

American Indian End of Life Considerations



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This document is meant to provide useful information for American Indian caregivers and cancer patients on end of life care, including:

- End of life needs specific to physical comfort, mental and emotional needs, spirituality and practical tasks
- Types of Care: traditional, palliative, and hospice
- Resources to help families get services and support

The Partnership for Native American Cancer Prevention (NACP) Outreach Cancer Series

This document is part of a series produced by the University of Arizona (UA) Outreach Core team members. The other guides in the series focus on:

- American Indian Cancer Statistics, Volume V
- Tips for Caring for In-Treatment American Indian Cancer Patients, Volume VI

Why is discussing end of life care important?¹

Although we want anyone who gets sick to get better, sometimes that is not possible. In the case of a cancer patient, if the cancer is continuing to grow and spread and treatment is no longer an option, the disease may become terminal (causing or ending in or approaching death).² End of life care is the term used to describe the support and medical care given during the time surrounding death.

For this stage of a disease, it is important to provide care that helps or soothes a person who is dying. The goals are to prevent or relieve suffering as much as possible and to improve quality of life while respecting the dying person's wishes.

Generally speaking, people who are dying need care in four areas:

- **Physical comfort, mental and emotional needs, spiritual issues, and practical tasks.**

The family will need support as well.

Physical Comfort¹

It is important to provide comfort care by assessing pain, breathing problems, skin irritations, digestive problems, temperature sensitivity and fatigue. Not everyone who is dying will experience these problems and there are things that can help someone who does.

Pain – Each person has different tolerances to pain and so it is important to ask frequently about the level of pain. Make sure pain-relieving medicines are given as prescribed; try to make sure the pain level does not get ahead of medications. If the pain remains uncontrolled, tell the provider as medications can be increased or changed.

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Breathing Problems – If your loved one is experiencing shortness of breath or breathing difficulties, try raising the head of the bed, or use a humidifier or fan to circulate air. If there is noisy breathing, caused by fluid collecting in the throat or by the throat muscles relaxing, try turning the person to rest on one side.

Skin Irritation – Sitting or lying in one position puts constant pressure on sensitive skin. Watch for discolored skin spots especially on heels, hips, lower back and the back of the head. Try turning the person from side to back every few hours to help prevent bed sores. Keeping the skin clean and moisturized is always important.

Digestive Problems – There are medications that can help control nausea, vomiting, constipation and loss of appetite. The causes and treatments of these vary and so talk with a provider right away. Do not force a loved one to eat; losing one's appetite is a common and normal part of dying.

Temperature Sensitivity – It is important to ask your loved one frequently if they are too hot or too cold, or watch for clues. Keep a sweater, blanket or heater close by and avoid electric blankets as they can get too hot.

Fatigue – It is common for a loved one to feel tired and have little or no energy. Try to use a bedside commode instead of walking to the bathroom. Use a shower stool in the shower and switch to sponge baths for safety and for conserving energy.

Mental and Emotional Needs¹

Understandably there are many mental and emotional that occur at end of life that may include depression, anxiety, fear, concern, grief, emotional pain and suffering, for example. Encouraging conversations may help to understand worries and reactions. Your loved one may be afraid to be alone and may appreciate a gentle touch. It is important to set a comforting mood, to listen and to be present. If your loved one is on hospice care, counselors are often available to help your loved one and the family. As applicable, traditional healers or medicine men may be engaged to also address mental and emotional needs.

Spiritual Needs³

Spiritual needs may include the need:

- for meaning and purpose
- to love and feel loved
- to feel a sense of belonging
- to feel hope, peace and gratitude.

Addressing the spiritual needs of a loved one is as important as all the aforementioned. Ways to support spiritual needs may be through prayer, religious meetings, traditional ceremonies, being with family, seeing friends, spending time in nature, or doing hobbies. It is important to focus on what has real meaning.

Practical Tasks^{4,5}

Everyday tasks need to be discussed and decided upon, such as paying bills, pet care, child care, communications with social networks, etc. It is important to name someone to make decisions and to have financial affairs in order. It is also important to discuss any cultural possessions or considerations so the family knows the wishes of the loved one. Although difficult, it is important to discuss how things should be handled. For example, it is important to let family members know where important documents are.

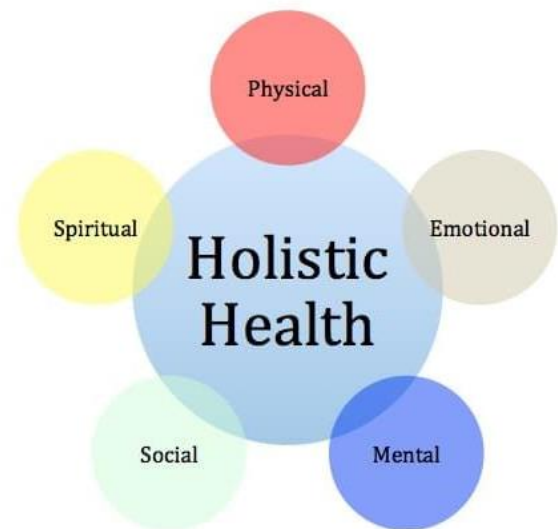
Consider creating an *advance health directive*, which puts specific requests about future health care in writing. This legally binding document encompasses two parts. The first is a *durable power of attorney* for health care, in which someone (a proxy) is named who can make medical decisions. The second part is a *living will*, in which the treatments wanted at the end of your life are specified, such as: dialysis, ventilators, feeding tubes, IV's, pain treatment, and organ donation after death. In addition, it is important to decide on a *Do Not Resuscitate* order. These documents, which are signed by both the loved one and the doctor, specifies that a full resuscitation effort is not needed, as applicable.

Traditional Care⁶

Although discussing the topic of end of life can be difficult, scary and seem taboo, including traditional care may add a level of comfort for a loved one. Traditional care can include elements of regaining balanced and meaningful relationships among self, spiritual forces, family, community and environment after a cancer diagnosis has been made.

Because holistic health and family are central core elements to American Indian values and beliefs, it is important to encompass these elements in providing care and to utilize family networks during this difficult time. The family can help to provide balance, harmony, and take responsibility to ensure a loved one has access to ceremonies which could include purification, prayer, smudging, drumming, singing, chanting or dancing – ways to honor life, experiences, challenges, successes, strengths and spirit.

Part of traditional care involves ensuring the needs and wants of the loved one is respected regarding next steps for cultural possessions, cultural knowledge, and cultural responsibilities. It may be important to name someone (a proxy) to ensure decisions are carried out and to discuss how things should be handled, especially if training or additional skills are needed for the proxy.



Palliative and Hospice Care⁷

Palliative care is administered to improve the quality of life of patients who have serious or life-threatening diseases with a prognosis of a year or so. The goal of palliative care is to prevent and treat symptoms as they occur. Palliative care focuses on medical, social, and emotional support. It's made up of a team of physicians, nurses, social workers, nutritionists, counselors, and spiritual figures. Treatment can be administered in the hospital, nursing home, outpatient care clinics, or at home.

Palliative care differs from hospice care because you or your loved one can start to receive treatment at the onset of illness in conjunction with medical treatments. Should a patient's illness become untreatable, this type of care can transition to hospice care.

Hospice care can begin when patients receive a prognosis of six months or less. This care focuses on relieving pain, discomfort, and distress for patients. It contains a team of physicians, nurses, social workers, home health aides, volunteers, and religious figures. This professional medical team can aid your family in the care process to help support you. Hospice care can be provided in the comfort of your own home, assisted living community, long-term care facility, or at the hospital.

Contact your local tribal or IHS medical social worker to obtain more information (see Resources section for IHS medical social worker information). A primary care provider will need to make the referral for either palliative or hospice care. An oncology team can also provide information. There are data available that show that American Indians do not utilize these services as much as they should.

Of all Medicare decedents in the United States (U.S.), 44.6% occurred under the care of a hospice program in 2011.⁷ While the AI/AN population comprises 0.9% of the U.S. population, they are only 0.2 of the users of hospice care.⁸

Resources

AARP offers state-by-state Advanced Directive Forms for patients. <https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/>

AARP provides a checklist of preparation in the event a loved one dies. <https://www.aarp.org/home-family/friends-family/info-06-2012/when-loved-one-dies-checklist.html>

The **American Indian Cancer Foundation** provides information to help improve early detections, treatment and survivor support for American Indian cancer patients. <https://www.americanindiancancer.org/>

The **American Cancer Society** lists concerns and state-by-state steps for finding a Hospice Program. <https://www.cancer.org/treatment/end-of-life-care/hospice-care/how-to-find.html>

The American Cancer Society also offers instructions on how to arrange A Living Will, Durable Power of Attorney, and Do Not Resuscitate (DNR) orders. <https://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-financial-and-legal-matters/advance-directives/types-of-advance-health-care-directives.html>

CaringBridge offers support to families. www.caringbridge.org

How to Get Palliative Care has resources that can aid you in helping your loved. <https://getpalliativecare.org/howtoget/>

Indian Health Service Medical Social Services Program is to help Indian clients maintain, regain, or enhance their level of social functioning when their ability to function is affected by actual or potential illness, disability, or injury. <https://www.ihs.gov/winnebago/services/socialservices/>

National Alliance for Caregiving is focused on advancing family caregiving through research, innovation and advocacy. www.caregiving.org

What Matters Now provides space for family and friends to stay up to date. www.whatmattersnow.org

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