# A Guide to Oral Anticancer Treatment

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8 Must Know Facts:
These are the facts that are most important for taking your anticancer treatment at home.

1. As the patient, you have a very important role in your care when taking oral medications.

2. In order for your medications to work best, they need to be taken exactly as prescribed to you.

3. Even though you are receiving treatment at home there are resources available to you for support, coping and managing your cancer treatment...you are not alone.

4. You should know what side effects to look for before starting therapy and tell your medical team about any side effects you experience.

5. Your medical team will help you manage the side effects you have.

6. Oral medications for cancer treatment require special measures for safe handling and disposal.

7. These medications are safe to have in your home, but should always be kept out of reach of children and pets.

8. Even though you are taking your medicine at home, you still need to see your medical team regularly to monitor the cancer and your treatment plan.

Details about these and other helpful information are found in this booklet.
Welcome

This guide provides answers to many common questions about oral medications for cancer treatment. Our goal at the University of Michigan Comprehensive Cancer Center is to provide our patients and families with the highest quality care. This means giving the necessary treatments as well as providing the education and support needed while you are on treatment. This book also contains suggestions to help you care for yourself during treatment.

This book should be used along with the *Chemotherapy and You* booklet produced by the National Cancer Institute. *Chemotherapy and You* is your main resource for information about chemotherapy, managing its side effects and understanding how to prevent them. It is very important to use this booklet as a resource during your entire chemotherapy treatment course. Copies of this booklet and other educational materials can be found at the Patient Education Resource Center (called the “PERC”) in the Cancer Center.

Your health care team will also provide you with verbal and written instructions about your cancer treatment. You should refer to these materials for information about your specific treatment plan.
What is Chemotherapy or Anticancer Treatment?

Chemotherapy (chemo) is the treatment of cancer with drugs that can destroy cancer cells. In addition to chemotherapy, there are many drugs that may “target” the cancer in other ways. Together, these drugs and chemotherapy are often called "anticancer" drugs. Most people don’t know that anticancer treatment includes many different drugs that are given in a variety of ways such as:

- Drugs that are given into the bloodstream through an IV (called intravenous chemotherapy or infusion therapy). These drugs can be given over minutes or hours. This process is called an infusion.
- Drugs are also given slowly and continuously over several days using a pump. This is called a continuous infusion.
- Drugs that are taken by mouth as pills or liquid (called oral chemotherapy or oral anticancer treatment)
- Drugs that are placed directly into a body area (called intracavitary chemotherapy)
- Drugs that are placed on the skin as creams

This book will focus on oral anticancer treatment. It is becoming more common to take anticancer treatment by mouth. Oral administration is convenient and allows you to have an active role in your care. This also means you, as the patient or the caregiver, has increased responsibility for your care. Oral medications have side effects and drug interactions just like IV drugs do. It is very important for you to take the medication exactly as prescribed. There are many ways we can help you throughout this process to make sure your oral medicine is working as well as possible. Information regarding any other types
of cancer treatment that you may receive will be given to you by your health care team.

This is a good place to stop and review the section called “Questions and Answers about Chemotherapy” in *Chemotherapy and You* (page 3).

**About Clinical Trials**

Your health care team may suggest that you consider participating in a clinical trial (also called a research study or protocol).

Clinical trials are used to test and develop new treatments. The goal of these trials is to find ways to improve cancer treatment. While a trial or study is active or in progress we will not know whether—there may be a potential benefit to you. The trial must be closed and the data analyzed before the treatment is made widely available to other patients.

There may be some additional risks associated with research. The research team will discuss in detail with you both the potential risks and the potential benefits of joining the trial. Your written permission must be given before you can start a clinical trial.

Oversight committees at the University of Michigan Medical Center conduct an extensive review of all clinical trials. These committees include an Institutional Review Board or IRB composed of cancer doctors, doctors in other specialties and lay people. The IRB reviews all clinical trials before they are available to patients and at different times during the research. This ensures that the clinical trial remains safe for patients.
All patients who are on a clinical trial receive the best supportive care possible. Their reactions to the treatment are watched closely. A prescriber can stop the treatment if it does not seem to be working. The patient may choose to leave the study at any time. If a patient leaves a study for any reason, standard care will be continued.

Clinical trials are voluntary. Your cancer will be treated whether you decide to join a trial or not. Talk to your doctor about any questions you have regarding clinical trials at the University of Michigan Comprehensive Cancer Center.
Preparing for Anticancer Therapy

Getting ready for anticancer therapy can be scary. Patients often experience many different feelings. We offer these 4 ways to best prepare you for anticancer treatment.

4 ways to prepare for your cancer treatment:

#1 Learn about anticancer therapy
To understand what anticancer therapy is, how it is administered and what side effects may occur during or after your treatment, read the booklet *Chemotherapy and You* before your treatment begins. This booklet provides information that will be used before, during and after treatment. As you review this material, write down your questions. Bring this booklet with your questions to your clinic appointment and discuss them with a member of your treatment team.

It is helpful to look at the anticancer therapy educational material given to you before you receive your first treatment. This includes items for clinical trials such as an informed consent, drug information sheets, nutrition information and more! This can be a lot to review, so it might be helpful to choose an information gatherer. This is someone who will read the information and let you know what you need to know, when you need to know it.

#2 Plan treatment into your day
Your healthcare provider has selected an oral form of therapy for your cancer treatment. It will be important to take the medication exactly as prescribed. Since you will be taking it or your caregiver will be giving you your medication, it will be important to use tools to help remind you or your caregiver how to take the medications in a safe and effective way. Some examples of helpful tools include medication diaries, treatment calendars, medication boxes, and reminder alarms. Your clinic or the Oral Medications for Cancer Therapy Service
can help you with reminder tools if needed. Many cancer treatments are given in “cycles”. A cycle consists of consecutive days of therapy, with a gap or “time-off” built in. Oral medications used for cancer treatment may also be given in cycles or may be given continuously depending on what the medication is and what type of cancer is being treated. The information specific to your cancer treatment will be summarized for you by your healthcare provider and the oral medication clinic.

#3 Schedule a pretreatment dental checkup if timing allows
The mouth can be a source of infection during some types of chemotherapy treatment. For this reason, it is helpful to have a checkup before you begin treatment if you have not had one in the last 6 months. It will be important to check with your cancer doctor if this is necessary for you, based on your specific oral medication.

This is a good time to review the mouth care section in the Chemotherapy and You booklet. You can find it on pages 35-37. Follow the instructions for mouth rinses that are described in this section.

#4 Take care of YOU
Treatment can be a stressful time for you and for those around you. It is important that you focus on your needs during this time. The following is a list of suggestions to help you:

✔ Ask for Help
Select someone close to you to organize help for the chores and activities you would normally do. Learning to accept help from others can be difficult, but may be necessary. If you can learn to let others help…they’ll be happy doing it, and you’ll be happy to have things done!
✓ Reduce Stress
Identify one or two ways to reduce stress and relax. Practice them before your treatment begins. Plan to use these techniques throughout your treatment.

✓ Gather Supplies
All patients should have a thermometer in their house and be able to read it. You may also want to use a medication diary or calendar to remind you of your medication schedule. We have included a diary in the pocket of this book. You can obtain more of these at the Patient Education Resource Center in the Cancer Center, or online at www.mcancer.org/patients.

Techniques for Stress Reduction
Below are a few suggested activities. Every patient is different and will find help in different ways. If an activity doesn’t help, try another.

- Deep Breathing Exercises
- Biofeedback
- Guided Imagery
- Distraction: Music, Art, Hobbies
- Journaling
- Yoga

Visit the Patient Education Resource Center on level B1 of the Cancer Center for information on these programs at the University of Michigan or visit our website @ www.mcancer.org.
Frequently Asked Questions About Filling Your Medication

Where can I fill my prescriptions?
Although you are able to take your prescription to any pharmacy to have it filled. **We recommend you fill your prescriptions for cancer treatment at our Cancer Center pharmacy.** Our pharmacy is more likely to have the medication in stock for you. Our pharmacy will provide assistance in navigating insurance coverage concerns if needed, including prior authorizations. Our pharmacists are very knowledgeable about your medication and can provide answers to your questions.

**Cancer Center Building:** Our outpatient pharmacy is located on the B1 level. Both prescription and non-prescription medications are dispensed or sold here.

**Hours:** Monday through Friday: 9 am to 5:30 pm

**Phone:** 734-647-8911

Will my health insurance cover oral anticancer treatment costs?
It is important to talk to your health insurance plan about what costs it will pay, BEFORE you begin your cancer treatment. The *Chemotherapy and You* booklet offers questions to ask your health insurance plan on page 7.

The UM Cancer Center Billing and Customer Service Office staff is available to discuss questions about chemotherapy costs and billing. They can be reached at (734) 647-8663. You may also stop by the Practical Assistance Center located on level 1 of the cancer center for help.
Frequently Asked Questions About Taking Your Medication

How should I take my medicine?
Your oral medicine should be swallowed whole, do not chew or crush them. It may have special instructions on how it should be taken (with or without food, separated from other medications, etc.) When you receive your medication from the pharmacy the pharmacist will provide counseling. Ask your healthcare team about any questions you have with how to take the medicine. They will review all important information with you on how to take your medication as well as answer any questions or concerns you might have.

What should I do if I forget to take a dose?
If you miss a dose of your medicine, take it as soon as possible. However if it is almost time for your next dose, skip the missed dose and return to your regular dosing schedule. Taking extra medication may cause additional or more severe side effects. Do NOT EVER double doses. If you are in a clinical trial, you will be given special instructions if you miss a dose.

What if I cannot swallow a pill or capsule?
If you are not able to swallow any of your pills or capsules, tell your healthcare team. There may be ways to dissolve your medications or they may come in liquid form. We will provide assistance to you.

What if the medicine does not stay down?
If you are unable to keep the medication down due to vomiting, be sure to inform members of your healthcare team. In general, you will not need to take another dose. If you have questions whether or not you should take your medication, please call your cancer clinic.
**Where should I keep my medication?**

Most oral medications for cancer therapy should be stored at room temperature, away from excessive heat and moisture. Do not store your medication in the bathroom. Check your medication label to see if special storage or handling is needed, such as refrigeration or protecting from light. Keep your medication in its original container or a medication box. Do not store this medication with other family members’ medications in effort to avoid someone else accidently taking this medicine. All medications need to be kept out of the reach of children and pets.
Starting Oral Anticancer Medications

The *Chemotherapy and You* book is a great resource when starting anticancer treatment. Refer to it first for any questions you may have. Contact your health care team for answers prior to beginning your medications. Your healthcare team is available at the numbers on the back page of this book.

The Oral Medications Pharmacy Service

You will receive a phone call from the Oral Medications for Cancer Therapy Service shortly after you begin treatment. This service will help make sure you’re able to get your medicine filled, that there are no drug interactions with your new medicine, that you understand how to take it and to see if you need any help in remembering to take it in the future. Please keep a list of all the prescribed, over the counter and herbal medications you take and any questions you have so they can be addressed during this phone call or during future clinic appointments. *We have included a medication record for your use in the back pocket of this handbook.*

What can I expect?

It is normal to be worried about the possible side effects of anticancer treatment. These feelings can be overwhelming before your treatment begins. It is important to discuss your concerns with your healthcare team. Remember that not all patients experience side effects. In fact, many people have few or no side effects from treatment. The severity and type of side effects that occur will depend on the treatment you are receiving.

Even though some side effects might be expected, you should always notify your health care team if any side effects occur.
Review the “Side Effects and Ways to Manage Them” section of *Chemotherapy and You* before you begin treatment. You will find a detailed description of some of the common side effects of chemotherapy, how to prevent them as well as how to manage them. You will also review this with your healthcare team. They will help you to become comfortable identifying side effects and ways they may be avoided or minimized during treatment. Your healthcare team will continue to provide information to you as you progress through your treatments. Remember that each anticancer treatment is different, and every patient may have a different experience.

**When should I contact my healthcare provider?**

Notify your healthcare team for the following:

- Shaking chills or fever (a temperature of 101°F or 38.3°C or greater)
  
  **Notify the clinic immediately if you develop a temperature, do not delay.**

- Unusual cough, sore throat, lung congestion or shortness of breath

- Burning discomfort when you urinate

- Redness, pain or sores in your mouth

- Nausea, vomiting or inability to eat or drink for more than 24 hours.

- Diarrhea (loose, watery stools) for more than 24 hours.

- Constipation (no bowel movement in 2-3 days)

- Bleeding or unusual bruising

- Pain not controlled by your current medications

- Any new or unusual symptom that concerns you
Precautions in the Home During Anticancer Treatment

Take precautions to protect you and your caregivers from contacting the anticancer medicine. Anticancer treatments may leave the body through urine, vomit, blood and stool. Please see the Oral Medications for Cancer Therapy document and talk to your health care team if you have questions about precautions.

Laundry

Use gloves to handle laundry soiled with chemotherapy to keep it from contacting your skin. Wash any soiled linen or clothes right away in your washer with your regular soap. If you do not have a washer, place the soiled items in a plastic bag until they can be washed.

Skin Care

Skin can become irritated from the chemotherapy. If you get chemotherapy or body wastes on your skin, wash the area with soap and water, then dry. Call your doctor if there is redness or irritation on the skin that lasts longer than one hour.

Body Wastes

Small amounts of chemotherapy are present in urine, stool, semen, and vomit. If you are exposed to body wastes, wash the area with soap and water. Others in your household may use the same toilet as long as all waste is flushed down the toilet. If you use a commode, bedpan, urinal or a basin for vomiting, wear gloves when emptying the waste, rinse the container with water and clean it at least once a day with soap and water.

If you do not have control of your bladder or bowels, use a disposable, plastic-backed pad, diaper or sheet to absorb urine and stool. When it becomes soiled, change immediately and wash the skin with soap and water. If you have an ostomy, wear gloves when emptying and changing the appliance.
If body wastes splash into your eyes, flush them immediately with water for 10 to 15 minutes and call your doctor.

**Pregnant and/or Breast Feeding Caregivers**
Pregnant or breast feeding women should wear gloves and gowns when caring for patients receiving chemotherapy.

**Sexual Activity and Pregnancy**
Your bodily fluids may contain small amounts of your chemotherapy. It is very important that you or your partner not get pregnant while on chemotherapy, as many of these medications are hazardous to fetal development. If you have questions about sexual activity discuss these with your health care team. This is very important for both men and women. Notify your physician if pregnancy occurs while you are receiving anticancer treatment.

**Hand Washing**
Hand washing is one of the most important things you can do to prevent infection. Wash your hands before and after the following:

- Eating
- Preparing food
- Going to the bathroom
- Touching body fluids (yours and others) such as blowing your nose
- Working with plants or soil
- Using gloves for a task or procedure

**Disposal of your oral medication**
Normally you will not have extra medications but if you do, see the Oral Medications for Cancer Therapy handout for information regarding disposal of oral medications for cancer treatment.
Monitoring Your Health

You are an active member in your healthcare team and there are aspects of your treatment for which the rest of the healthcare team will greatly depend on you or your caregiver. To fulfill your important role, we will need you to:

- Provide feedback to your healthcare team
- Monitor how you are feeling
- Promptly report any side effects you are experiencing
- Keep record of how you are taking your medicine

How to Contact Your HealthCare Provider

**Monday through Friday (8am to 5pm):**

Call (734) ________________

**After hours, weekends and holidays:**

Call the page operator at (734) 936-6267 and ask to speak to the following physician:

- Hematology/Oncology Physician on Call
- Gynecologic /Oncology Physician on Call
- Bone Marrow Transplant Physician on Call
- Neurologist on Call
- Other: ___________________________
Resources

There are many resources available to patients and their families at the University of Michigan Comprehensive Cancer Center that will help you throughout your treatment. These resources are found in the Patient and Family Support Services Handbook available in each clinic, at the Patient Education Resource Center and at our website. Studies have shown that patients who take oral anticancer therapy at home often feel isolated and use fewer resources than patients who are in the center for infusion anticancer therapy. Don't hesitate to seek resources if you need them or if you need support through your treatment.

The Patient Toolkit

Each patient at the University of Michigan Comprehensive Cancer Center receives a complimentary plastic file box called a “Patient Toolkit”. This box contains important information to help you manage your treatment needs during cancer therapy and has room to hold all of your treatment related records. Items in the toolkit include a Support Services handbook, business card holder, medication record, appointment and medical records tools and information about key topics such as complementary therapies, insurance and supportive care. If you have not received a toolkit, ask at your clinic or visit the Patient Education Resource Center where you can obtain at no charge.

Do You Have a Toolkit?

Information about patient and family resources is found in the Patient Toolkit and at the Patient Education Resource Center on Level B1 of the Cancer Center or online at www.mcancer.org
Patient & Family Resources

Information about the programs available to you are found on our cancer center website: www.mcancer.org/patients, or at the Patient Education Resource Center on level B1 of the Cancer Center.

Some of the resources you will find in the Patient Support Handbook include:

- Nutrition Services at the Nutrition Counseling Clinic on level B1 of the Cancer Center.
- Managing emotions, stress, depression and anxiety at the PsychOncology Clinic in the Cancer Supportive Care Center on level 3 of the Med INN Building.
- Guided Imagery and Meditation Appointments and Workshops to gain skills that help reduce anxiety and manage treatment. These are available through the PsychOncology clinic at the Cancer Supportive Care Center on level 3 of the Med INN Building.
- The use of art and music to cope and express emotions are tools used in Art and Music Therapy appointments. These are available through the PsychOncology clinic at the Cancer Supportive Care Center on level 3 of the Med INN Building.
- Lodging, transportation, prescription and other practical assistance is provided at the Practical Assistance Center on level 1 of the Cancer Center.
- Hair loss resources, community organizations and websites for hair loss products are offered at the Practical Assistance Center on level 1 of the Cancer Center.
- Information about radiation therapy, side effects and resources available at the Patient Education Resource Center (PERC)
**Fertility Program**
Some men and women who receive chemotherapy become infertile, which means they are unable to have children. If you plan to have children, talk to your doctor before your treatment begins. The UM Cancer Center has a Fertility Counseling Program for cancer patients. Information about this program can be found online at [www.mcancer.org](http://www.mcancer.org) or by calling 877-907-0859.

**Patient Education Resource Center**
The Patient Education Resource Center (or PERC) offers many resources (videos, books, brochures, tapes). The PERC is located on level B1 of the Cancer Center and can be reached at (734) 647-8626. Hours of operation are Monday through Friday, 9am to 4:30pm.

**Symptom Management and Supportive Care Program**
This program offers a number of supportive care clinics located in the Supportive Care Center on level 3 of the Med INN building including:
- Oral Medications for Cancer Therapy Service
- Symptom Management and Supportive Care Clinic
- Medication Management Clinic
- Nutrition Services and the Nutrition Counseling Clinic
Important Phone Numbers

Symptom Management and Supportive Care Program 1-877-907-0859
- Oral Medications for Cancer Therapy Service
  CC-Oral-Chemo@med.umich.edu
- Symptom Management and Supportive Care Clinic
- Medication Management Clinic
- Nutrition Services

Fertility Counseling Program 1-877-907-0859
Finance and Billing Services 734-647-8663
(Cancer Center)
Home Med 1-800-862-2731
Infusion Appointments 734-647-8908
Infusion Centers Call Main Number (734-647-8908)
And ask for the specific infusion area:
  Cancer Center Infusion
  Med INN Infusion
  Canton Center Infusion

Skills Lab Appointments 1-877-907-0859
PsychOncology Clinic Appointments 1-877-907-0859
UMHS Paging Operator 734-963-6267

This document is not intended to take the place of the care and attention of your personal physician or other professional medical services. Our aim is to promote active participation in your care and treatment by providing information and education. Questions about individual health concerns or specific treatment options should be discussed with your physician.

Staff of the following programs provided information for this handbook:
Cancer Patient Education, Medical Oncology, Oncology Nursing, and the Patient & Family Support Services Program

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UHMS Pharmacy Services
Oral Medication for Cancer Therapy Service