

Highlights

- Treatment methods for cancer patients have changed a lot over the last several years. Today, some new cancer therapies are taken by mouth, which is called “oral treatment” or “oral therapy.”
- A treatment that includes long-term, ongoing oral therapy is simpler and less complicated than traditional intravenous (IV) therapy.
- Along with the advantage of treating cancer at home, there’s a shift in control and responsibility from the healthcare provider to the patient. This can present new challenges and issues for some patients.
- The term “treatment adherence” has been used more often recently as the number of myeloma patients on oral therapies has increased. Adherence means staying on a set plan or regimen.
- The success of oral treatment adherence depends on good communication between healthcare providers and their patients, education about diseases and treatments, staying well-informed, and establishing social support.
- Providers can help patients address concerns about adherence, manage side effects, set medication reminders, and overcome insurance and treatment cost barriers.
- Patients should be informed that numerous resources are available to help them and their families deal with problems in establishing good medication routines and oral treatment adherence at home.

Introduction

For decades, chemotherapy has been the main treatment for cancer. Chemotherapy is usually given to patients intravenously (IV) through a needle inserted into a vein. Patients needed to travel to a well-controlled and carefully monitored healthcare setting such as a clinic or a hospital to receive treatment. In this setting, doctors are able to monitor their patients to ensure that they are receiving their chemotherapy treatments on time and in the correct dose.

Over the last several years, there have been many changes in how cancer is treated. Many new therapies are now taken by mouth (orally).

- An estimated 25 percent of anticancer therapies in clinical trials have been designed to be taken orally.
- This number is expected to climb to 50 percent or higher in the future.

Oral therapy now plays, and will continue to play, a critical role in treating blood cancers. With doctors increasingly prescribing oral medications, the issue of treatment adherence (taking medication as prescribed) is of great importance. Medications may not work effectively if patients do not take them as prescribed by their doctors.

Oral cancer therapies have clear and obvious benefits for myeloma patients. There are four US Food and Drug Administration (FDA) approved oral medications for the treatment of myeloma. They are:

- Thalidomide (Thalomid®)
- Lenalidomide (Revlimid®)
- Pomalidomide (Pomalyst®)
- Ixazomib (Ninlaro®)

Benefits of oral therapy include:

- **Improved quality of life.** It is simpler, faster, and less painful for a patient to swallow a pill than to receive chemotherapy through an IV.
- **Convenience.** A patient is no longer required to go to a healthcare setting for each dose of treatment. Daily activities, such as a job, maintaining family life, and travel are no longer dictated by frequent visits to the clinic or the doctor’s office.

- **Time.** Infusions of IV drugs can take hours and includes travel to the treatment center. Taking a pill takes minutes.

When a patient gets a prescription for an oral cancer drug, there is a shift in control and responsibility from the healthcare provider to the patient. While IV therapy is administered by a healthcare team, oral cancer therapy requires patients to assume responsibility for taking their own medication and to adhere to the treatment. Patients must be able to understand and follow their treatment plans. The effectiveness of a patient's treatment may be affected by his or her ability to follow the treatment plan.

What is Oral Adherence? The World Health Organization (WHO) defines adherence as the extent to which a person's behavior in taking medication or making lifestyle changes agrees with recommendations from a healthcare provider. Adherence to an oral therapy means that a patient:

- Agrees to the therapy recommendation from the healthcare team
- Fills and picks up the medication from the pharmacy
- Takes the correct medicine
- Takes the correct dose
- Takes medication at the correct time
- Never misses a dose
- Never takes an extra dose
- Does not take a dose with foods, liquids or other medications that are not allowed
- Refills the prescription from the pharmacy as prescribed
- Takes the medication for the prescribed amount of time

Experts state that adherence rates for oral cancer therapy can vary range between 20 and 100 percent. Poor adherence can take a variety of forms, including missing doses or taking extra doses, taking an incorrect dose (too much or too little), taking the medication at the wrong time of day, or stopping therapy too soon.

Poor adherence can result in the following:

- Drug resistance, which is a reduction in how well a drug will work in curing or controlling a disease or condition
- Poor response to therapy
- Progression of the disease
- Increased doctor visits, lab tests, and hospitalizations
- Death

Barriers to Treatment Adherence

WHO has stated that adherence to oral medications is the single most important changeable factor affecting treatment outcomes. Poor adherence can make even the best treatments not effective. Improving patient adherence, on the other hand, is more likely to improve treatment outcomes. The following are barriers that make it difficult for patients to adhere to treatment.

- **Lack of insurance/cost of medication.** Some patients have no health insurance or insurance with high costs. Many patients cannot afford the cost of their medication. Some patients may take less than the prescribed dose to make their medication last longer or go without treatment altogether.
- **Effects of the illness.** Patients may feel too sick or too stressed to understand and follow their treatment plans. Some side effects of myeloma, such as debilitating pain and fatigue, may complicate a patient's ability to adhere to a treatment plan.
- **Complexity of treatment plan.** Some patients have complex treatment regimens that are difficult to follow. Additionally, doctors often prescribe myeloma patients medications to manage the symptoms of their disease and/or the side effects of treatment. These medications are often prescribed PRN ("as needed") and should only be taken when needed for a specific complaint such as pain or nausea. The combination of PRN medications and scheduled oral cancer therapy can cause patients to feel both overwhelmed and confused, resulting in either taking too little or too much medication.
- **Lack of social support.** Some patients do not have assistance at home to help them take their medications when they feel too ill to manage their own care.
- **Poor communication between patients and healthcare providers.** Patients may not have a good understanding of why they need to take their medication or the importance of adhering to a treatment plan. Patients may feel uncomfortable communicating with their healthcare providers to clarify treatment issues or discuss side effects.
- **Medication side effects.** Some patients experience side effects from their medication. As a result patients skip doses or completely stop taking the medication without talking to their doctors.
- **Patients skip doses.** Patients who feel well and do not have symptoms of the disease may either forget to take their medication or may believe that they can skip doses

or stop taking their medication altogether. Patients may not understand the nature of a chronic disease and the need for adherence to their treatment plan to control their disease. Also, some patients who do not see an immediate improvement in their health may assume that the medications are not effective and stop taking them. That is not always correct. Some medications take a longer time to work.

- **Patients' overuse of medication.** Some patients increase the dose of their medication with the mistaken idea that "more is better" leading to increased toxicity and side effects.

Other barriers include limited access to a pharmacy, length of treatment, cognitive impairment (trouble remembering or concentrating) and other medical issues.

Solutions and Strategies for Treatment Adherence

It is important for patients to overcome any obstacles that may prevent them from following their treatment plans. Here are some suggestions.

Patient/Doctor Communications. Patient education is essential to ensure that oral treatments are taken correctly. Healthcare providers can help patients become well informed, educated, and proactive about their treatment plans. Doctors, nurses, social workers, and patients should work together to address any concerns that may affect treatment adherence at home. Resources are available to help patients and their families create good medication routines.

Patients should not hesitate to reach out to their healthcare providers if they:

- Have any questions
- Have unexpected side effects
- Think they may have incorrectly taken their medication
 - Missed doses
 - Taken too much or too little medication
 - Stopped taking the medication altogether

Talk with your healthcare team:

- Ask questions about your treatment.
- Prepare a written list of questions and concerns prior to your appointments.
 - What are the benefits of my treatment?
 - What is the dose?

- When do I take my medication, and do I need to take it with or without food?
- What is the dose schedule? How often do I take the medication and at what time?
- What if I miss a dose?
- How long will I need to continue to take this medication?
- When can I expect the treatment to have an effect?
- What potential side effects do I need to report between visits and what can wait until my next appointment?
- What is the plan for follow-up appointments, monitoring, and testing? If I can't afford the medication, is there financial assistance available or another medication I can take?

Bring a family member, friend, or caregiver to your appointments and ask that person to take notes and write down the doctor's answers to your questions.

Doctors and nurses must be able to discuss all aspects of treatment thoroughly with their patients. Consider getting a second opinion from another doctor if you are experiencing communication problems with your healthcare team.

Managing Side Effects. If side effects are managed, patients will be more likely to continue to take their medication. Side effects from oral treatments are similar to those of IV treatments. Patients need to know what potential side effects to expect and whom to call for healthcare support. Most symptoms can be managed at home but some symptoms can worsen quickly. Healthcare providers need to instruct patients on what to do in these situations.

Talk with your healthcare team.

- Confirm how, when and whom to contact with questions or concerns that arise between appointments (get a name, number, and times to call).
- Be honest with the doctor about side effects, concerns and goals with your medications.
- Discuss treatment options for nausea (upset stomach), vomiting, appetite changes, sleep disturbances, and other, more common side effects of treatment.

See the LLS booklet *Understanding Side Effects of Drug Therapy*, which provides questions to ask your healthcare team, guidance on what to expect during treatment, and information on common side effects and their management. Visit www.LLS.org/booklets.

Insurance/Cost Barriers. Paying for healthcare and treatment-related expenses is a major concern for many people living with myeloma and other types of blood cancers. Oral cancer treatments can be costly and present an obstacle for many myeloma patients. This ultimately threatens treatment adherence and disease outcome.

There are health insurance options and resources to help patients and their families cope with the financial aspects of cancer care and treatment costs.

Know your coverage. It is not uncommon for patients to discover that they are underinsured when diagnosed with cancer. Patients need to know:

- What is covered by their insurance
- How to protect their benefits
- What resources are available to deal with gaps in insurance coverage
- What out-of-pocket expenses to expect

If an insurance company denies coverage for a recommended treatment or medication, a patient may be able to get the decision overturned by appealing the insurance company's denial of the claim. If the company rejects the appeal, the patient can seek an external appeals process with the help of a state insurance agency, a social worker, or an attorney. Doctors can refer patients to the appropriate place or person who can help. See the LLS booklet *Cancer and Your Finances* for more information. Visit www.LLS.org/booklets.

Talk About Insurance and Financial Issues. While you may feel uncomfortable sharing personal financial information with your doctor, it is important to discuss this honestly, especially if you may have trouble paying for medication. Ask questions about the cost of treatment and ask if there are other options. Limiting stress and making sure you can get your prescriptions and adhere to your treatment plan is essential to your treatment outcome.

- Talk about payment options with your healthcare team or the financial services department.
- Talk to your doctor about the cost of your oral medication.
- Ask about prescription assistance programs.
- Ask to be referred to a social worker, patient navigator, or case manager.
- Ask your insurance company if your medication is covered on their "approved" drug list (this is usually called a "formulary"). If the medication is not on your

insurance's formulary, ask your doctor if there is another equivalent drug that he or she can prescribe as an alternative.

- Ask your doctor if the medication you are taking is available in a generic form, which is often less expensive.

Seek Financial Assistance. There are a number of ways to find financial assistance for treatment-related expenses, including prescription costs and transportation costs. Work closely with the financial services department at your treatment center to obtain the highest reimbursement allowed by your insurance company.

LLS Financial Assistance. LLS has resources for patients who need financial assistance.

- The LLS Co-Pay Assistance Program helps eligible patients with certain blood cancer diagnoses pay treatment co-pays and other insurance-related expenses. For more information call (877) 557-2672 or visit www.LLS.org/copay to submit an application.
- LLS is part of the Cancer Financial Assistance Coalition (C-FAC), which encourages communication and collaboration among its member organizations who have joined forces to address the needs of cancer patients. This group educates patients and providers about resources and advocates for cancer patients facing the financial burdens of cancer care. To use this resource visit www.cancerfac.org.

Contact our LLS Information Specialists at (800) 955-4572 for information about financial assistance or visit www.LLS.org/finances. You may also visit www.LLS.org/resourcedirectory to find additional organizations that can help.

Help with Prescription Drugs. Health insurance plans may not cover all the costs of your treatment, and even patients who have prescription drug plans may find that their plan's formulary does not cover certain drugs that they need. There are, however, a number of resources for assistance in paying for prescription drugs.

People without adequate insurance to cover the cost of prescription medications for cancer treatment may want to explore these options.

- Major pharmaceutical manufacturers often provide patient assistance or prescription assistance programs. These pharmaceutical companies may be able to help by providing uninsured and underinsured (or even insured) patients with free or reduced-cost medications. Contact one of our Information Specialists at (800) 955-4572 to find out if the drug company that makes your prescription has this type of program.

- The National Association of Counties (www.naco.org) and various state programs also provide ways to cut drug costs.
- Co-pay assistance programs and foundations help pay for prescription drug co-pay obligations or insurance plan premiums.

Setting Reminders. When patients take their oral medications at home, their healthcare team is not supervising each dose. Patients are responsible for their own, often complex, therapy regimens. Patients should consider using different methods, or reminders, to help adhere to their treatment plan. Here are some options to try.

- **A medication list.** Create a list of all medications, both prescription and non-prescription, along with the prescribing doctor's name and contact information. Keep a copy for yourself and review it together with your doctor.
- **Pharmacy resources.** Ask a pharmacist about any “compliance tools” that may be available to assist in organizing medications. Pharmacies also provide written materials about each drug prescribed, its potential side effects and its interactions (patients should be sure to read this information). Dosing information is also usually printed on the label on the bottle or box of the medication. Other information from the doctor and pharmacy can be stored together in a folder to refer to as needed.
- **Pill boxes.** Pill boxes can be used as a visual cue to help remind patients which medications to take each day. Organizing the week's pills by day may also help plan for and anticipate when to refill prescriptions. Use one pill box for “required” or “scheduled” medications and put PRN (as needed) medications in another box. Only take the PRN medications as needed. Do not take more than the suggested amount per day.
- **Calendars/Diaries/Checklists.** Calendars, diaries, and checklists are tools that can help patients track their medications. They can also be used as reminders to order refills and to help patients anticipate adequate supply for travel or vacations. LLS has developed a free adherence calendar. Please visit www.LLS.org/MyelomaOralDrugs or call an Information Specialist to order a copy.
- **Mobile phones/Alarms.** Mobile phone alarms and text reminders can also be used to alert patients to take their medications. Some patients also use alarm clocks or kitchen timers to serve as reminders. Various alarms can also prompt patients to eat before their scheduled medication time.

- **Electronic pill bottles.** Newer technology has introduced the computerized pillbox, a device that manages up to a month's supply of drugs and reminds patients when a dose is due. Cost is a factor as these electronic devices are expensive, and it may not be convenient to carry around a month's supply of medication for patients who are working or traveling. However, it may be worth both the cost and the inconvenience if a patient is busy and tends to forget to take the medication as prescribed.
- **Smartphone medication-reminder apps.** Patients can download applications to their mobile phones to help them adhere to their treatment plan. These apps assist patients in setting up reminders to take their medication. Visit the App Store on iTunes (iPhone, iPod, iPad) or the Google Play Store on Android devices to find complete information on medication reminder apps. Use “medication reminder” as your search term.

Oral treatment adherence can be improved through the use of many of the reminder methods discussed above. Patients should consider which methods are easiest and most effective for their own individual needs. Using more than one type of reminder may be a good idea, too.

Establishing Social Support

Connecting with other myeloma patients who are going through the same experiences or have “been through it” can be helpful to many people as they gather information and seek support. Patients can participate in local support groups, the LLS Community, discussion boards, online chats, and other peer-to-peer support networks as additional resources to find ways to adhere to a treatment plan. See *We're Here to Help* on page 6 for LLS resources.

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We're Here to Help

LLS is the world's largest voluntary health organization dedicated to funding blood cancer research, education, and patient services. LLS has chapters throughout the United States and in Canada. To find the chapter nearest to you, visit our website at www.LLS.org/chapterfind or contact:

The Leukemia & Lymphoma Society

3 International Drive, Suite 200
Rye Brook, NY 10573
(800) 955-4572
Email: infocenter@LLS.org.

LLS offers free information and services for patients and families affected by blood cancers. The following is a list of various resources available to you. Use this information to learn more, to ask questions, and to make the most of your healthcare team's knowledge and skills.

Consult with an Information Specialist. Information Specialists are master's level oncology social workers, nurses and health educators. They offer up-to-date disease and treatment information. Language services are available. For more information, please:

- Call: (800) 955-4572 (M-F, 9 a.m. to 9 p.m. EST)
- Email: infocenter@LLS.org
- Live chat: www.LLS.org
- Visit: www.LLS.org/information specialists.

Free Information Booklets. LLS offers free education and support publications that can either be read online or downloaded. Free print versions can be ordered. For more information, please visit www.LLS.org/booklets.

Información en Español (LLS information in Spanish).

For more information, please visit www.LLS.org/espanol.

Telephone/Web/Video Education Programs. LLS offers free telephone/web education programs and videos for patients, caregivers, and healthcare professionals. For more information, please visit www.LLS.org/programs, www.LLS.org/educationvideos and www.LLS.org/professionaled.

LLS Community. LLS Community is an online social network and registry for patients, caregivers, and supporters of those with blood cancer. It is a place to ask questions, get informed, share your experience, and connect with others. To join, visit CommunityView.LLS.org.

Online Blood Cancer Discussion Boards and Chats.

Online discussion boards and moderated online chats can provide support and help cancer patients reach out to and share information with others in similar circumstances. For more information, please visit www.LLS.org/chat or www.LLS.org/discussionboard.

LLS Chapters. LLS offers community support and services in the United States and Canada including the *Patti Robinson Kaufmann First Connection Program* (a peer-to-peer support program), in-person support groups, blood cancer conferences, and other helpful resources.

- Call: (800) 955-4572
- Visit: www.LLS.org/chapterfind.

Clinical Trials (Research Studies). New treatments for patients are ongoing. LLS Information Specialists can help conduct clinical trial searches. To learn about clinical trials and how to access them, please:

- Call: (800) 955-4572
- Visit: www.LLS.org/clinicaltrials.

Advocacy. LLS Office of Public Policy (OPP) engages volunteers in advocating for policies and laws that encourage the development of new treatments and improve access to quality medical care. For more information, please:

- Call: (800) 955-4572
- Visit: www.LLS.org/advocacy.

Resources

American Cancer Society (ACS)

www.cancer.org
(800) 227-2345

ACS's Road to Recovery program has volunteer drivers who transport patients to and from doctor's appointments.

CANCERCare

www.cancercare.org
(800) 813-HOPE or (800) 813-4673

Provides free services, support, information and practical help to anyone affected by cancer, including individuals with cancer. The organization offers guidance on financial issues and gives financial assistance to help with some types of costs.

Foundation for Health Coverage Education (FHCE)

www.coverageforall.org

(800) 234-1317

FHCE educates individuals about free or low-cost insurance in the state they live in. FHCE has developed a customized matrix for every state that details insurance opportunities, and has provided this matrix to each state's insurance professionals. The foundation offers downloadable information about each state's public and private healthcare options and locates resources and applications for health coverage programs by state.

GoodRx

goodrx.com

GoodRx provides prices and discounts for prescription drugs at local and mail-order pharmacies in the United States. They also offer information about drug side effects, prescription assistance programs, and the availability of generics.

Healthcare.gov

www.healthcare.gov

This government-maintained website includes information about the healthcare changes happening as a result of the Patient Protection and Affordable Care Act of 2010. It provides information about finding insurance options in your state; offers comparisons of care quality in different hospitals, home healthcare agencies and nursing homes; provides an overview of the healthcare law; and provides healthcare option information for different groups of people, e.g., families with children, individuals, people with disabilities, seniors, young adults and employers.

HealthWell Foundation

www.healthwellfoundation.org

(800) 675-8416

This foundation provides financial assistance to cover prescription drug co-payments, deductibles, and health insurance premiums for patients with chronic or life-altering illnesses.

NeedyMeds

www.needymeds.com

NeedyMeds is a central source of information for people who cannot afford medicine or other healthcare expenses. Programs such as assistance for specific diseases and conditions, application assistance, state-sponsored programs and Medicaid sites are listed.

Partnership for Prescription Assistance (PPA)

www.pparx.org

(888) 4PPA-NOW or (888) 477-2669

PPA brings together pharmaceutical companies, doctors, other healthcare providers, and patient advocacy and community groups to help eligible patients (i.e., those who lack prescription drug coverage) get needed medicines for little or no cost. The partnership offers access to many public and private patient assistance programs, including programs offered by pharmaceutical companies.

Patient Access Network Foundation (PANF)

www.panfoundation.org

(866) 316-7263

PANF provides co-payment, deductible or co-insurance assistance.

Patient Advocate Foundation (PAF)

www.patientadvocate.org

(800) 532-5274

PAF draws upon the expertise of case managers, attorneys, and doctors who work with patients and their insurers, employers, and creditors to resolve insurance problems, job discrimination issues and debt crisis matters. The PAF website features a comprehensive state-by-state directory of financial resources for housing, utilities, food, transportation, medical treatment and children's needs. On the PAF website you can find the National Underinsured Resource Directory, which is intended to help underinsured individuals and families locate valuable resources and seek alternative coverage options or methods for better reimbursement (www.patientadvocate.org/help4u.php). Also available on the website under "PAF Publications," is a step-by-step guide to appealing a denied insurance claim, *Your Guide to the Appeals Process*. The PAF Co-Pay Relief Program offers financial assistance for qualified persons. Call (866) 512-3861 or visit www.copays.org for more information.

RxHope

www.rxhope.com

(877) 267-0517

RxHope helps patients determine if they are eligible for a pharmaceutical company's patient assistance program and then helps guide patients through this process, which may involve more than one pharmaceutical company.

State Health Insurance Assistance Program (SHIP)

www.shiptalk.org

SHIP can answer questions about Medigap policies, long-term care insurance, Medicare health plan choices and Medicare rights and protections. They can also help with filing an appeal.

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