other Minerals				
US Savings Bonds				

	Value	Joint or Marital Property	Husband's Separate Property	Wife's Separate Property
Other Bonds				
Stock				
Accounts Receivable				
Rents Receivable				
Notes Receivable				
Automobiles and other				
Interest in any business				

21. Please indicate, by checking the appropriate option, how you want your assets to pass when you die

\_\_\_\_\_ Option A. I want my assets to pass to my spouse and children as follows:  
To spouse, if surviving.  
If my spouse predeceases me, my assets will be divided in equal shares among my children.  
If any of my children predecease me, that child's share shall be distributed to his or her children in equal shares.  
In the event that my spouse and all of my children and descendants fail to survive me, I want my assets to be distributed as follows:

\_\_\_\_\_ Option B. I am unmarried with children and want my assets to pass

\_\_\_\_\_ Option C. I am unmarried and have no children. I want my assets to pass in equal shares as follows:

22. Special Provisions for family heirlooms, jewelry, or other items

ITEM	SPECIAL IDENTIFYING FEATURES	RECIPIENT
Traditional Regalia		
Native rugs	4 with turquoise	
Concho belt		
Diaries/journals	Notice the lock on the cover!!!	
Pottery		
Jewelry		
Eagle feather fan		
Sacred pipe		



## NACR “Native American Palliative Care” Curriculum – Objectives 1-5

### What are Advance Medical Directives?

- A person's documented, written notice stating what medical interventions a they want or do not want if they become too ill to speak for themselves.
- Advance Medical Directives include:

Living Wills

Medical Durable Power of Attorney  
(for health care)

CPR Directive

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

127

### How does a Living Will work?

- A Living Will states whether or not a person wants artificial life support systems used if he or she becomes terminally ill.
- The doctor and relatives can use the Living Will to make the “hard decisions” when a loved one is close to death.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

128

### What does artificial life support mean?

- Artificial life support can include:  
  
Life sustaining procedures including nourishment.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

129

### What is a Medical Durable Power of Attorney?

- It is a signed paper that gives the responsibility to a designated person called the “agent” to make decisions on behalf of the patient if he/she is determined to be mentally incompetent or incapacitated.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

130

### What is a CPR Directive?

- A CPR Directive means that if your heart stops beating you want to be left alone with no medical intervention taking place.
- This is also known as a Do Not Resuscitate or DNR.

CPR means Cardiopulmonary Resuscitation.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

131

### How do I make Advance Directives?

To make an Advance Directive a person needs to ask themselves some very hard to answer questions.

Some people talk to loved ones when making these decisions. Others talk to professionals in the health care system.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

132



## NACR "Native American Palliative Care" Curriculum – Objectives 1-5

### How do I make Advance Directives?

- Once you have made your decisions, write them down.
- Document them with the signatures of two (2) witnesses.
- Keep your Advance Directive handy so your loved ones and care givers will know your wishes.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

133



### How do I make Advance Directives?

- Once you have made your decisions, write them down.
- Document them with the signatures of two (2) witnesses.
- Keep your Advance Directive handy so your loved ones and care givers will know your wishes.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

134

### Interactive Activity - Small Group

-  Please from groups of 3-5 individuals each
-  Please share with your group the following information for how you would want to be taken care of when in need.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

135

### Ask yourself these questions

- Who do I want to make decisions about my health care and life if I am no longer able to do so?
- When I am close to the end of my life on this earth, what do I want to happen?
- What kind of treatments or extraordinary efforts do I want taken on my behalf?
- Under what conditions do I want to be kept alive?

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

136

### Ask yourself these questions

Is there any condition when I wouldn't want to be artificially alive?

How comfortable do I want to be?

How do I want people to treat me?

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

137

### Small group activity

Please take 15 minutes to share your answers with one another in your groups.

After 15 minutes, we will ask for volunteers who are willing to share something they learned from the individual decision making process that takes place when making a living will.




Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

138



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5




**Summary**

-  In this session you have learned the parts of a will and advance directives and why you need to have them.
-  You must be of age to make a will (18 years) and a living will (19 years old).
-  You must have witnesses. (in most states)

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

139

**Summary**

-  You should keep your will(s) in a safe place where loved ones can find it.
-  You must be of sound mind.
-  Tell your family about your wishes.

Native American Cancer Research (303-838-9359) EOL Obj. #4, living wills and wills  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

140

**Native American Palliative Care and End-of-Life Curriculum**

Linda Burhansstipanov, MSPH, DrPH (Cherokee Nation of OK)  
 Lisa Castro, Grants Manager  
 Lisa Harjo, MA (Choctaw Nation)  
 Rose Lee (Navajo Nation)  
 Terri Rattler (Oglala Lakota)  
 Native American Cancer Research  
 3022 South Nova Road  
 Pine, CO 80470-7830  
 Phone: 303-838-9359; Fax: 303-838-7629  
 Native Cancer Survivor's Support Network: 1-800-537-8295  
 Web Page: <http://www.NatAmCancer.org>

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

141

**Module Objective #5**

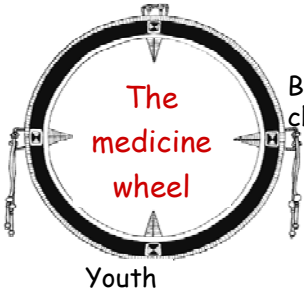
5. The workshop participant will be able to identify examples of how Native cultures perceive death and dying.

"The mystery of all endings is found in the birth of new beginnings. There is no ending to the journey of the four directions. The human capacity to develop is infinite. The medicine wheel turns forever." Phil Lane, Jr. p. 71

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

142

Elders / End of life / death



Youth

Death is part of the Medicine Wheel ... and the "Circle of Life"

variation from Phil Lane Jr., *The Sacred Tree, Four Worlds*  
Development Press, Lethbridge, Alberta, Canada, 1984

143

**Query: Why do you think death ceremonies are important?**

helps with the grieving process for family and for the person who is dying (i.e., preparing for death ceremonies)

helps community recognize and honor the loss of a valued individual

thank you January Scott!

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

144



# NACR "Native American Palliative Care" Curriculum – Objectives 1-5

**Importance of death ceremonies (continued)**

helps the family and grievors know that they are supported by the community.

helps grievors "express" and not "repress" their grief

Death is part of the / wheel / "circle" ...

thank you January Scott!

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying" Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care" 145

**What is the underlying theme?**

- Non-Native cultures frequently perceive death as a very separate part of the life cycle.
- But *all* cultures have special ceremonies that accompany the death of a loved one. Like "funerals"

**QUERY:** What are some examples of things other cultures, religions, or people do to acknowledge the death of a loved one?

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying" Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care" 146

**Stereotypical examples of how cultures "respond" to the death of a loved one**

Irish funerals?

the wake  
food, alcohol  
sharing of good stories about the deceased

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying" Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care" 147

**Stereotypical examples of how cultures "respond" to the death of a loved one**

Catholic funerals?

solemn mass:  
colonnade from church to mortuary  
food at family's home

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying" Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care" 148

**Stereotypical examples of how cultures "respond" to the death of a loved one**

New Orleans funerals?

music / parade in streets  
group praying / crying

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying" Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care" 149

**So what are examples of how some Native cultures "respond" to the death of a loved one**

Example of 1 SW tribe

3 day mourning period  
no mention of the person's name

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying" Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care" 150



## NACR "Native American Palliative Care" Curriculum – Objectives 1-5

**So what are examples of how some Native cultures "respond" to the death of a loved one**

Another SW tribe

Special ceremony to prepare the body for mother earth

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

151

**How do Native communities discuss the "death" process?**

- Death and dying are referred to using different words / phrases by Native communities - a lot of differences!

"cross the river" "walk on" "move on"  
"passing on to the other side"  
"gone to the spirit world"  
and of course the one popularized by Hollywood,  
"gone to the happy hunting grounds"

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

152

**How do Native communities discuss the "death" process?**

As diverse as Native cultures are, most refer to dying as part of the "Circle of Life".

The medicine wheel

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

153

**Native communities and the "death" process**

- Traditionally, ceremonies were implemented, sometimes over many months, for the chronically ill or dying patient.
- Allows the dying patient make peace with this world and prepare for the next.

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

154

**Native communities and the "death" process**

- Allows the loved ones to raise upsetting issues and consequently to address them with the help of others.
- The entire family is affected.
- This includes the extended family which can consist of adopted relatives and respected elders and healers within our communities.

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

155

**Native communities and the "death" process**

- Most Natives choose to "go to the spirit world" while in their home setting, surrounded by family and community members.
- Many of the cultural support systems that help prepare for the passing existed a few decades ago. These may or may not be present in our local communities today.

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

156

# NACR "Native American Palliative Care" Curriculum – Objectives 1-5

## Native communities and the "death" process

- Preparation for death by the individual and the family differs among tribal Nations
- Preparation of the body
- Preparation of the spirit
- "Passing" ceremonies

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

157

## Interactive Activity - Small Group

- Please form groups of 3-5 individuals each
- Please share with your group the following information for how your tribe / culture handles a family member's death and dying process

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

158

## Small group activity

1. How does your culture prepare for the death of a loved one?
2. How does your culture believe the body should be prepared for burial / burning, etc.?
3. How does your culture believe the spirit should be prepared for passage to the next life / world?
4. What types of ceremonies does your culture do to help deal with death and dying of a loved one?

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

159

## Small group activity

Please take 15 minutes to share your answers with one another in your groups.

After 15 minutes, we will ask for volunteers who are willing to share something they learned from their group.

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

160

## Summary

- This session provided an overview of different ways cultures perceive death and dying.
- Our tribal Nations approach the death process very differently from one another.
- Our death ceremonies help us grieve and confront the passage of a loved one from this place on earth to the spirit world.

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

161

## Summary

- No single ceremony related to death is "right" for everyone.
- We each have our own private and public ways to deal with death.
- All of us deal with both the death of loved ones and with our own death.

Native American Cancer Research (303-838-9359) EOL Obj. #5, "Native perceptions of death and dying"  
Part of NACR's Cultural Modification to ELNEC Module #4 "Ethical/Legal Issues in End-of-Life Care"

162

