APPOINTMENT COMPANION

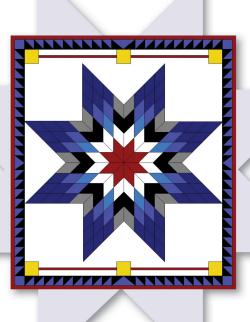


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How to use the Appointment Companion

The Appointment Companion booklet can help you during treatment. You should take this booklet to every visit.

It becomes difficult to remember things like appointment dates, preparation instructions, medication types and questions to ask.

You will be able to write down information as it is offered to you by your health care team. Writing down information at the time it is presented will keep you from getting confused during this overwhelming journey.

It is also important to understand that even with this companion, some important information can "slip through the cracks."

If you ever have any questions related to your medical care, don't hesitate to contact your health care team. If you still have difficulty getting the information you need, please contact your Patient Navigator.



Acknowledgements

We offer appreciation to all the organizations contributing to this guide. Our hope is that this Appointment Companion will aid the journey of tribal members throughout the Northwest. The Northwest Tribal Appointment Companion was developed based on information contributed by many individuals and organizations.





Individuals

- · Chace Mickelson, Patient Navigator, Shoshone-Bannock Tribes
- Jasen Henderson, Patient Navigator, Confederated Tribes of Grand Ronde
- George Valdez, Confederated Tribes of Grand Ronde
- Cover logo by Katrina Ramsey and Maisie MacKinnon

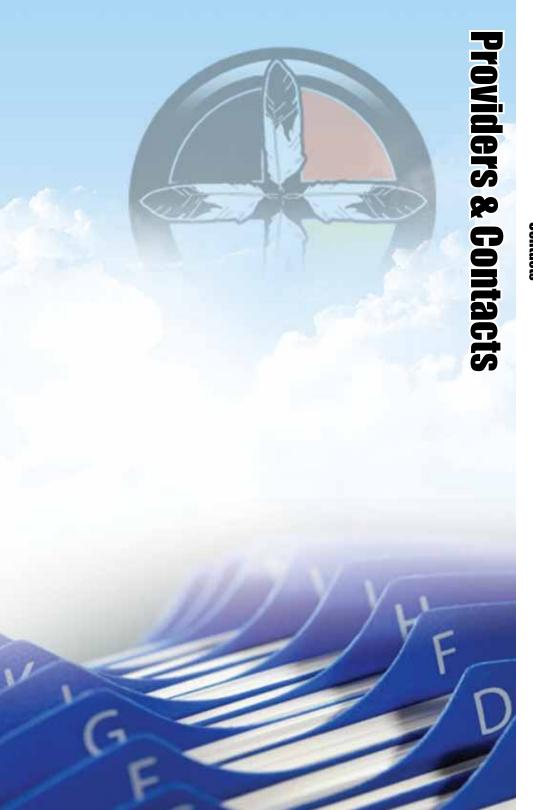
Organizations

- Seattle Cancer Care Alliance
- 'Imi Hale Native Hawaiian Cancer Awareness Network
- Native American Cancer Research
- Native CIRCLE
- · Shoshone Bannock Tribes
- Confederated Tribes of Grand Ronde
- Northwest Portland Area Indian Health Board
 - Northwest Tribal Cancer Navigator Program
 - Northwest Tribal Comprehensive Cancer Program

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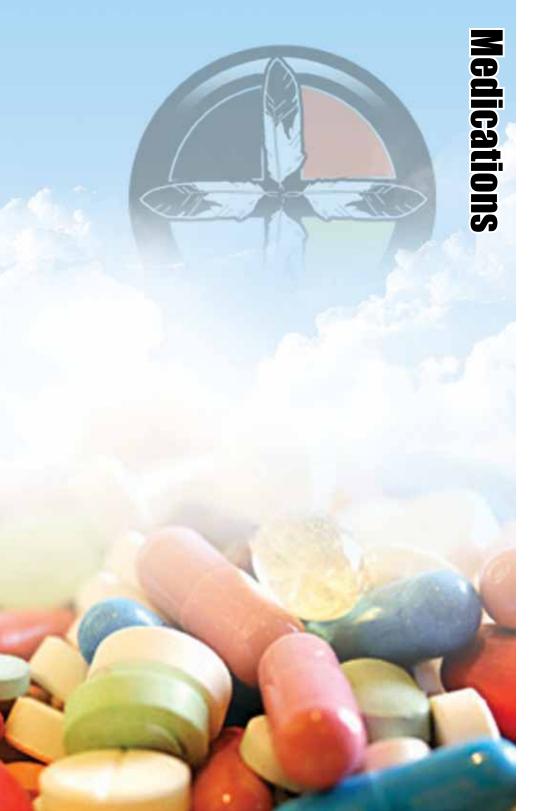


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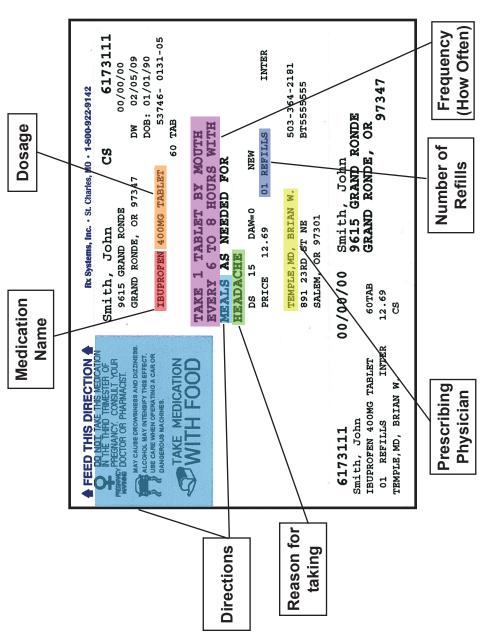
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Patient Medications

This section is for you to write down any medications you are taking. Medications may include prescriptions and nonprescription medicines.



Patient Medications

Date Finished			
Reason for taking			
Frequency (How Often)			
Prescribing Physician			
Dosage			
Medication Name			

Allergies (All Known):

Date Finished					
Reason for taking					
Frequency (How Often)					
Prescribing Physician					
Dosage					
Medication Name					

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Date Finished					
Reason for taking					
Frequency (How Often)					
Prescribing Physician					
Dosage					
Medication Name					



Questions to Ask Yourself and Other Important Individuals during Appointments

When patients begin to meet with their healthcare team on a regular basis, they are often unsure of what questions to ask for their situation.

It is very important to remember that every question is important and appropriate regarding your physical, mental and emotion health. One of the most important roles of a provider is to ensure that you understand exactly what is happening to your body during the treatment process.

If you don't ask questions, physicians may think that you understand the complexity of the situation.

The list below, which is available at www.cancersurvivors.org, and modified by cancer navigators, will give you questions to ask yourself and members of your healthcare team.

By no means do you have to ask every question on the list; it is highly recommended that you highlight the questions that you feel are important to ask your provider and then write the answers in the Appointment Notes section found later in this companion.

Questions to Ask Yourself

Before Decisions Are Made About Treatment

- Is this the doctor I want to handle my care?
- Am I comfortable with him/her?
- Is s/he someone who understands how I feel and is sensitive to my needs?
- Do I have enough information to make a decision?
- Who do I want with me when I get a diagnosis?
- Should I have a second opinion?
- Should I go to another facility for further tests or treatment?
- Which hospital do I want to go to for treatment?

•	Additional Questions and Notes:	

Questions to Ask Your Doctor(s)

When S/He Orders Tests

- What will the procedure be like?
- What will you learn from the test?
- Why is it important for me to have this test?
- Will I need to be hospitalized for the test?
- Can it be done on an outpatient basis instead?
- How much will the test cost?
- What are the risks in doing the test?
- When will we get the results?
- What decisions will I have to make if the test is positive?
- Are there other alternatives to this test?

•	Additional Questions and Answers:
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Questions to Ask About Treatment

- What treatments are available?
- What treatment do you recommend?
- Is this treatment necessary for me?
- Are there any alternatives? What are they?
- Why do you think this treatment is preferable?
- What do you expect the results to be?
- How safe is the procedure?
- What are the side effects of the treatment and what can be done to relieve them?
- Can I be put on a treatment program that won't interfere with my work?
- How will we determine how well the treatment is working?
- When can I call you to ask further questions?
- Do I have a type of cancer which would be better treated at a specialized center?

•	Additional Questions and Answers:



Questions To Ask the Anesthesiologist

- What medication will I be given before going into the operating room?
- Who will give me the medication and the anesthesia?
- How will they be given to me?
- Will my allergies be a problem?
- What type of anesthetic will you give me?
- What are the side effects?
- What are the risks?
- How long will the operation take?
- How long will it be before I wake up?
- Will I go to a recovery room after the operation?
- Is a general anesthetic necessary for this operation?
- Will any of the over-the-counter medicines I'm taking be a problem?

•	Additional Questions and Answers:



Questions to Ask Your Surgeon before an Operation

- Why do you want to do the surgery?
- · Exactly what will you do -- in simple terms?
- How long will I be in the hospital?
- What are the chances of cure with surgery?
- What other treatments can you use instead of surgery?
- How many of these or similar operations have you personally performed?
- Are there any less extensive, less deforming, less painful operations than the one you are suggesting?
- How disfiguring will the operation be?
- What are the risks of the surgery?
- What are the risks of the other possible treatments?
- What is the risk of death or serious disability?
- Do you feel the benefits outweigh the risks? Why?
- What are the possible consequences of postponing the operation?
- What will happen if I don't have the surgery?
- How much will it cost? Is the surgery covered under my insurance?
- How long will my recovery take.
- How disabling will it be? How long will this last?
- Will I have to have drains, catheters, intravenous lines, transfusions?
- What are the possible after-effects?
- Whom do you suggest I see for a second opinion?
- Can this surgery be done on an outpatient basis?

•	Additional Questions and Answers:
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Questions to Ask Hospital Staff

- What is scheduled to happen to me?
- Who can I best get information from when there are delays or when I don't understand what is going on?
- What is the purpose of this test? What will it determine?
- What is this drug for? When medication is changed or different from what you usually take, ask staff to check and make sure it is prescribed by your doctor for you.
- Do I have to stay in bed?
- Can I walk around the ward or leave it and go to other public areas of the hospital?
- What are the usual visiting hours and procedures?

•	Additional Questions and Answers:
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Questions to Ask Before Leaving the Hospital

- How long will I have to take it easy?
- · Will I need to stay in bed at home? For how long?
- Will I need help at home?
- Will I be able to care for myself?
- When can I resume normal activities? Drive a car? Have sex? Play sports?
- Will I have to follow a special diet or regimen?
- What symptoms should I keep track of and report to you?
- What symptoms can I safely ignore?
- When can I go back to work?
- What medications should I continue to take?
- What strengthening techniques do you recommend?
 - How Often?

•	Additional Questions and Answers:



Questions to Ask About Radiation Therapy

- Who will be responsible for my radiation treatment?
- Who should I talk with when I have questions about the treatment?
- Can I work during the time I am receiving treatment?
- Is there a more convenient place where I can get these treatments?
- How long will each treatment take?
- How many sessions will there be?
- What side effects can I expect?
- What should I do if these side effects occur?
- What side effects should I report to the doctor?
- How much will this cost?
- How much risk is involved?
- What are my alternatives?
- What is likely to happen if I don't have these treatments?
- Do I need to be on a special diet or regimen during these treatments?
- Do I need to put something special on my skin if I get "burned" by the treatments?
- What special attention do I need to pay to the area of my body that is being treated?

•	Additional Questions and Answers:



Questions to Ask About Chemotherapy

- Who will be giving me these treatments?
- What are the names of the drugs to be used?
- What are these drugs supposed to do?
- What are the possible side effects?
- What should I do if I have side effects?
- Which side effects should I report to the doctor immediately?
- How will the drugs be given to me?
- How often will the treatments be given?
- How long will each treatment take?
- How long will the whole series last?
- Can I take other medications at the same time?
- Can I drink alcohol?
- How long do the side effects last AFTER the chemotherapy?
- Do all chemotherapy drugs make you nauseous?
- Is there any special nutritional advice I should follow?
- Are there any special precautions I need to take while on chemotherapy?
- · How much will these treatments cost?

Additional Ouestions and Answers.

- · What are the risks involved?
- What are my alternatives?

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Questions to Ask Before Agreeing to Investigational or Experimental Treatment Procedures

- What exactly does the experimental treatment involve?
- Have I signed a consent form?
- Has the doctor explained the procedures to be followed?
- Has the doctor explained the purpose for the procedure?
- What are the risks involved?
- Will the treatment make me sicker?
- What are the benefits of this new treatment?
- What are my alternatives?

•	Additional Questions and Answers:



Questions to Discuss With Your Navigator, Social Worker, or Therapist

- How do I share my diagnosis of cancer with my family?
 Should I protect them from knowing what is going on?
- What resources exist in this community for people with my disease? For financial help? For information about my illness? For legal help? For counseling help?
- What can I do about all of these feelings and mood changes I am experiencing? Is it normal to feel these things? Angry? Sad? Scared? Overburdened? Picked on?
- How can I deal with the things that are happening to my body? The way I look? My lack of energy? How I feel about myself?
- Will I lose my interest in romance and sex? How can I handle it if my partner is no longer attracted to me because of my illness?
- What is wrong with me? Some of my friends seem scared or distant since I've gotten cancer. How can I talk with them about this? How do I bring the subject up?
- How can I get myself and my family to look at and plan for the possibility of death? What can I do if they deny it or are uncomfortable when I bring the subject up?
- How do I develop the quality of life I want right now and still take care of my responsibilities to family and friends?
- Why do I sometimes feel guilty about having cancer? Is it normal to think sometimes that I'm being punished for past sins? Or, that I caused myself to have cancer?
- I sometimes feel crazy and/or angry with my family and friends. Is this normal? What can I do about this?
- How can I relax and let my body do its job of curing me when there are so many stressful things happening to me?



Continued: Questions to Discuss With Your Navigator, Social Worker, or Therapist

- How can I get my spouse or lover to talk with me about what is happening and how s/he feels about my illness?
- How do I handle their being angry at me for being sick?
- What are some of the psychological gains or payoffs I might be getting from having cancer?
- How do I sometimes use having cancer as a way to manipulate others into doing or giving me what I want?
- What is the cost to me and my relationships when I do this?
- What can I do when I feel angry or upset with my doctor?
- What can I do if I feel I'm being treated unfairly by the hospital, insurance company, doctor, or therapist?
- How can I deal with friends who try to persuade me to look into different cancer cures, diets, religions, or therapies?

•	Additional Questions and Answers:





Ways to Treat Cancer

Ways to Treat Cancer

Cancer treatment can be very confusing. This section will provide you information about the types of treatment for your cancer. Depending on your particular type of cancer you may be receiving surgery, chemotherapy, radiation, or other therapies. This information can be gathered from:

National Cancer Institute: www.cancer.gov Chemocare.com; chemocare.com/bio



Calendar

This Calendar is a place for you to write down important events and dates.

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Symptoms and Side Effects Defined

Vomiting: Ejection through the mouth of the contents of the guts. The act of "throwing up."

Nausea: An unpleasant, wave-like feeling in the back of the throat, or belly that may or may not lead to the urge or need to vomit. The feeling that you are going to "throw up."

Appetite loss: Decreased eating and drinking, which may contribute to increased hunger. When an individual no longer feels the want to eat or drink.

Diarrhea: The poop containing fluids or unformed stools. The severity of diarrhea is measured by how often an individual has to "go to the bathroom," and also how much diarrhea is released in each event.

Constipation: Less often bowel movements that are difficult or incomplete passage of poop and/or passage of excessively hard, dry poop.

Pain: an unpleasant feeling and emotional experience arising from actual or potential tissue damage or described in terms of such damage.

Fatigue: An overwhelming constant feeling of exhaustion and decreased ability for physical and mental work.

Tingling in feet/toes: A prickling or stinging sensation which may be experienced by patients who have chemotherapy or radiation treatment.

Flu-like symptoms: Can be multiple symptoms such as, fever/chills, body aches, diarrhea, vomiting, and other such related symptoms.

Activity level: Production of energy or motion; the state of being active.

Depression: Loss of interest or pleasure in living. Continued sadness that lasts over an extended period of time.

Skin Changes: Any change in the skin such as: color, sensitivity, blisters or other skin abnormalities.

Definitions based on Taber's Medical Dictionary, 16th ed. 1989.

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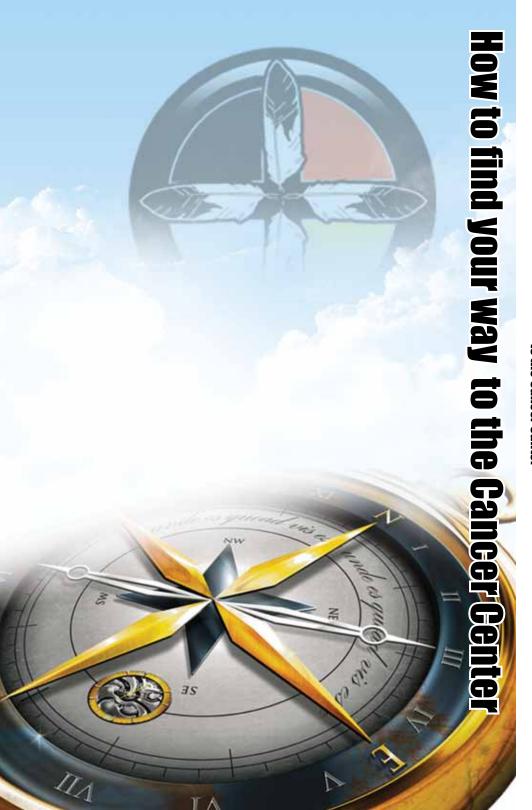
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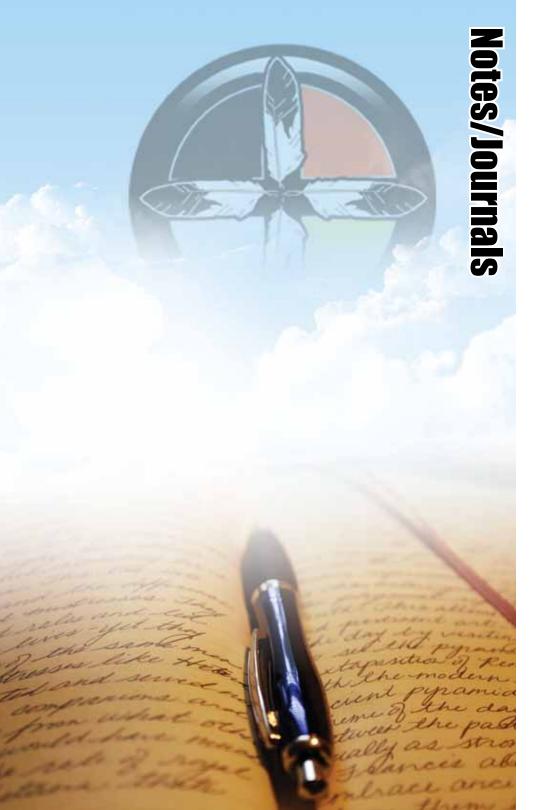
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How to Find Your Way to the Cancer Center

This section has information on how to get to the cancer center and how to find the correct office once you get there.



Notes































































































National Resources

Cancer Information Service (CIS)

1-800-4-CANCER (1-800-422-6237)

1-800-332-8615 (TTY)

www.cancer.gov (click "Need Help?" and then click on the "LiveHelp" icon to instant message with an information specialist).

CIS information specialists have access to comprehensive, accurate information on a range of cancer topics in English and Spanish. They are knowledgeable, caring, and experienced at explaining medical information. The service is free, confidential, and information specialists spend as much time as needed for thorough and personalized responses.

Cancer Care

(800) 813-4673 info@cancercare.org www.cancercare.org

National nonprofit organization that provides free professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones and the bereaved. Programs - including counseling, education, financial assistance and practical help - area provided by training oncology social workers and are completely free of charge.

Native American Cancer Research

(800) 537-8295 info@natamcancer.net www.natamcancer.org

This is a community based, American Indian, non-profit resource.

Local Resources



Local Resources



