

No. 28 in a series providing the latest information for patients, caregivers and healthcare professionals

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.”
- Along with the advantage of treating cancer at home, there is 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 cancer 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.
- There are many resources available to help patients 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 travel to a clinic or a hospital to receive treatment. In these settings, 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).

- There are over 50 oral anti-cancer medications approved by the United States Food and Drug Administration (FDA).
- An estimated 25 to 30 percent of anti-cancer therapies in clinical trials have been designed to be taken orally.

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

Visit www.LLS.org/drugs to learn more about specific drugs, including method of administration and side effects.

Benefits of oral therapy

- Taking a pill takes minutes; infusions of IV drugs can take hours.
- It is less painful to swallow a pill than to receive IV drug therapy.
- Travel to a clinic or hospital is not required for each dose of treatment.
- Daily activities such as work, family life and travel are no longer interrupted by frequent visits to the clinic or the doctor's office.

With an oral cancer drug, control and responsibility shifts from the healthcare provider to the patient. Intravenous

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(IV) therapy is given by the healthcare team. When a patient gets a prescription for an oral cancer drug, the patient is responsible for taking the medication correctly. Patients must be able to understand and follow their treatment plans. If the patient does not follow the oral medication regimen exactly as prescribed, the treatment may not work as well.

In addition to drugs used to treat cancer, a patient's oral medications may include

- Pain medications
- Anti-nausea medications
- Other medications to manage side effects
- Other medications to manage medical conditions not related to the cancer

These medications should also be taken as prescribed in order to be most effective. Make sure all your providers have a full list of all the medications, vitamins and supplements that you are taking.

What is Oral Adherence? The World Health Organization (WHO) defines adherence as the extent to which a person's behavior in taking medication, following a diet, and/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 or receives it by mail 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
- Takes the medication for the correct amount of time

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 decrease in how well a drug will work in curing or controlling the disease
- Poor response to therapy
- The disease getting worse
- More doctor visits, lab tests, and hospitalizations
- Death

Barriers to Treatment Adherence

The World Health Organization (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 likely to improve treatment outcomes. The following barriers 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, some may go without treatment altogether.
- **Side effects or symptoms of the illness.** Patients may feel too sick or too stressed to understand and follow their treatment plans. Some side effects, such as debilitating pain and fatigue, may make it hard for a patient 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 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, and they may take either too little or too much medication.
- **Lack of social support.** Some patients do not have someone 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. Remember—all of your questions are important. Do not feel embarrassed to ask members of your healthcare team questions. You deserve to have your concerns addressed.
- **Medication side effects.** Some patients experience side effects from their medication. As a result patients may 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 skip doses or stop taking their medication altogether. However, the medication needs to be taken for the full amount of time prescribed to be effective. The patient may feel well because the medication is working. Also, some patients do not see an immediate improvement in their health and may assume that the medication is not effective and stop taking it. Some medications take a longer time to work. Your healthcare team will help determine if your medication is working. Do not stop taking a medication without talking to your healthcare team first.
- **Patients' overuse of medication.** Some patients increase the dose of their medication with the mistaken idea that “more is better” leading to more side effects or complications.

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

Solutions and Strategies for Treatment Adherence

If you are prescribed an oral treatment, it is important to overcome any barriers that may prevent you from following your treatment plan. Here are some suggestions to help you cope with these problems.

Patient/Doctor Communications. Education is essential to ensure that oral treatments are taken correctly. The members of your healthcare team will work with you to explain how to take your medication and to address

any concerns that may affect your ability to take the medication. Resources are available to help you and/or your caregiver create a good medication routine.

Do not hesitate to reach out to your healthcare team if you

- Have any questions
- Have unexpected side effects
 - Ask your provider whom you should call if you experience symptoms or side effects after office hours or on weekends.
- Think you may have incorrectly taken your medication
 - Missed doses
 - Taken either too much or too little medication
 - Stopped taking the medication altogether

Talk with the members of 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?
 - What is the dose schedule? How often do I take the medication and at what time?
 - Do I need to take the medication either with or without food?
 - What do I do 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?
 - Will this medication interact with other prescription or over-the-counter medications, vitamins or supplements?
 - 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. You can also ask the doctor if you can record the conversation so that you can listen to it again later. Most smart phones have a recording feature.

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

Visit www.LLS.org/FamilyWorkbook and view *Caring for Your Child During Treatment for information on helping children to take medication.*

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. Most symptoms can be managed at home but some symptoms can worsen quickly.

Talk with your healthcare team.

- Ask the members of your healthcare team what possible side effects to expect.
- 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 common side effects of treatment.

Visit www.LLS.org/booklets (filter by Side Effect Management) to view the Side-Effect Management series for information on common side effects and their management.

Insurance/Cost Barriers. Paying for healthcare and treatment is a major concern for many people living with blood cancer. Oral cancer treatments can be costly. This can make it more difficult for some patients to adhere to their treatment plan.

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 who have been diagnosed with cancer to find they are underinsured. This means that the insurance policy may not cover certain services or the patient may still have to pay high out-of-pocket costs.

You need to know

- What is covered by your insurance
- How to protect your 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, you may be able to get the decision overturned by appealing the insurance company's denial of the claim. If the company rejects the appeal, you can seek an external appeals process with the help of a state insurance agency, a social worker, or an attorney. Your healthcare team can refer you to the appropriate place or person who can help. **Visit www.LLS.org/booklets to view *Cancer and Your Finances* for more information.**

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. Making sure you can get your medications 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 an equivalent drug that he or she can prescribe instead.
- 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.

- LLS offers financial support including insurance premium and medication co-pay assistance, as well as travel and other needs, to eligible individuals with blood cancer. Contact our LLS Information Specialists at (800) 955-4572 or visit www.LLS.org/finances for information about financial assistance.
- 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.

You may also visit www.LLS.org/ResourceDirectory to find more organizations that can help.

Help with Prescription Drugs. Health insurance plans may not cover all the costs of your treatment. Even if you have a prescription drug plan, you may find that the drug is not on the plan's formulary (list of covered drugs). There are, however, a number of resources for assistance in paying for prescription drugs.

- 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 you take oral medications at home, your healthcare team will not supervise each dose. You are responsible for following your treatment regimen. This regimen may be complex. You can use different methods or reminders to help you adhere to your treatment plan.

- **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 your 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. Many pharmacies also send alerts by text, email or phone to remind you when a refill of your medication is ready to be picked up.
- **Daily habits.** Find activities you do every day at the same time you need to take your medication, such as brushing your teeth or feeding your pets. Use these activities to help remind yourself to take your medications. Taking medications as prescribed is a very important part of self care. Take your medication when you meditate, journal, go for a walk, or do another form of daily self care.
- **Pill boxes.** Pill boxes can be used as a visual cue to help remind you which medications to take each day. Organizing the week's pills by day may also help you to 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 and/or checklists.** Calendars, diaries, and checklists are tools that can help you track your medications. They can also be used as reminders to order refills and to help patients anticipate adequate supply for travel or vacations. LLS has a free adherence calendar. Please visit www.LLS.org/booklets or call an Information Specialist to order *A Medication Resource for Blood Cancer Patients*.

- **Mobile phone alarms and/or other 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. These electronic devices can be 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 you are busy and tend to forget to take the medication.
- **Caregivers and family.** Ask your caregiver to remind you to take your medications. If your spouse, partner or someone else living in your home takes medications on the same schedule, take your medications together so that you can remind each other and stay on track.

Using medication reminders and strategies that will help you to follow your medication regimen can greatly improve oral treatment adherence. Consider which methods are easiest and most effective and the best fit for your individual needs. Using more than one type of reminder may be a good idea, too.

Establishing Social Support

Connecting with other patients who are going through the same experiences as you or have "been through it" can be helpful to many people as they gather information and seek support. You 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* for LLS resources.

Acknowledgement

The Leukemia & Lymphoma Society appreciates the review of this material by

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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

Contact an Information Specialist at (800) 955-4572
Email: infocenter@LLS.org

LLS offers free information and services for patients and families touched by blood cancers. The following entries list various resources available to you. Use this information to learn more, to ask questions, and to make the most of your healthcare team.

Consult with an Information Specialist. Information Specialists are master's level oncology social workers, nurses and health educators. They offer up-to-date disease, treatment and support information. Language services (interpreting and translation) are available. Please contact our Information Specialists or visit our website for more information.

- Call: (800) 955-4572 (Monday through Friday, from 9 am to 9 pm ET)
- Email: infocenter@LLS.org
- Live chat: www.LLS.org/InformationSpecialists
- Visit: www.LLS.org/InformationSpecialists

Clinical Trials Support Center (CTSC). Research is ongoing to develop new treatment options for patients. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. When appropriate, patients and caregivers can work with Clinical Trial Nurse Navigators who will help find clinical trials and personally assist them throughout the entire clinical trial process. Visit www.LLS.org/CTSC for more information.

Free Information Booklets. LLS offers free education and support booklets that can either be read online or ordered. Please visit www.LLS.org/booklets for more information.

LLS Health Manager™ App. This free mobile app helps you track side effects, medication, food and hydration, questions for your doctor, and more. Also available in Spanish and French Canadian. Visit www.LLS.org/HealthManager to download for free.

Financial Assistance. LLS offers financial support including insurance premium and medication co-pay assistance, as well as travel and other needs, to eligible individuals with blood cancer. For more information, please

- Call: (877) 557-2672
- Visit: www.LLS.org/finances

Información en Español. (LLS information in Spanish). Please visit www.LLS.org/espanol for more information.

Telephone/Web Education Programs. LLS offers free telephone/Web and video education programs for patients, caregivers and healthcare professionals. Please visit www.LLS.org/programs for more information.

LLS Community. The one-stop virtual meeting place for talking with other patients and receiving the latest blood cancer resources and information. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. Visit www.LLS.org/community to join.

One-on-One Nutrition Consultations. Access free one-on-one nutrition consultations provided by a registered dietitian who has experience in oncology nutrition. Dietitians assist callers with information about healthy eating strategies, side effect management and survivorship nutrition. They also provide additional nutrition resources. Please visit www.LLS.org/nutrition to schedule a consultation or for more information.

Weekly Online Chats. Moderated online chats can provide support and help cancer patients to reach out and share information. Please visit www.LLS.org/chat for more information.

Podcast. *The Bloodline with LLS* is here to remind you that after a diagnosis comes hope. Listen in as patients, caregivers, advocates, doctors and other healthcare professionals discuss diagnosis, treatment options, quality-of-life concerns, treatment side effects, doctor-patient communication and other important survivorship topics. Visit www.LLS.org/TheBloodline for more information and to subscribe.

LLS Chapters. LLS offers support and services in the United States and Canada including the *Patti Robinson Kaufmann First Connection Program* (a peer-to-peer support program), local support groups, and other great resources. For more information about these programs or to contact your chapter, please

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

Other Helpful Organizations. LLS offers an extensive list of resources for patients and families. There are resources that provide help with financial assistance, counseling, transportation, patient care and other needs. Please visit www.LLS.org/ResourceDirectory for more information.

Advocacy. The 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

Information for Veterans. Veterans with HCL who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veterans Affairs. For more information please

- Call: the VA (800) 749-8387
- Visit: www.publichealth.va.gov/exposures/agentorange

World Trade Center (WTC) Survivors. People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be eligible for help from the World Trade Center (WTC) Health Program. People eligible for help include

- Responders
- Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
- Survivors who were in the NYC disaster area, lived, worked or were in school in the area
- Responders to the Pentagon and the Shanksville, PA crashes

For more information, please

- Call: WTC Health Program at (888) 982-4748
- Visit: www.cdc.gov/wtc/faq.html

People Suffering from Depression. Treating depression has benefits for cancer patients. Seek medical advice if your mood does not improve over time—for example, if you feel depressed every day for a 2-week period. For more information, please

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at www.nimh.nih.gov and enter “depression” in the search box

Resources

CancerCare

www.cancercares.org

(800) 813-HOPE or (800) 813-4673

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

GoodRx

www.goodrx.com

GoodRx provides prices and discounts for prescription drugs at local and mail-order pharmacies in the United States. It also offers 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, eg, 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.

Patient Access Network Foundation (PANF)

www.panfoundation.org

(866) 316-7263

This foundation provides co-payment, deductible or co-insurance assistance.

Patient Advocate Foundation (PAF)

www.patientadvocate.org

(800) 532-5274

This foundation provides direct services to patients with chronic, life threatening and debilitating diseases to help access care and treatment recommended by their doctor. On the website under “Connect with Services” see “Services and Programs” to learn more. The PAF Co-Pay Relief Program offers financial assistance for qualified persons. Call (866) 512-3861 or visit www.copays.org for more information.

The Pharmaceutical Research and Manufacturers of America's (PhRMA's) Medicine Assistance Tool (MAT)

www.medicineassistancetool.org

The Medicine Assistance Tool (MAT) is a search engine designed to help patients, caregivers and health care providers learn more about the resources available through the various biopharmaceutical industry programs. The Medicine Assistance Tool is not its own patient assistance program, but rather a search engine for many of the patient assistance resources that the biopharmaceutical industry offers.

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.shiptacenter.org

(877) 839-2675

This program provides local, in-depth, and objective insurance counseling and assistance to Medicare-eligible individuals, their families, and caregivers.

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