

Oral Oncology Tools for Patients and Caregivers



Oral Oncology Medication Tools

For Patients and Caregivers

In this toolkit, various educational pieces and support resources are available to you, as listed below, to help with navigating your care while taking your oral oncology medications. Some of the resources are interactive, such as the checklists and notes pages. These interactive tools allow you to type into the designated blank spaces, and either save a copy of the tool and your added notes to your computer or print select pages you may wish to use in the future.

List of Tools

Patient Tools

Question Guide

Understanding the Treatment Plan: Questions for Your Health Care Team

This resource provides examples of the types of questions you and your caregiver may want to think through when meeting with your health care team, including important information about your medications.



Checklist

Considerations to Help **You Adhere to Treatment**

This resource provides useful information to help you understand medication adherence and nonadherence, as well as how to correctly take your oral oncology medications.



Treatment Calendar

Keeping Track of Your Therapy

This resource provides a useful template to keep track of your therapy by writing down your oral oncology medication schedule and medical appointments.



Know the Facts

Getting Your Specialty Medication From a Specialty Pharmacy

This resource provides information on specialty medications and specialty pharmacies.



Caregiver Tools

Checklist

Considerations for Giving Care to Patients With Cancer

This resource provides useful information to help you with giving care to patients with cancer, including in the home, at the doctor's office, or in a hospital, as well as managing medications.



Go to HCP.Novartis.com/care-management to download individual resources.

Navigation



Click on the image of each tool shown above to navigate directly to the first page of the tool



Click on the back arrow to return to this "List of Tools" page



click on the checklist boxes

You can type in the note lines

Understanding the Treatment Plan

Questions for Your Health Care Team: Question Guide

When your treatment is prescribed, your health care team will tell you how to correctly take your oral oncology medication. This resource provides examples of the types of questions you and your caregiver may want to think through when meeting with your health care team, including important information about your medications.

Ask Your Health Care Team: Questions on Dosing

Prescribed treatment



What is the name of the oral oncology medication prescribed to me?

Strength per dose



What is the correct amount (for example, strength/number of pills) for each time that I take my oral oncology medication?

Additional information about the treatment

Where can I find more information about the medication (for example, websites, hotlines)?

Treatment summary



What does my oral oncology medication treat and what is the goal of therapy?

When to use



Is there a certain time of day that I should take my oral oncology medication?

Frequency



How often should I take my oral oncology medication?

With or without food



Should I take my oral oncology medication with or without food or water? If my oral oncology medication should be taken without food or water, how long before and after eating or drinking should I wait to take my treatment?

Ask Your Health Care Team: Questions on Combination Use

Combination use—Can my oral oncology medication be used in combination with the other medications that I am currently taking?

Medications to avoid—Are there any other medications that I should avoid while I am taking my oral oncology medication?

Ask Your Health Care Team: Questions About Side Effects



Side effects

What are the common side effects or adverse reactions that I may experience when taking my oral oncology medication?



Managing side effects

What can I do to safely manage or alleviate these side effects at home?



When to contact vour doctor

When should I contact my doctor or nurse for assistance regarding side effects?



Dietary restrictions

Are there any dietary restrictions with my oral oncology medication that I should be aware of?



Behavioral risks

What behavioral risks may result from taking my oral oncology medication (for example, limiting sexual activity, exercise, and other physical activity)?



Environmental risks

What environmental risks may result from taking my oral oncology medication (for example, safely disposing of waste)?

Health Care Provider Contact Information

One of the most important considerations for correctly taking and adhering to your oral oncology medication is making sure that you contact your doctor or nurse with any questions related to your treatment and course of therapy. Consider recording the following information for your health care provider(s):



Considerations to Help You Adhere to Treatment

Checklist

When your medication is prescribed, your health care team will tell you how to correctly take your oral oncology medication. To help you adhere to your treatment, this checklist provides information on how to keep track of taking your medication.

Adherence means correctly taking medications or making lifestyle changes based on your doctor's recommendations.

Nonadherence means missing doses, taking doses in addition to those prescribed, or taking doses either in the wrong amount or at the wrong time.

Nonadherence may lead to several challenges, including:

Drug resistance and poor response to therapy



Disease progression



Increased associated medical expenses



Added risk of further illnesses and decline of overall health



Treatment Adherence Checklist

	Ask your doctor or nurse any questions that you may have about your oral oncology medication when your treatment is prescribed
	Tell your doctor or nurse your medical history and all other medications and combination therapies that you are currently taking, including prescribed medications, over-the-counter medications, herbal products, and supplements
	If possible, use the same pharmacy to fill all of your prescriptions to help ensure that a personal medication profile is created and maintained for your course of treatment
	Tell your doctor or nurse if you are experiencing any issues obtaining your oral oncology medication from the pharmacy
	If instructed by your doctor or nurse, use a personalized treatment calendar that lists the dates and times that you should take your oral oncology medication, and take this calendar with you to your medical appointments to show to your health care team
	Have a designated, consistent, and safe area in your home to store your oral oncology medication
	Let your family members or any other caregivers who are assisting you with your treatment know about your therapy and provide them with the materials given to you by your doctor or nurse
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Resources

For more information on adherence resources, please visit the following:

American Cancer Society http://www.cancer.org

Cancer Support Community
http://www.cancersupportcommunity.org

National Cancer Institute http://www.cancer.gov

CancerCare
http://www.cancercare.org

Centers for Disease Control and Prevention

http://www.cancercare.org http://www.cdc.gov/cancer

Reference: World Health Organization. Adherence to long-term therapies—evidence for action. 2003. https://www.who.int/chp/knowledge/publications/adherence_report/en/. Accessed November 12, 2020.



Keeping Track of Your TherapyTreatment Calendar

Month:	Regimen:	Treatment Time:

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

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Getting Your Specialty Medication From a Specialty Pharmacy

Know the Facts

Your doctor may prescribe a specialty medication for your medical condition that you may need to get from a specialty pharmacy. To walk you through the process, here is some helpful information to let you know what you can expect.

What are specialty medications?

Specialty medications are complex therapies that treat serious and chronic medical conditions, such as cancer, multiple sclerosis, rheumatoid arthritis, acromegaly, Crohn's disease, and others. These medications may require:

- Special handling and storage (for example, refrigeration or temperature control)
- · Clinical support and regular follow-ups to make sure that you are taking your medication correctly
- Individual counseling and education by phone (for example, side effect management, dosing instructions, or symptom control)

Generally, specialty medications are prescribed by specialists (such as oncologists, hematologists, or endocrinologists) and, depending on the drug, may come in the form of injections, infusions, or oral therapies.

What are specialty pharmacies?

Specialty pharmacies provide you or your doctor with the specialty medications that you are prescribed. In addition to the specialty medication, specialty pharmacies may offer a range of support services throughout the course of your therapy. Below are examples of several of the services that specialty pharmacies may provide to you at no additional cost.

Reimbursement Support	Support with verifying your insurance benefits and how to pay for your medications, including discussing any options to help minimize your out-of-pocket costs
Convenient Delivery	Safe, convenient, and confidential delivery of your specialty medication to your home, your doctor's office, or any other location of your choice, and at a time that best fits your schedule
Supplies	Free standard supplies for injectable medications that you or a caregiver would use, such as syringes, adhesive bandages, sharps containers (for disposing used needles), and alcohol swabs
Special Storage and Handling	Special handling and insulated packaging to ensure quality storage
Medication Information	Medication information about the specialty medication prescribed to you, including personalized instructions on how to take your medication
Counseling and Education	Nurses and pharmacists can help you learn more about your disease and treatment and provide you with educational materials and tools
24/7 Clinical Support	Nurses and pharmacists are available to answer your questions 24 hours a day, 7 days a week
Refill Reminders	Proactive refill reminders through automated phone calls or computer-based programs
Coordination of Care Support	Ongoing communication with your doctor to make sure that you are on track with your therapy

Why do I have to get my specialty medications through a specialty pharmacy?



Insurance companies recognize that patients who have complex medical conditions and take specialty medications may need additional services and support that traditional retail and mail-order pharmacies do not offer, so they work with you and a specialty pharmacy to provide you with more access to resources.

Depending on your specific insurance company, you may be required to receive your specialty medication through a specialty pharmacy. Sometimes, your specialty medication may only be available from a specialty pharmacy. Your doctor's office will be able to help you review your options.

How does a specialty pharmacy work with my doctor?



Your doctor will always be your primary health care provider, but your specialty pharmacy will also become part of your overall care team and can help answer questions you may have about your therapy or provide other support as needed.

How do I get my medications through a specialty pharmacy?

Visiting the Doctor



Step 1

Visit your doctor, discuss your symptoms, and complete any follow-up tests as needed



Step 2

Your doctor may then discuss your diagnosis with you (most likely on a separate visit) and if needed, may prescribe a specialty medication



Step 3

Your doctor's office staff (such as a reimbursement specialist, office manager, or physician assistant) may talk about your options and how you can receive your specialty medication

Using a Specialty Pharmacy



Step 4

Your doctor's office staff will help you determine and navigate through the appropriate way in which to obtain your specialty medication

Starting Therapy



Step 5

After you receive your specialty medication, your doctor's office and specialty pharmacy may both contact you to see how you are feeling and discuss any barriers you might have to taking your therapy as prescribed. For example, they may call to ask you to discuss treatment goals, side effect management, any missed doses, or if you receive your drug shipments regularly, as well as answer any questions regarding your disease or treatment.

IMPORTANT NOTE: When your specialty pharmacy calls you, it is possible that you may not recognize the caller ID, as many of them use toll-free numbers. You may want to take note of your specialty pharmacy's caller ID number so you know that when they call you, you can pick up.

What do I need to do next?



Talk to your doctor to determine how best to obtain your specialty medication. Your insurance company may dictate the specialty pharmacy from which you can obtain your specialty medication.

What does this cost me?



Your insurance company will determine your available coverage and you will be responsible for paying a portion of your medication's costs (through your insurance plan's deductible or coinsurance/co-payment). In general, you do not have to pay any additional fees to the specialty pharmacy for the services it offers related to your therapy, as it is part of your insurance plan.



Considerations for Giving Care to Patients With Cancer

Caregiver Checklist

As a caregiver, you play an important role in the course of the patient's cancer treatment. Caregivers typically help patients with scheduling appointments, monitoring medication side effects, communicating with doctors and nurses, providing transportation, and assisting with financial and legal matters. To help you organize and manage these tasks, this checklist provides information that may assist you in your role as a caregiver.

Caregiving in the Home

Identify tasks that involve hands-on patient care and those that are routine in nature, and become familiar with the level of effort involved

Hands-on Tasks

- In-home supervision (safety, comfort, companionship)
- Personal hygiene (bathing, skin/hair care, oral hygiene)
- Medical/nursing care (monitoring adherence to oral medication, assisting in-home mobility)
- Recreation (activities with family members and/ or friends)

Routine Tasks

- Food preparation (preparing, cooking, serving)
- Managerial assistance (medical appointments, finances, legal matters)
- Transportation (medical appointments, errands, recreation)
- Patient's prior responsibilities (caring of children and pets)
- Housework (laundry, garbage, outdoor maintenance)

If you need assistance with these tasks, ask the patient or his or her family members about other individuals who could potentially be appropriate helpers

Caregiving at the Doctor's Office or Hospital

At the start of the medical appointment, consider letting the doctor review the list of questions you and the patient have, so he or she knows which issues are important to you
If you or the patient feel that you need more information beyond what's discussed at the medical appointment, ask the doctor or nurse to recommend reading material or websites to provide a better understanding
Refer questions about insurance claims, billing, and other administrative matters to the office's administrative personnel
Write down contact information for the doctors and nurses who will be part of the patient's care team, including phone numbers, email addresses, office hours, and after-hours contact information

Caregiving to Manage Medications

When the patient receives the prescription from the doctor, make sure that both you and the patient can read the drug name and dosage, understand what the medication does, and know what to do if there are side effects
Be sure to tell the doctor of all other medications that the patient is currently taking, including prescribed medications, over-the-counter medications, herbal products, and supplements
When picking up the prescription, check that the order correctly lists the patient's name and pills at the right dosage
Maintain a medications log to track if the patient is correctly taking the oral oncology medication as prescribed

Reference: University of California, San Francisco, Caregivers Project/Osher Center for Integrative Medicine. Orientation to caregiving – a handbook for family caregivers of patients with brain tumors. UCSF Helen Diller Family Comprehensive Cancer Center website. 2013. http://cancerucsf.edu/_docs/crc/Caregiver_GEN.pdf. Accessed November 12, 2020.

Patient Health Care Binder



Assembling a binder or notebook that contains the patient's medical information may help you as the caregiver feel more prepared and in control when it comes to making decisions, preventing medical errors, and having access to accurate information. If you think that this tool may be helpful to you, consider putting together the following information in a health care binder:

Contents	Considerations
Pathology reports, MRIs, PET scans, and CT scans	Ask the doctor for a copy of these reports on CD-ROM or flash drive in case the patient decides to pursue a second opinion or alternative treatments; these reports contain the most important information about the tumor and diagnosis and will direct the treatment options
Lab reports and blood tests	Ask the doctor for a copy of these reports; having copies on hand will allow you and the patient to quickly refer to them if needed
Medications log	Include all current medications being taken, along with their associated dosages, dates, side effects, any problems experienced, and who prescribed them
Treatment log	Include all treatments that the patient has undergone (for example, radiation, surgery, or chemotherapy), along with their associated dates, side effects, any problems experienced, and provider information
Calendar pages	Include medical and treatment appointments, home care, and therapy schedules
Health history	Record important health information, such as the patient's insurance policy number, emergency contact information, history of other serious illnesses, allergic reactions to medications, and other conditions for which the patient is currently being treated
Notes and questions	Use this section to write notes during appointments or maintain a file of questions that you need the doctor to answer

Key: CT - computerized tomography; MRI - Magnetic Resonance Imaging; PET - Positron Emission Tomography.

Resources



For more information on caregiver resources, please visit the following:

American Cancer Society http://www.cancer.org

Cancer Care http://www.cancercare.org

Cancer Support Community

http://www.cancersupportcommunity.org

Centers for Disease Control and Prevention

http://www.cdc.gov/cancer

National Cancer Institute http://www.cancer.gov

University of California, San Francisco

http://cancer.ucsf.edu/_docs/crc/Caregiver_GEN.pdf

Reference: University of California, San Francisco, Caregivers Project/Osher Center for Integrative Medicine. Orientation to caregiving – a handbook for family caregivers of patients with brain tumors. UCSF Helen Diller Family Comprehensive Cancer Center website. 2013. http://cancer.ucsf.edu/_docs/crc/Caregiver_GEN.pdf. Accessed November 12, 2020.







To access more resources, go to HCP.Novartis.com/care-management

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