

Tips for Caring for In-Treatment American Indian Cancer Patients



The Partnership for Native American Cancer Prevention,
U54CA143924

Hopi NARCH, S06GM128012

July 2019

Volume VI, Issue I

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This document is a guide specific to American Indian cancer patient survivors and caregivers on:

- Important communications with health professionals about cancer diagnosis and prescription medication use
- The role of caregivers for cancer patients and how to promote self-care for caregivers
- Additional cancer resources

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
- American Indian End of Life Considerations, Volume VII

Caregiving of Cancer Patients

At least 4.6 million people living in the U.S. care for someone with cancer.¹ Cancer patients often rely on family, relatives, close friends, and/or co-workers as their primary caregiver.

Caregiver duties and responsibilities can include:^{2,3}

1. **Assisting with personal care:** bathing and grooming, dressing, toileting, and exercise
2. **Basic food preparation:** preparing meals, shopping, housekeeping, laundry, and other errands
3. **General health care:** overseeing medication and prescriptions usage, appointment reminders and administering medicine
4. **Mobility assistance:** help with getting in and out of a wheelchair, car or shower
5. **Personal supervision:** providing constant companionship and general supervision
6. **Transportation:** driving to and from activities, running errands, and help getting in and out of wheelchair-accessible vehicle
7. **Emotional support:** being a stable companion and supporter in all matters personal and health-related
8. **Care for the elderly:** orienting or grounding someone, relaying information from a doctor to family members for an older person
9. **Back-up care (or respite) services:** providing other caregivers a break
10. **Home organization:** help with organizing, packing or cleaning for a trip, or general house care and cleaning
11. **Health monitoring:** following a care plan and noticing any changes in the individual's health, recording and reporting any differences

An estimated 8.3 hours a day are spent caring for cancer patients and increases to 9.4 hours per day for terminal cancer patients.¹

Possible questions to ask doctors when first diagnosed:^{4,5}

- ❖ What kind of cancer is it?
- ❖ What stage is the cancer?
- ❖ How does the diagnosis affect other diagnoses?
- ❖ What are the options for treatment?
- ❖ When does treatment start?
- ❖ How do treatment options affect current health status?
- ❖ Has the cancer spread to other areas of the body?

Medical appointments⁶

It is important to keep all medical appointments. Use the medical appointments as an opportunity to ask questions and to learn more about the condition. As a caregiver, help interpret, translate, or reiterate information to the patient if they do not understand. It is important to have a doctor or nurse translate results to your understanding. Write down any vital questions before the scheduled appointment.

Documentation. A lot happens during a medical appointment; therefore, during each medical appointment, take notes and ask for copies of lab reports and test results. Collect pertinent information (visit summary sheets, business cards, payment, next appointment sheets) from each visit and place in a binder. Don't forget to bring the binder to appointments. Using a medical appointment log is helpful to record appointments, doctor's name, and reason for the doctor visit (For example, see Table 1).

Table 1. Doctor Appointment Log Sheet, An Example

Doctor Appointment Log				
Date of Appointment	Time	Location	Doctor	Purpose of Visit; Items Needed
Friday, Aug 26	9:30 am	Banner – Campbell St.	Dr. Lee	Ultrasound; medication list
Tuesday, Oct 15	8:00 am	TriCore – Scottsdale	Dr. Smith	Labs; need to fast from midnight

Medications⁶

It is important to understand prescription medication:

- ❖ Who prescribed the medication?
- ❖ When do I take the medication?
- ❖ Why am I taking this medication?
- ❖ What is the medication?
- ❖ Where was it prescribed?

Documentation. A medication log sheet can be used to track daily medications and as a reminder for patients and caregivers when medication is needed (see Table 2). If an allergic reaction occurs or there are changes with other medication prescriptions, it is important to notify providers. Make sure to ask if there are any questions.

Table 2. Medication Use Log Sheet, An Example

Medication Use Log Sheet							
Medication Name	Purpose	Units	Dosage	Frequency	Pharmacy	Contact Info	Notes
Lorazepam	Nausea	0.5 mg	1 tablet	1 time/day	Walgreens	621-5072	Take with food
Lovenox	Blood thinner	100 mg/ml	1 syringe	1 time/day	WalMart	834-7835	Same time each day

Monitoring Vitals⁶

It is important to keep track of vitals to more readily detect changes and to establish reference measures. Using a log is helpful to keep track of weight, blood pressure, heart rate, etc. (see Table 3).

Table 3. Daily Vitals Log Sheet, An Example

Daily Vitals Log Sheet							
Date	Time	Weight	Temp	Blood Pressure	Heart Rate	Oxygen	Notes
7/26/19	8:30 am	142 lbs	98.6°	128/90 mmHg	65 bpm	98%	Weight with shoes

Caregiver Tips⁷

Compromised Immune System

During phases of chemotherapy treatment, the immune system is suppressed and cancer patients are prone to becoming sick. It is vital to have cancer patients stay away from other sick people along with over populated environments (e.g. family gatherings, grocery stores, movie theaters, etc.) to prevent further illness or infections. Handwashing, wearing masks, and using sanitizing wipes are important to maintain a healthy environment and to provide protection.

Respecting Decisions

Listen to loved ones and support their decision-making, even if they do not agree with you or the doctor. Ask an oncology team member for referrals to *support groups*. Social workers are often used as support while at the hospital during treatments. Additional community-based support groups can be beneficial to strengthen an individual's well-being, physically and emotionally.

Coping

Find ways to help each other through healthy conversations, enjoyable outings, or having quiet time. Coping with difficult emotions, such as feeling stressed, angry, and sad are common in cancer patients and caregivers. Find out what works best for the both of you.

Ask for help and support

Caregivers are given many roles and responsibilities. Maybe create a schedule and a list of daily tasks and distribute to other family members, friends, so everyone can contribute to relieve stress and burning out as a caregiver.

Finances

A person who is diagnosed with cancer will often have financial struggles. Talk with a social worker or financial counselor to see if financial assistance is available for help with hospital bills, utility bills, and mortgage/rent. The American Cancer Society provides assistance with wigs, transportation, hotel, gas/food cards during hospital stays and outpatient treatment appointments. Professional and community agencies or services might provide transportation and mobile food delivery.

Self-care for Caregivers⁷

Caregivers need to be healthy in order to help others. As a caregiver, the companionship, the feeling of being needed and wanted, and the love between caregivers and cancer patients is important and it becomes imperative that caregivers take care of themselves. Below are suggestions on self-care:

- ❖ Exercise for at least 30 minutes a day.
- ❖ Eat healthy by maintaining a balanced diet. During long clinic visits, pack healthy snacks and water.
- ❖ Minimize screen-time (phones, television, laptops).
- ❖ Limit alcohol and tobacco use.
- ❖ Rest as much as you can.
- ❖ Try to get respite care. Feeling stressed, tense and angry can often make situations awkward and those same emotions can feed off to others.
- ❖ Utilize services and programs that can help with caregiving.
- ❖ As much as possible, find the balance between the role as a caregiver and that of an independent person with your own life.

Resources

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** provides research, support, and promoting a healthy lifestyle to help prevent cancer. <https://www.cancer.org/>

The **Cancer Care** provides emotional, physical, and financial support for cancer patients, survivors, caregivers, and health professionals. <https://www.cancercare.org/>

Cancer.Net provides additional resources to assist with informed health decisions for cancer patients and caregivers. <https://www.cancer.net/>

The **Cancer Supporting Community** is a non-profit network that provides support for cancer patients and caregivers. <https://www.cancer.net/>

The **Leukemia and Lymphoma Society** is tailored to blood cancers and their organization offers assistance for caregivers and cancer patients. <https://www.lls.org/>

The **Lotsa Helping Hands** is an online tool to help coordinate scheduling with appointments and/or daily tasks. Essentially, it is designed to make life easier for caregivers and volunteers. <https://lotsahelpinghands.com/>

The **National Cancer Institute** conducts and supports cancer research to help people with healthy longevity. <https://www.cancer.gov/>

The **Native American Cancer Research Corporation** provides information on cancer prevention, cancer risk reduction, cancer screening, cancer education, training, and research. <http://natamcancer.org/index.html>

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