

Summer 2016

## Oral Therapies in Myeloma Medication Adherence

In a new patient education **video** titled, “Oral Therapies in Myeloma: Medication Adherence,” physician Kenneth Shain, nurse practitioner Leslie Lauersdorf, and nurse Beth Finley-Oliver of the Moffitt Cancer Center in Tampa, FL discuss myeloma treatment.

Dr. Shain explains that five new drugs have been approved for myeloma treatment just within the past three years. Three of these treatments – pomalidomide (Pomalyst®), panobinostat (Farydak®), and ixazomib (Ninlaro®) – are given as oral therapies (pills taken by mouth) instead of as injections or infusions. More oral treatments are expected to be developed in the future, making this an increasingly important option in cancer treatment.

Oral therapies for myeloma have many benefits, including freedom and mobility for patients and their families. Replacing infusions and injections with oral medications gives patients the ability to travel outside the realm of a hospital, infusion center, or doctor’s office.

Along with oral treatments for myeloma, the issue of medication adherence has become an important concern. The World Health Organization 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.” In other words, adherence to a medication regimen means that patients are expected to:

- Agree to the therapy recommendation from the healthcare team
- Take the correct medicine
- Take the correct dose



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- Take medication in the correct quantity
- Take medication at the correct time
- Never miss a dose
- Never take an extra dose
- Take medication for the prescribed amount of time

Not taking pills as prescribed can result in drug resistance (reduced effectiveness of the drug in curing or controlling the disease), low response to therapy, disease progression, increased doctor visits, lab tests, and hospitalizations.

A potential drawback of oral medications is fewer appointments with the healthcare team since patients are not getting infusions or injections, and therefore, potentially less opportunity to discuss side effects they might be having. The healthcare professionals in this video urge patients to call their nurse or doctor right away if they’re having any problems that could affect adherence, including trouble remembering to take their pills, experiencing negative side effects, or difficulty getting the medication and/or affording the medications. The patient, the doctor, the nurse, and the social worker are an important team and open communication is key to supporting the patient.

## PATIENT RESOURCES

View our new **video** on oral therapies in myeloma, and access the **calendar**, **fact sheet**, and other oral therapy resources, **visit** [www.LLS.org/MyelomaOralDrugs](http://www.LLS.org/MyelomaOralDrugs)

View other disease-specific education and support videos, **visit** [www.LLS.org/educationvideos](http://www.LLS.org/educationvideos)

Order or download myeloma booklets and other disease-specific and support information, **visit** [www.LLS.org/booklets](http://www.LLS.org/booklets)

Access upcoming and past telephone/web programs, transcripts, program slides and audio replays, **visit** [www.LLS.org/programs](http://www.LLS.org/programs)

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## Additional Support

### Information Specialists

– available to answer your questions  
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Call **1-800-955-4572** or email  
[infocenter@LLS.org](mailto:infocenter@LLS.org)

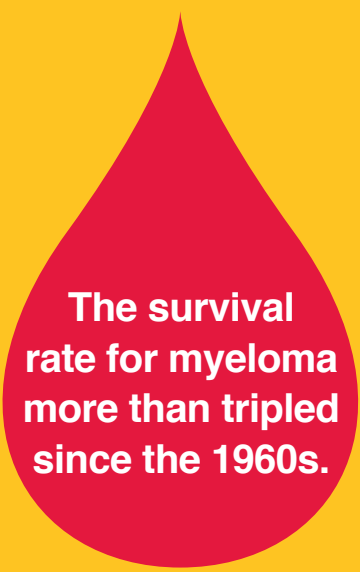
**Myeloma Blog** – discuss key issues for  
myeloma survivors.  
Visit [www.LLS.org/myelomablog](http://www.LLS.org/myelomablog)

**Patti Robinson Kaufmann First  
Connection Program** – connect with a  
trained volunteer who has been affected  
by myeloma to share similar experiences.  
Visit [www.LLS.org/firstconnection](http://www.LLS.org/firstconnection)

**Myeloma Chat** – online forum to share  
experiences and chat with others.  
Facilitated by an oncology social worker  
and held every Tuesday, 8 PM to 10 PM ET.  
Visit [www.LLS.org/chat](http://www.LLS.org/chat)

**LLS Community** – interactive, online  
patient and caregiver social network and  
registry.  
Visit [communityview.LLS.org](http://communityview.LLS.org)

**Myeloma Links** – monthly e-newsletter  
reporting on disease news, clinical trials,  
and support for living with myeloma.  
Visit [www.LLS.org/signup](http://www.LLS.org/signup)



The survival  
rate for myeloma  
more than tripled  
since the 1960s.

## CO-PAY ASSISTANCE

The LLS **Co-Pay Assistance Program**  
helps you pay your insurance premiums  
and meet co-pay obligations. For more  
information visit [www.LLS.org/copay](http://www.LLS.org/copay) or  
call **1-877-557-2672**.

## Patient Tips on Medication Adherence

Myeloma patients know how important it is to stick to the correct regimen when taking oral medications. In a new video produced by The Leukemia & Lymphoma Society (LLS), two myeloma survivors, Ken and Henry, discuss the challenges of taking oral medications over long periods of time.



With oral therapy comes a shift in responsibility from the healthcare provider to the patient. As Ken explained, “It’s my health on the line!” However, putting patients in charge of their own medications can present challenges, especially for complicated therapy regimens. Patients may occasionally forget to take their pills. For this reason, everyone in this video recommends that patients find and use reminder systems that work for them.

Some patients use simple strategies, like keeping their medicine bottles next to their toothbrush, so they just take a pill each time they brush their teeth. Ken also describes the technique of turning the pill bottle upside down after he has taken it to indicate that he has already had that pill for the day. For patients with fairly simple dosing schedules, such as once-per-day or twice-per-day regimens, these types of approaches may be an adequate reminder system.

Another technique many patients find helpful is a plastic weekly pill container. Henry uses one containing 7 separate compartments labeled with the days of the week. Once a week, he fills all 7 compartments with the correct pills for each day, and the container allows him to see at a glance whether he has taken that day’s doses or not. These types of pill containers can usually be found in drugstores or retail stores that contain a pharmacy.



For a more high-tech approach, some patients find it helpful to use electronic devices as reminder systems. Ms. Lauersdorf often suggests that patients set a daily alarm on their mobile phone to remind them to take their pills at the same time each day. Patients can set as many alarms as they need for multiple medications. For patients with smartphones, several applications (apps) are available at no cost designed specifically to track medications and remind users when to take them. Once information about timing and dosing of each medication is entered into the app, the system alerts you with a message and a sound to remind you of each dose. Some apps have additional features, such as showing images of what each pill looks like, and many also remind patients when to refill their prescriptions or when their next doctor appointment is scheduled.

Still others prefer to keep a written log of which pills they have taken and at what times. This approach is used in many clinical trials, as participants are often required to keep track of their medication adherence in a “diary” or written calendar. Diaries allow the clinical trial coordinator to see how the patient is taking their medication and to go over the schedule with the patient if necessary. The LLS has also created an **oral adherence calendar** that serves as a resource for patients to record when and what medications to take and to jot down questions for their next doctor visit.

Ken also notes that if patients are having trouble remembering to take their pills at the right time, they should not hesitate to ask family members or caregivers for help keeping track of the medication schedule and administering pills when needed.

Most importantly, patients taking oral medications for myeloma need to reach out to their doctor, nurse, or another member of the care team if they have taken their medication incorrectly, missed doses, taken too much or too little medication, or stopped taking the medication altogether. At every office visit, patients should also discuss with their healthcare team if they are having any difficulty getting their medication from their pharmacy, affording their pills, if side effects are making it difficult to tolerate their medications, or if they are having any other problems sticking to the prescribed regimen.

Henry says he knows medication adherence is of the utmost importance because, as he puts it, “I understand that this is my lifeline, and it’s for my benefit.”

**For more suggestions or ideas about ways to help you adhere to your prescribed oral myeloma medication regimen, or for additional information and support, patients are encouraged to contact an Information Specialist at The Leukemia & Lymphoma Society at 1-800-955-4572 or [infocenter@LLS.org](mailto:infocenter@LLS.org).**

Clinical trials are careful studies done by doctors to test new drugs or treatments, or new uses for approved drugs or treatments. The goal of clinical trials for blood cancers is to improve treatment and quality of life and to find cures.