# Oral Anticancer Treatment Handout



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#### Welcome

Our goal at the Michigan Medicine Rogel Cancer Center is to provide our patients and families with the highest-quality care. This means giving the necessary treatments and providing the education and support needed while you are on treatment. This education folder has suggestions to help you care for yourself during treatment and will answer many common questions that you may have about oral medications for cancer treatment.

Use this handout along with the **Chemotherapy and You** booklet from 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 oral anticancer treatment course. You can find copies of this booklet and other educational materials online National Cancer Institute at <u>cancer.gov</u>.

Your health care team will give you verbal and written instructions about your cancer treatment. Look at these materials often for information about your specific treatment plan.

#### When should I call my health care team?

Call us if you have any of 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 pain when you urinate.
- Redness, pain, or sores in your mouth.
- Nausea, vomiting
- Inability to eat or drink for more than 24 hours.
- Diarrhea (loose, watery stools) for more than 24 hours.
- Constipation (no bowel movement in two to three days)
- Bleeding or unusual bruising
- Pain that is not controlled by your current medications.
- Any new or unusual symptom that concerns you

#### What is the number to call?

•	During business hours Monday through Friday between 8:00 am - 5:00 pm
	call (734) 647-8902

•	After hours, weekends, and holidays call the Paging Operator at (734) 936-6267 and ask to speak to the following doctor on call:
	☐ Hematology/Oncology
	☐ Gynecologic/Oncology
	☐ Bone Marrow Transplant
	□ Neurologist
	Other:

#### **Important Phone Numbers**

Brighton Specialty Care Pharmacy	810-263-2400
East Ann Arbor Health Center Pharmacy	855-276-3002
Fertility Counseling Program -Women Center for Reproductive Health	734-763-4323
Fertility Counseling Program - Men Rogel Cancer Center	734-647-8579
Finance and Billing Services (Cancer Center)	734-647-8663 or
	(734) 647-8663
HomeMed	800-862-2731
Michigan Medicine Paging Operator	734-936-6267
Nutrition Clinic Appointments	877-907-0859
Oral Medications for Cancer Therapy Service	(734) 232-6366
CC-Oral-Chemo@med.umich.edu	
Patient Accounts (billing)	800-992-9475
Practical Assistance Center	877-907-0859
PsychOncology Clinic Appointments	877-907-0859
Rogel Cancer Center Pharmacy	734-647-8911
Rogel Cancer Supportive Care Center	877-907-0859
Social Work	800-888-9825
Taubman Center Pharmacy	734-936-8260
University of Michigan Home Care Retail Store	734-647-3364

#### **Anticancer/Chemotherapy Therapy**

#### What is Anticancer Therapy?

Anticancer therapy is the treatment of cancer with medications that can destroy cancer cells. These medications are also called "chemotherapy", "targeted therapy", or "oncolytics". These names refer to the different ways that medications fight cancer. You may hear some or many of these names when talking or reading about your medicine.

This handout will focus on **oral anticancer treatment**. It is becoming more common to take anticancer treatment by mouth. Taking oral cancer medication is convenient and allows you to play an active role in your care. This also means that you, as the patient or the caregiver, have more of a responsibility in your care. Oral medications have side effects and drug interactions just like IV drugs. It is very important that you take the medication **exactly as prescribed**. There are many ways we can help you throughout this process to make sure your oral medication is working as well as possible. In addition, you may get information about other types of cancer treatment from your health care team.

This is a good place to stop and review the section called "Questions and Answers about Chemotherapy" on Page 3 of **Chemotherapy and You**.

#### What are Clinical Trials?

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

Clinical trials help develop and test new treatments. In cancer, clinical trials are designed to answer questions about new ways to:

- Treat cancer
- Find and diagnose cancer
- Prevent cancer
- Manage symptoms of cancer or side effects from its treatment

While a trial or study is active, we will not know if there is any 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 the potential risks and benefits of joining the trial. You must give your written permission, also called "consent", before you can start a clinical trial.

You will receive the best supportive care possible and we will watch any reactions to the treatment closely. Your doctor can stop the treatment if it does not seem to be working. You may choose to leave the study at any time. If you leave the study, you will continue to receive standard care.

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 might have regarding clinical trials at the Michigan Medicine Rogel Cancer Center.

## Preparing for Anticancer/Chemotherapy What can I do to prepare for my anticancer treatment?

Getting ready for anticancer therapy can be scary. You may have a lot of different feelings. We offer these suggestions to best prepare you for anticancer treatment.

1. **Learn about anticancer therapy**: we suggest that you read the information in your folder **before your treatment starts**. This will help you understand anticancer therapy, how it is given, and what side-effects may occur during or after your treatment. We also suggest that you read the booklet **Chemotherapy and You** from the National Cancer Institute (available at cancer.gov). This booklet provides information you will use before, during, and after treatment. As you review this material, write down your questions. You can use the section at the back of this handout to write down your

questions. Bring this folder and your questions to your clinic appointments and discuss them with a member of your treatment team.

Before your first treatment, we will give you a packet with more educational materials. Be sure to review them before you receive your first treatment. The packet includes items for clinical trials such as an informed consent, drug information sheets, nutrition information, and more. It may be a lot of information to review so it might be helpful to choose a person that will help you read through the information and to keep it organized.

- 2. **Consider fertility programs:** Some men and women who get chemotherapy become infertile. This means they will face challenges when trying to conceive a child. If you plan to have children in the future, talk to your doctor **before** your treatment starts. Michigan Medicine's Center for Reproductive Medicine offers fertility preservation interventions and counseling for women. Men are seen in the Rogel Cancer Center for fertility counseling. You will need to have a referral from your oncologist to go to this clinic. Talk with your oncology team if you have any questions.
- 3. **Plan treatment into your day:** It is important to take the medication exactly as prescribed. Below are some tools that you can use to remind you to take your medication or for your caregiver to give you the medication.

#### Helpful tools:

- Medication diaries
- Treatment calendars
- Medication boxes
- Reminder alarms

Your clinic, or the Oral Medications for Cancer Therapy Service, can help you with reminder tools, too. Many cancer treatments are given in "cycles". A cycle consists of consecutive days of therapy, with a gap or "time-off" built in. Some types of oral anticancer medications may also be given in cycles or may be given without a gap. Your healthcare provider and the oral medication service will summarize for you the information specific to your cancer.

- 4. **Schedule a before treatment dental check-up if time allows:** Your mouth can be a source of infection during some types of chemotherapy treatment. Check with your doctor to see if this appointment is necessary for you, based on your specific oral medication.
- 5. **Practice good self-care:** Treatment can be a stressful time for you and those around you. It is important that you focus on your needs during this time.
- 6. **Learn to accept help from others**: It's important to focus on your own needs during this time. This may mean learning to accept help from others. Allow someone to help with routine things like doing laundry or going to the grocery store. Learning to accept help from others can be hard, but may be necessary so that you can get the rest you need.
- 7. **Gather supplies**: Purchase an oral or ear thermometer. Make sure that you can read it. A raised temperature may mean that you need medical attention. You may also want to use a medication diary or calendar to remind you of your medication schedule.

#### How will I manage the stress of cancer?

Psychological stress is used to describe what you may feel when you or a loved one are under mental, physical, or emotional pressure. Stress can be caused by daily activities and routine events, as well as by more unusual events, such as a serious illness. When people feel that they are unable to manage or control changes caused by cancer or normal life activities, they are in distress. If you need extra support talk with your oncology team. They will help you by making referrals for supportive care and services.

#### Support services and resources

Studies have shown that patients who take oral anticancer therapy at home often feel isolated and use fewer resources than patients receiving infusion anticancer therapy at the Rogel Cancer Center. Don't hesitate to seek resources if you need them or if you need support through your treatment. Below you'll find a list of some of the programs and services that are available to you. For more information, visit the Rogel Cancer Center web site at: www.rogelcancercenter.org

- Chemotherapy information
- Side effect management
- Complementary Therapies: Art, Music, Guided Imagery
- Families Facing Cancer
- Grief and Loss
- Life Images
- Nutrition Services
- Patient Education Program
- Physical Therapy (PT) and/or Occupational Therapy (OT)
- Patient Assistance Center: Wig Bank, Financial Assistance, etc.
- PsychOncology Clinic
- Social Work
- Spiritual Care
- Support Groups

#### Tips to manage stress

Everyone responds differently to stress. Below are some things that may help reduce your stress:

- Training in relaxation, meditation, stress management or guided imagery
- Counseling or talk therapy
- Getting social support in a group setting
- Listening to soothing music
- Journaling
- Engaging in physical activity

What do I need to know about taking anticancer treatment at home?

#### 7 must-know facts:

- **1.** In order for your medications to work best, they need to be **taken exactly as prescribed**.
- **2.** You will need to keep a record of when and how you are taking your medication.
- **3.** Know what side effects to look for **before** starting therapy.
- **4.** Tell your health care team about any side effects you are having so we can help you manage them.
- **5.** It is safe to have oral anticancer medications in your home, but they require **special measures** for safe handling and disposal. Keep them out of reach of children and pets.
- **6.** Even though you are taking your medication at home, you still need to see your health care team regularly to monitor the cancer and your treatment plan.
- **7.** Even though you are receiving treatment at home, resources are available to you for support, coping and managing your cancer treatment. **You are not alone**.

#### **Starting Oral Anticancer Medications**

The **Chemotherapy and You** booklet is a great resource when starting anticancer treatment. Refer to it first for any questions you may have. If you do have questions, call your health care team. Phone numbers are located on page four of this handout.

#### What is the Oral Medications for Cancer Therapy 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 you get the medication prescribed for your cancer treatment.
- Make sure your new cancer medication does not interact with other medications you might be taking.
- Give you information about the possible side effects of your medication.
- Help you to remember to take your medication as prescribed.

Please keep a list of all the medications you are taking. This includes prescription, over-the-counter, herbs, and supplements you take. Bring this list and any questions you have to our next clinic appointment. We have included a medication record for your use in the folder.

#### How will I manage the side effects?

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 health care team.

**Remember, 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 get.

Even though some side effects may be expected, make sure to **always** notify your health care team when any side effects occur.

Review the "Side Effects and Ways to Manage Them" starting on page 14 of **Chemotherapy and You** before you begin treatment. You will find 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 health care team. They will help you to become comfortable identifying side effects and ways they may be avoided or reduced during treatment. Your health care 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 health care provider?

- Call if you have any of the signs or symptoms we describe on page 2 of this handout.
- You should also call if you are having any other side effects from the cancer therapy.
- Call if you have any other questions or concerns.

Contact your doctor or the Rogel Cancer Center Oral Medication for Cancer Therapy Program at (734) 232-6366.

Call your doctor or nurse if you are having a side effect, even one that might be expected. See the phone numbers at the beginning of this handout.

#### What precautions do I need to take in the home?

You need to take precautions to protect you and your caregivers from coming in contact with your anticancer medication. Anticancer treatments leave your body through urine, vomit, blood, and stool. You may get additional information from your health care team on what precautions to take in the home.

#### Precautions for Body fluids

Small amounts of chemotherapy are present in your urine, stool, semen, and vomit. If you are exposed to body wastes, wash the area that is touched with soap and water.

- Wash your hands well with soap and water after using the toilet.
- Wash your skin if urine, vomit, or stool gets on any part of your body.

• Wear gloves when disposing of urinal or commode waste and cleaning of equipment.

Others in your household may use the same toilet as long as all waste is flushed down the toilet.

#### What precautions should my caregivers take?

Caregivers should also follow precautions to prevent coming in contact with your anticancer medicine.

- Wash hands before and after giving oral medications, or wear gloves when handling the medication.
- Wear gloves when disposing of urinal or commode waste and cleaning of equipment.
- Wash skin if touched by urine, vomit, or stool.

#### How does the anticancer medication affect sexual activity and pregnancy?

During treatment with chemotherapy, some of the side effects may decrease your interest in sex. If you are feeling well, it is usually safe to have sex with certain precautions in place. Sex can be a problem if you are bleeding from the genital area, have recently had surgery, or if your immune system is very weakened. Talk with a member of your health care team before engaging in sexual activities in case there are concerns about your condition.

Chemotherapy can have poor effects on a developing baby. **You must take extra measures to avoid pregnancy**, such as using two forms of birth control.

- Use barrier protection, such as condoms or dental dams (for oral sex).
   Chemotherapy can be found in semen and vaginal fluid. Barrier protection will keep your partner safe.
- Tell a member of your health care right away if you become pregnant during chemotherapy treatment.

#### How important is hand washing?

Because your immune system is weakened, it's much easier for you to get sick. Hand washing is one of the most important things you can do to stop infection. Wash your hands:

- After using the toilet.
- After changing diapers or cleaning up a child who has used the toilet.
- After blowing your nose, coughing, or sneezing.
- After touching an animal, animal feed, or animal waste.
- After handling pets, pet food or pet treats.
- After touching garbage.
- Before, during, and after preparing food.
- Before eating food.
- Before and after caring for someone who is sick.
- Before and after treating a cut or wound.

#### How do I dispose of my oral medication?

Generally, you should not have any have extra medications. If you do, read the

handouts: **Disposing of Unused Medications** and **Medication Disposal for Non-Controlled and Controlled Substances.** These handouts

**Do not** flush any unused medication down the toilet!

will teach you how to safely dispose of unused medication.

If you take one of the following medications, you will need to return the extra medication to the manufacturer Celgene for disposal:

- Thalidomide (Thalomid)
- Lenalidomide (Revlimid)
- Pomilidomide (Pomalyst)

Celgene will pay for the shipping costs. Call 1-888-423-5436 to set up a delivery of shipping materials.

#### **Frequently Asked Questions**

#### Where can I fill my prescription?

Most oral anticancer medications can only be filled at specialty pharmacies. Your prescription will first be sent to our cancer center's pharmacy to determine where your prescription needs to be filled and help you navigate financial and physical access to the medication.

Our pharmacy will assist in navigating insurance coverage concerns including prior authorization. Also, our pharmacists are very knowledgeable about your medication and can answer any questions you may have.

If you live in Michigan and would like your medication shipped, call our specialty pharmacy for enrollment.

#### Where is the cancer center's pharmacy located?

The outpatient pharmacy is located on Level B1 of the Rogel Cancer Center. It

sells prescription and non-prescription medications.

**Hours:** Monday through Friday from 9:00 a.m. to 5:30

p.m.

**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.

Prior authorization: Is an extra step that some insurance companies require before they decide if they will pay for your medication.

The Rogel Cancer Center pharmacy can help you navigate this process if your insurance company requires it. The Oral Medications Pharmacy service patient financial coordinators can discuss questions about medication costs and billing. They can be reached at (734) 232-6366.

#### How should I take my medication?

Your oral medication must be swallowed whole. Do not chew or crush it. There may be special instructions on how to take your medication: with or without food, separate from other medications, etc. When you get your medication from the pharmacy, the pharmacist will provide counseling. If you have any questions about how to take your medication, talk to your health care team. 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?

Never double the dose of anticancer medication.

If you miss a dose of your medication, 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. **Never double doses**. If you are in a clinical trial, you will receive 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 health care team. There may be ways to dissolve your medications or they may be available in liquid form.

#### What if the medication does not stay down?

If you are unable to keep the medication down due to vomiting, be sure to let your health care team know. In general, you will not need to take another dose. If you have any questions about taking your medication, please call your cancer clinic.

#### Where should I store 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 protection from light.

#### **Very Important!**

- Keep your medication in its original container or a medication box.
- Do not store this medication with other family members' medications. You do not want someone else to take your medication.
- Keep all medications out of reach of children and pets.

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