

take one **FREE**



WHERE
INFORMATION
EQUALS HOPE

Third Edition

Medication Adherence

→ CONTENT REVIEWED BY A DISTINGUISHED
MEDICAL ADVISORY BOARD



Caring for cancer differently...

It's all in the delivery

Taiho Oncology, Inc., is focused on bringing novel technology to cornerstone chemotherapies for a wide range of tumor types—including colorectal cancer and a variety of solid tumors. By developing oral oncolytic therapies, we are aspiring to deliver more meaningful moments to patients, and to redefine the way the world treats cancer.

To learn more, please visit www.TaihoOncology.com.

Introducing

 **TAIHO ONCOLOGY**
Making the human connection

IN THIS GUIDE

- 3 Follow Directions: The importance of medication adherence
- 4 Why It Matters: Benefits and risks of proper adherence
- 6 Brand Name vs Generic
- 7 Survivor Story: Karen Manzini
- 8 Working With Your Team: Importance of good communication
- 9 Side Effects: Adherence easier when these are managed
- 10 Practical Tips
- 12 Caregiving: How to help patients stick to the schedule
- 13 Caregiver Story: Cate Edwards
- 14 Find Support: Financial and emotional resources
- 15 Advocacy & Assistance Resources
- 17 Your Personal Medical Journal



COLORECTAL CANCER SURVIVOR

“My current medication plan works perfectly for me because it allows me to be in remission while also maintaining a great quality of life.”

~ Karen Manzini,
Stage IV colorectal cancer survivor

PATIENT RESOURCE

- Chief Executive Officer **Mark A. Uhlig**
- Publisher **Linette Atwood**
- Co-Editor-in-Chief **Charles M. Balch, MD, FACS**
- Co-Editor-in-Chief **Lillie D. Shockney, RN, BS, MAS**
- Co-Editor-in-Chief **Paula T. Rieger, MSN, RN, CAE, FAAN**
- Senior Vice President **Debby Easum**
- Vice President, Operations **Leann Sandifar**
- Managing Editors **Lori Alexander, MTPW, ELS**
Deb Whippen
- Staff Writers **Traci Rork**
Dana Schneider
- Graphic Designer **Michael St. George**
- Medical Illustrator **Todd Smith**
- Production Manager **Jennifer Hiltunen**
- Vice Presidents, Business Development **Amy Galey**
Kathy Hungerford
Stephanie Kenney
- Account Executive **Melissa Amaya**
- Office Address **8455 Lenexa Drive**
Overland Park, KS 66214
- For Additional Information **prp@patientresource.com**
- Advisory Board **Visit our website at PatientResource.com to read bios of our Medical and Patient Advisory Board.**

For Additional Copies: To order additional copies of *Patient Resource Cancer Guide: Medication Adherence*, visit PatientResource.com, call 913-725-1600, or email orders@patientresource.com.

Editorial Submissions: Editorial submissions should be sent to editor@patientresource.com.

Disclaimer: Information presented in *Patient Resource Cancer Guide: Medication Adherence* is not intended as a substitute for the advice given by your health care provider. The opinions expressed in *Patient Resource Cancer Guide: Medication Adherence* are those of the authors and do not necessarily reflect the views of the publisher. Although *Patient Resource Cancer Guide: Medication Adherence* strives to present only accurate information, readers should not consider it as professional advice, which can only be given by a health care provider. Patient Resource, its authors, and its agents shall not be responsible or in any way liable for the continued currency of the information or for any errors, omissions or inaccuracies in this publication, whether arising from negligence or otherwise or for any consequences arising therefrom. Patient Resource, its authors, and its agents make no representations or warranties, whether express or implied, as to the accuracy, completeness or timeliness of the information contained herein or the results to be obtained from using the information. The publisher is not engaged in rendering medical or other professional services. The publication of advertisements, whether paid or not, and survivor stories is not an endorsement. If medical or other expert assistance is required, the services of a competent professional person should be sought.

© 2015 Patient Resource LLC. All rights reserved.
PRP PATIENT RESOURCE PUBLISHING®

For reprint information, email prp@patientresource.com.

CO-EDITORS-IN-CHIEF



Charles M. Balch, MD, FACS
Professor of Surgery, University of Texas Southwestern Medical Center
Editor-in-Chief, Patient Resource LLC
Editor-in-Chief, Annals of Surgical Oncology
Past President, Society of Surgical Oncology



Lillie D. Shockney, RN, BS, MAS
University Distinguished Service Associate Professor of Breast Cancer
Director, Johns Hopkins Avon Foundation Breast Center
Director, Johns Hopkins Survivorship Programs



Paula T. Rieger, MSN, RN, CAE, FAAN
Past President, Oncology Nursing Society

FOLLOW DIRECTIONS

The importance of medication adherence

▲ **An increasing number of cancer patients** are now able to take oral anti-cancer medications from the comforts of home. While this is more convenient for patients going through treatment, the convenience comes with more responsibility. Taking your medication correctly might not seem like a difficult task, but even the most motivated and organized patient can have difficulties at some point—which can be dangerous. Studies show that nearly 25 percent of all cancer patients take one or more oral medications as a part of their comprehensive cancer care. This guide will explain some of the common reasons patients get off schedule and provide solutions to help you stay on track.

WHAT DOES MEDICATION ADHERENCE MEAN?

The word “adherence” refers to taking the right dose of the right drug at the right time. It’s non-adherence when patients don’t follow their scheduled regimen exactly as prescribed. Some patients may simply forget to take their medications, while others may stop taking them in general because they start feeling better or because of financial reasons. There are two types of non-adherence:

- **Primary non-adherence** – The patient doesn’t fill a new prescription.
- **Secondary non-adherence** – The patient doesn’t take the medication as prescribed or doesn’t refill their prescription.

WHY IS IT IMPORTANT?

Taking your medication exactly as prescribed by your doctor is important in the fight against cancer because it can influence the effectiveness of your medication during treatment. Most anti-cancer drug regimens are designed to maintain a specific level of drugs in your system for a specific duration of time, based on your cancer type, stage, previous treatments and several other factors. Non-adherence can lead to unnecessary side effects, physician visits, hospitalizations and even cancer progression.

WHAT ARE COMMON CAUSES FOR NON-ADHERENCE?

Research shows that of all the patients taking medications for chronic illnesses, approximately half aren’t taking them exactly as prescribed by their doctor. In a national survey, one-third of cancer patients admitted they didn’t always follow the regimen exactly, with more than half admitting they occasionally forget to take a dose. Other known reasons for non-adherence include skipping doses to avoid side effects; splitting doses to save money; not filling (or refilling) prescriptions because of high copays or lack of insurance; complex and confusing treatment regimens; a lack of under-

standing of the actual purpose of the drug; or a belief that the treatment is unnecessary (especially in patients without symptoms).

A different form of non-adherence occurs when patients take too much of their medication. This may happen as a result of the misconception that if a treatment works well, two doses will work twice as well, or as a result of taking doses too close together (possibly after missing a dose). This type of medication non-adherence has the potential to be extremely dangerous and can even lead to an increased risk of death.

Most patients start their treatments with the best of intentions, but rates of adherence tend to taper off over time. For example, medication adherence for women taking tamoxifen for breast cancer is generally high during the first year but gradually decreases over the five years of recommended therapy—even though it’s proven to reduce the rate of recurrence and extend lives when taken as prescribed.

Many physicians believe that treatment fatigue (the feeling of wanting to escape the confines of cancer treatment) may contribute to reduced medication adherence in individuals with long-term treatment plans. Treatment fatigue may also occur in patients who are not yet willing to accept cancer as a part of their lives.

In the following pages, you will learn more about the importance of sticking to your prescribed treatment plan and how proper medication adherence can benefit your health, well-being and chance of survival. ■

STEPS TO FOLLOW | WHAT IS MEDICATION ADHERENCE?

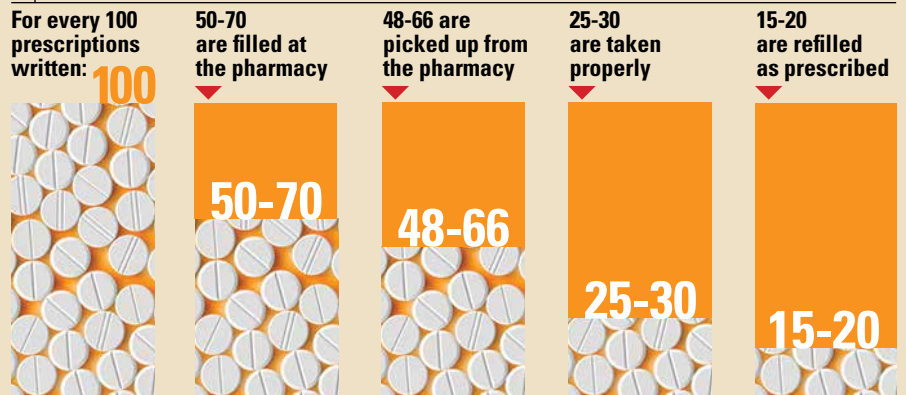
The right drug >> At the right dose >> At the right time >> On the right schedule >> Under the right conditions >> With the right precautions

OVERALL MEDICATION ADHERENCE STATISTICS FOR ALL CONDITIONS INCLUDING CANCER

BY THE NUMBERS MEDICATION ADHERENCE

- \$290 billion** Estimated annual cost of medication non-adherence in the U.S.
- 1 out of 6** Number of patients hospitalized within 90 days of treatment/therapy likely as a result of anti-cancer drug interactions
- 125,000** Number of deaths in the U.S. every year resulting from medical non-adherence
- 50** Percentage of patients who abandon treatment once they have to fill five or more prescriptions a month
- 20 to 30** Percentage of anti-cancer prescription medications that are never filled
- 6** Number of months at which the rate of medical adherence starts to decline
- \$2,000** Additional annual cost per patient in physician visits as a result of non-adherence

MEDICATION ADHERENCE STATISTICS



Source: National Association of Chain Drug Stores, Pharmacies: Improving Health, Reducing Costs, July 2010. Based on IMS health data.

WHY IT MATTERS

Benefits and risks of proper adherence

▲ While oral therapies have been proven to be highly effective and convenient cancer treatments, they are only as successful as your willingness to adhere to them. Your ability to stick to the schedule may depend on your understanding of the treatment regimen, your financial situation and your ability to manage the side effects that accompany many medications.

In fact, the many benefits of these oral anti-cancer drugs can be quickly outweighed by the risks involved when you no longer take your medication as prescribed. Always learn as much as you can about your specific medication, and ask your doctor, nurse or pharmacist for assistance whenever necessary.

BENEFITS OF MEDICATION ADHERENCE

Anti-cancer medications were once only available to be given through an intravenous (IV) line. Advances in anti-cancer drug research have led to the development of medications that can be given orally. This development offers many benefits compared with



IV anti-cancer treatments, most notably, the convenience and comfort of being able to take your anti-cancer medications in your own home, without the need to travel to a hospital or doctor's office. Many new oral anti-cancer drugs are more effective than some IV drugs and are associated with less risk of side effects. Lastly, being able to take anti-cancer medications orally gives patients a sense of greater control over their own care. Many cancers are now considered to be chronic diseases that are managed with oral medications at home, much like other chronic diseases such as diabetes and arthritis.

Effectiveness

The effectiveness of anti-cancer drugs is probably the most important factor when

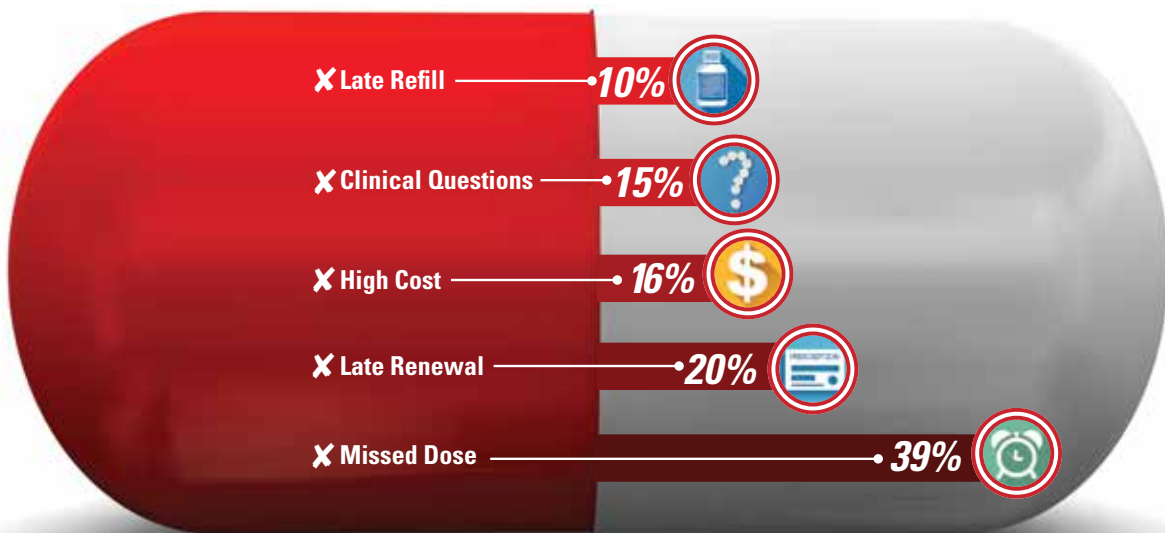
patients are considering their treatment options. Patients typically prefer oral treatment to intravenous therapy, but only if the oral treatment has been shown to be as effective as other options. In some cases, it's not a matter of simply deciding between IV and oral chemotherapy, for example, many include changing treatment types altogether. Recent advancements in some targeted therapy drugs, which target specific mechanisms of cancer cell growth, offer many cancer patients a more effective treatment option than conventional chemotherapy. These drugs usually come with fewer side effects as well.

Convenience and comfort

Two highly significant benefits of oral treatment include their convenience and their

WHY PATIENTS DON'T TAKE THEIR MEDICINE

For many diseases, only about half the patients take their medication as prescribed.



ability to keep you more comfortable than other options. Patients who take oral anti-cancer drugs can cut back considerably on traveling for treatment, and spend considerably less time in the doctor's office or hospital. While also avoiding the needle sticks associated with IV therapies, patients who take oral drugs get to spend more time with their friends and family and encounter fewer interruptions to their daily life. This type of treatment does come with more patient responsibility, however, as the responsibility of taking the right drug at the right time in the correct way shifts from the health care team to you and your caregivers. Feeling overwhelmed is common because it's often difficult to fully understand how to take your anti-cancer drugs correctly and safely for the entire duration of your treatment plan.

Control

Many cancer patients feel empowered when they have control over their treatment regimen, and this can improve their overall sense of well-being. That can often lead to better decision-making abilities regarding health and wellness and their treatment in general.

"I feel like as long as I continue taking hormone therapy drugs, I'm still actively fighting cancer," said Dr. Oliver Bogler, a male breast cancer survivor, who was diagnosed in 2012 and continues to take hormone therapy. "That's more comforting and encouraging to me than doing nothing and feeling helpless."

Treatment regimens are the most beneficial if decisions are shared by you and your health care team, so communicate often to make sure you're all on the same page. Patients should never make changes to their treatment plan unless instructed to do so by their doctor.

POTENTIAL RISKS OF NON-ADHERENCE

Medical non-adherence can have a serious impact on a patient's cancer care and can lead to increased side effects, unnecessary changes to the treatment plan, hospitalization and poor outcomes. It's dangerous when patients deviate from their original plan without being told to do so by their doctor. Patients can misunderstand the instructions, accidentally skip a dose, deliberately stop

MEDICAL ADHERENCE FACT



» Non-adherent patients are 17 times more likely to be hospitalized than adherent patients.

A. Dragomir et al. (May 2010). Impact of Adherence to Antihypertensive Agents on Clinical Outcomes and Hospitalization Costs. *Medical Care*, 48 (418-425)



COMMON REASONS FOR NON-ADHERENCE TO ORAL ANTI-CANCER DRUGS

- ▶ Forgetfulness
- ▶ Attempt to avoid side effects
- ▶ Complex treatment schedule
- ▶ Several daily medications
- ▶ Misunderstanding of drug instructions
- ▶ High drug cost
- ▶ Treatment fatigue
- ▶ Misunderstanding of treatment
- ▶ Lack of confidence in the treatment
- ▶ Feeling well enough to skip doses
- ▶ Presence of other illnesses or conditions
- ▶ Depression
- ▶ Cognitive impairment
- ▶ Functional difficulties (inability to open drug containers, poor vision, difficulty swallowing)
- ▶ Inadequate follow-up with health care team

refilling their prescriptions or take less than recommended.

Poor treatment outcome

The most serious consequence of medical non-adherence is running the risk that your treatment will be ineffective. Studies show that not taking anti-cancer medication as prescribed by a doctor can lead to cancer progression or recurrence. Because of how the drugs work, even small alterations to a treatment regimen can lead to failure.

Increased side effects

The amount of anti-cancer drugs in your system can influence the amount and severity of the side effects you encounter. Too much medication in your system may be caused by:

- 1 **Doses taken too close together** – Patients might double up after missing a dose or get confused by their treatment regimen.
- 2 **Drug interactions** – Drug interactions can result when your anti-cancer medication reacts with certain other medications, supplements or foods. You should talk to your health care team about potential drug interactions and pay attention to any known interactions listed on your prescription.

3 **Intentional "overadherence"** – Overadherence can occur when a patient takes more medication than prescribed, believing that a higher dose can increase the drug's effectiveness. While this is less common than non-adherence, it can still be equally as dangerous.

Unnecessary changes in treatment

When patients reduce or quit taking their anti-cancer medication without telling their health care team, the doctor may think the lack of response is because the treatment is ineffective. On the other hand, if a patient takes too much medication and suffers from increased side effects, the doctor may believe the patient is unable to tolerate the drug. These misunderstandings can result in unnecessary diagnostic tests, unwarranted dose changes or a switch to a new drug altogether. All of these factors can cause patients to miss out on what otherwise might have been the best treatment option available to fight their cancer type. ■

ADDITIONAL RESOURCES

- ▶ **American Society of Clinical Oncology:** www.cancer.net
The Importance of Taking Your Medication Correctly
Safe Storage and Disposal of Cancer Medications
- ▶ **CancerCare:** www.cancercare.org
Adherence
- ▶ **Script Your Future:** www.scriptyourfuture.org

BRAND NAME VS GENERIC

PROCESS FOR DRUG DEVELOPMENT

Once a new anti-cancer medication has been developed and approved by the FDA, the manufacturer is given a patent. This legal exclusivity typically protects the drug from being copied for up to 20 years. When the patent expires, other pharmaceutical companies are allowed to copy the drug's formula and produce a generic version. This version must also be approved by the FDA.

The entire process of pioneering and developing a drug can take years and cost a considerable amount of money. Because generic drugs aren't being produced from scratch, the development is streamlined and the formula is ultimately cheaper to make. In addition, generic manufacturers usually do not pay for advertising and other promotions. Multiple companies may make generic versions, and competition usually drives prices down.

Generic drugs are the bioequivalent of their brand-name counterparts, meaning they are identical in dose, strength, quality, performance and the way they're administered. Chemically designed to be just



FDA REGULATIONS FOR GENERIC DRUG MANUFACTURERS

The generic drug must:

- ▶ Use the same active ingredient as the brand-name drug
- ▶ Use the same strength/dose
- ▶ Be administered the same way (pill, capsule, liquid, etc.)
- ▶ Deliver the same amount of the drug into the bloodstream
- ▶ Look different than the original (size, shape or color)
- ▶ Have different markings and a different name

▲ Thanks to the continued development of new cancer-killing drugs, patients have more options than ever as they work with their doctors to choose a treatment regimen. The majority of these prescription medications come in both brand-name and generic form, but what are the differences between the two types?

Many patients are scared that generic drugs aren't as effective as brand-name medications because generics cost significantly less. What they may not realize is that the two are essentially the same. All medications – generic and brand-name – must undergo extensive testing by the U.S. Food and Drug Administration (FDA) to ensure they're both effective and safe before they're approved for patients. Generic drugs may be an effective option for you to ensure you're getting the treatment you need at a much lower price.

as effective as the original medication for a fraction of the cost, generic drugs save Americans billions of dollars per year on lifesaving treatments.

However, not all drugs currently have a generic equivalent, so talk to your doctor about your options.

LOOKS CAN BE DECEIVING

While two drugs may contain basically the same ingredients, generic drugs are required by law to look different than the brand-name versions. As new generic versions are being produced by different companies, the way your medication looks can change over time. The shape may change, for example, or the pill may be a different color. However, just because they look different doesn't mean they are different. The drug's appearance depends on the manufacturer, and certain pharmacies only carry specific brands. As you refill a prescription, be aware of this potential change, and be sure to ask your pharmacist if you're unsure about your new prescription. He or she can explain any changes and confirm that you have the right medication.

Your pharmacist and doctor can also explain the technical details of your medication and explain why the original version of a drug might be the only option for your treatment. Some doctors might not know a generic version exists, but if cost is an issue, ask about all available brands and compare them when choosing your treatment plan. ■



SAFETY FIRST

» All of these powerful prescription pills come with safety instructions that you must pay attention to and understand in order for them to be more helpful than harmful. Keep track of your medication adherence so that you can help your doctor more accurately evaluate the effectiveness of your treatment plan and decide whether to change the dose or drug if necessary. Here are some common instructions that may accompany many medications prescribed to cancer patients:

- ▶ Swallow whole; do not open the capsules or break/chew/crush the pills.
- ▶ Must be taken with food or with a full glass of water.
- ▶ Must be taken on an empty stomach.
- ▶ Drug can interact with other drugs, supplements or foods.
- ▶ Grapefruit and Seville oranges are known to influence the amount of medication absorbed into a patient's system and therefore should be avoided with certain drugs.

Ask your doctor or pharmacist about any specific instructions that come with your medications to ensure you're taking them safely.



After a routine colonoscopy, Karen Manzini was diagnosed with Stage IV colorectal cancer at the age of 59. Without symptoms and without warning, she went from feeling great to facing the fact that survival might not be an option. Not even a year since her diagnosis, Karen is currently cancer-free and continues taking the life-saving medications that gave her a fighting chance. Today she gratefully travels, spends time with family and friends, and wants to support and encourage other cancer patients who are facing the same odds of surviving this disease.

POSITIVE ATTITUDE, STRICT MEDICATION MANAGEMENT ARE KEYS TO **MOVING FORWARD**

➤ **Within a week of being diagnosed** in November, I had a laparoscopic procedure to remove the cancerous tumor along with six infected lymph nodes. The beginning of my cancer journey was mostly a blur, but after being hospitalized for three nights, I recovered quickly and within a month I was with my husband in his hometown in Italy trying to decide what to do next.

While he completely understood my fears and wanted to help, most Italians prefer not to even mention the word cancer. In fact, my mother-in-law called it “that ugly disease.” Regardless, we personally chose to tell everyone that I had cancer even though it made some uncomfortable.

Looking back, I had no problem talking about having cancer because I didn’t feel like it was my fault or that I should feel guilty for having this disease. No one else should either.

Thankfully, I found the Colon Cancer Alliance (CCA) early on, which allowed me to connect with patients and caregivers who had a wealth of knowledge to share. Between their website and Facebook page I learned about everything from treatment options and side effects to how to deal with psychological and financial problems.

While making treatment decisions we consulted with three oncologists in the U.S. and three in Italy, and also researched alternative treatments. I’m still not sure where we found the energy and concentration required to make these decisions so quickly, but by the holidays, we decided that oral chemotherapy (along with immune-boosting supplements) would begin just three months after my diagnosis.

I began taking 3,000 mg of oral capecitabine (Xeloda) every other week and would get a 600 mg infusion of bevacizumab (Avastin) every three weeks, taking around a half an hour. While it was

very emotional starting chemo and I did experience some mild side effects, overall I have tolerated it pretty well physically and have been very lucky.

The Avastin did raise my blood pressure, so I’ve added another medication to my regimen to keep that under control. I recently began maintenance therapy but other than some fatigue, nothing really keeps me from leading a normal and active life. My current medication plan works perfectly for me because it allows me to be in remission while also maintaining a great quality of life.

While researching your cancer and your treatment options, I can’t stress enough how important it is to be your own advocate, because the health care system isn’t perfect. Find as many experienced individuals as you can because there are countless survivors who genuinely want to help others get through this experience equipped with as much knowledge as possible.

I advise patients that no matter what, try your best to keep a positive outlook which can help to improve your life physically and mentally. I didn’t ignore all of the scary statistics that surrounded my type and stage of cancer, but I certainly didn’t want to focus on them either.

Make sure that when you feel tired that you take the time to rest and that you accept help from those who offer. As a cancer patient, it’s easy to get ahead of yourself and constantly worry about everything, most times unnecessarily. I found that by surrounding myself with positive people and having a positive attitude, I was more at peace. Remind yourself that statistics are just numbers... and every single day that you wake up – you are waking up as a cancer survivor. ■



Importance of good communication

▲ Even though the responsibility of treatment might fall directly on you and your caregiver, there are several reasons why it's important for you to continue to communicate with your entire health care team.

The doctors and nurses in charge of your care can help you understand your medications and the challenges you may face. They can also refer you to other health professionals who can help you through complicated insurance policies and financial assistance programs so you can more easily afford your medications.

Open and honest communication will ensure you get the most accurate information and support necessary to maintain your cancer treatment regimen. In addition to your doctors, friends and family may also provide much needed support and comfort.

WHERE TO START

Effective communication begins with clear and concise instructions and information given to you by your health care team. Your doctor should describe your treatment regimen in a way you understand, and you should speak up when you have any questions. Whether your plan includes new drugs or changes to a drug you already take, don't be shy about getting more information if you're confused. In cases where you feel your treatment plan may be too complex, see if your doctor or nurse can simplify your instructions. Ask about treatment options that include fewer drugs that you can take less often (for example, once a day as opposed to three times a day). Your plan can be tailored to your needs, so work with your health care team to create a customized treatment plan that can be easily managed.

CLARIFY AND VERIFY

Don't be embarrassed to admit you don't understand the instructions that come with your medication. You may need to take your medication once a day, at certain times throughout the day or on specific days of a treatment cycle. Clarify any uncertainty about your treatment schedule before begin-



ning, and always ask questions if the instructions are unclear.

To take your medicine safely, make sure you understand how the drugs you're taking will interact with certain foods, supplements or other medicines. You need to know what to avoid so you can prevent dangerous side effects and adverse reactions, which can impact the overall success of your treatment. Common items such as antacids and grapefruit have been known to affect how certain medications work. Ask your doctor about any interaction that may occur and what precautions you can take to avoid them. Follow-up with your pharmacist or check the prescription drug label if you have any questions about known interactions.

HONESTY IS THE BEST POLICY

In general, people want their doctors to think they're "good" patients, so they tell their doctor what they think the doctor wants to hear. As a result, they may claim they're taking their drug as prescribed, even if that's not entirely true. Honesty is vital when talking to your doctor about adherence. You must tell your doctor if you stopped taking your drug or have skipped doses for any reason and, if so, for how long and why. If your drug has not produced the expected result and your doctor thinks you've been taking it as prescribed, he or she will think the drug is not working for you and may change drugs. That change could negatively affect the course of your disease. Don't take that chance—be honest!

DRUG DIARY

Keeping track of your adherence is an important part of being successful. It can be helpful for many patients to write down any



IMPORTANT QUESTIONS TO ASK YOUR MEDICAL TEAM

Ask your medical team the following questions BEFORE you begin taking any type of medication:

- ▶ What is this drug used for? How is it going to help me?
- ▶ What are the generic and brand name(s) for this drug? Is a generic version an option?
- ▶ How long will I be taking this drug? How long does this specific prescription last, and will I need refills?
- ▶ Should I take this medication with food or other medications? Or must I take separately?
- ▶ What if I have trouble swallowing my medication?
- ▶ What are the possible side effects, how do I monitor them, and what should I do if they occur?
- ▶ How likely is it that these side effects will develop?
- ▶ What side effects should I report (such as a certain level of fever, etc.)?
- ▶ Does this drug have any known interactions with other drugs, supplements, foods or drinks? How do I monitor for drug interactions, and what should I do if they occur?
- ▶ How long does it take for this drug to start working? How can we tell if it's working? Are there certain tests I'll need to take while I'm taking this medication?
- ▶ What should I do if I miss a dose? What if I take too much? What if I vomit shortly after taking a dose?
- ▶ Are there any precautions I need to be aware of while taking this drug?
- ▶ Are there any special instructions about how this drug should be stored?
- ▶ If I have any remaining doses, how should they properly be disposed of?

side effects they experience during treatment so they remember to tell their doctor. Keeping track of the details allows your doctor to manage and monitor these side effects and will also help you keep track of your medication schedule. If you miss a dose or take one late, tell your treatment team to see what they recommend. Your doctors will constantly review tests and scans to accurately monitor your response to treatment, and the more information you're able to share, the better able they are to measure the effectiveness of your treatment. The information you provide can help them determine whether to change the dose or even change the drug based on your reaction. Although dosing changes are sometimes necessary, don't ever make changes to your treatment regimen without being told to do so by your doctor. ■

SIDE EFFECTS

Adherence easier when these are managed

▲ Unfortunately many cancer treatments may cause side effects, which can cause some patients to alter how they take them. You shouldn't assume you will experience all of the side effects listed with your regimen, but if you do the good news is that advances have been made in preventing or managing many of them. Managing these effects is important because if you feel better, you're more likely to complete your treatment as planned by your oncologist.

If you're encountering side effects from your oral medications, try some of the following tips to lessen their severity, and talk to your doctor about other ways they can be managed. Also reach out to other cancer survivors about their experiences and what helped them find relief. And remember, be careful when reading about other patient experiences on Internet forums and chat boards. Many times, those posting represent the minority of patients; those who experienced no side effects often don't take the time to post comments.

FATIGUE

Several factors may cause cancer-related fatigue, including the cancer itself. Cancer can alter your hormones, weaken your muscles or trigger other changes in your body, which all may lead to fatigue. Various types of treatments may contribute to fatigue, primarily because the body needs extra energy to repair the healthy tissues damaged during treatment.

What to try:

- Participate in regular physical activity, such as walking, yoga or bike riding.
- Ask your doctor about psychostimulant drugs, which help improve your alertness.
- Take frequent rest periods or naps, but limit each nap to 45 minutes.
- Save energy, set priorities about what you can do and delegate duties.
- Eat a well-balanced diet to help promote healing and restore your energy.

NAUSEA AND VOMITING

Certain medications damage the lining of the stomach, causing these two very common and uncomfortable side effects for cancer patients.

What to try:

- Ask your doctor about anti-nausea medications that can be taken preventively.
- Stay hydrated by slowly drinking cold, clear liquids (ginger ale, juice or tea).
- Try meditation, deep and controlled breathing or self-hypnosis.
- Eat several small meals or snacks throughout the day instead of three large meals.
- Avoid spicy or fried foods, and try to stay away from unpleasant odors.
- Keep a diary to find connections between certain foods that make you feel sick.

DIARRHEA

Loose or watery stools combined with painful stomach cramps and discomfort can be made worse by stress. If this condition isn't treated, dehydration, loss of important nutrients, weight loss and fatigue are all possible.

What to try:

- Follow a clear-liquid diet to help the lining of your intestines heal.
- Eat bland, low-fiber foods (white rice, bananas, toast, applesauce).
- Avoid fluids and food that can irritate the digestive tract (alcohol, caffeine, dairy, orange juice, prune juice).
- Avoid very hot or cold beverages.
- Eat more frequently in small amounts.
- Try eating foods with probiotics, healthy bacteria found in certain yogurts.

MOUTH SORES

Small cuts or ulcers may form in the lining of the inside of the mouth and may also affect the gums, tongue, roof of the mouth and lips.

What to try:

- Check your mouth twice each day with a small flashlight and tongue depressor, and clean your mouth and teeth gently with a soft toothbrush or mouth swab.
- Ask about medications that coat the lining of your mouth.
- Keep your mouth and lips moist by using lip balm, sipping water or sucking on ice.
- Eat foods at room temperature.
- Avoid alcoholic beverages; tobacco; and spicy, acidic, greasy, fried or coarse foods.

SKIN REACTIONS

Painful or itchy rashes can develop as dry, flaky, red and irritated skin.

What to try:

- Ask your doctor about corticosteroid creams that may help.
- Moisturize at least twice daily with thick cream made for sensitive skin.
- Wear loose-fitting clothes.
- Avoid contact with hot water; opt for lukewarm water instead.
- Use mild soap that does not contain alcohol, perfume or dye.
- Protect skin from the sun by always covering up and/or applying sunscreen.

PERIPHERAL NEUROPATHY

Peripheral neuropathy is a disorder of the nerves that are outside the brain and spinal cord. The symptoms of peripheral neuropathy usually include numbness and tingling, a decreased sensation of hot and cold, unpleasant sensations when touched, muscle weakness and cramping and balance problems.

What to try:

- Ask your doctor about substances to protect against nerve damage.
- Try exercise to ease discomfort and strengthen muscles.
- Ask your doctor about chemoprotective agents that can be given before or with a chemotherapy drug that's likely to cause peripheral neuropathy.
- Stretch in the morning to decrease pain.
- Move your hands and feet in all directions before you get out of bed.
- Ask your doctor about massage, acupuncture and transcutaneous electrical nerve stimulation (TENS).
- Avoid snug shoes or socks and extreme hot or cold temperatures.

MENOPAUSAL SYMPTOMS

Natural menopause typically occurs when a woman is between 45 and 55 years old. However, certain types of cancer treatment can cause premature menopause at an earlier age.

What to try:

- For vaginal dryness, try over-the-counter vaginal moisturizers. (Don't confuse them with vaginal lubricants.)
- For pain during sexual intercourse, try over-the-counter vaginal lubricants.
- Avoid spicy foods and hot beverages if you're experiencing hot flashes. Wear cotton clothing in layers that absorb moisture and are easy to remove. ■



SIDE EFFECTS

Go to www.PatientResource.com/Treatment_Side_Effects.aspx for more information

PRACTICAL TIPS

▲ **Long-term adherence often** requires more commitment and organization than patients are prepared to take on. However, several practical tips and tricks can help you adhere to your anti-cancer medications.

Not every suggestion will make sense for every person, so look for ideas and methods that fit easily into your lifestyle. Try to include one or a combination of the following tips to help keep you on track.

EDUCATE BEFORE YOU MEDICATE

Learning about your drug is one of the most effective ways to improve adherence. Once you know how to take your drug correctly and safely, ask follow-up questions about anything you don't understand before you begin treatment. See page 8 for a list of questions to ask your medical team or pharmacist to help you become more familiar with your medication.

MAKE A PLEDGE AND COMMIT

The simple act of writing a pledge to adhere to your anti-cancer medication can help reinforce your commitment to taking your medication correctly. Clearly state why it's important for you to adhere to your medication: "I will take my [drug name] today to help me fight my cancer." Refer to your pledge daily or as needed for a constant reminder of the significance of taking your medications.



MOBILE APP

MEDICATION REMINDERS

- ▶ **MediSafe Meds & Pill Reminder** / free (Android, iOS)
- ▶ **Dosecast – Medication Reminder** / free (Android, iOS)
- ▶ **Med Helper Pill Reminder** / free (Android, iOS)
- ▶ **Drugs.com Medication Guide** / free (Android)
- ▶ **Pill Reminder by Drugs.com** / free (iOS)
- ▶ **Pill Reminder AnyTimer** / free (Android)
- ▶ **MedCoach Medication Reminder** / free (Android, iOS)
- ▶ **PocketNurse** / free (Android)
- ▶ **Pill Monitor Free – Medication Reminders and Logs** / free (iOS)
- ▶ **RXmindMe Prescription** / free (iOS)

Visit the App Store on iTunes (iPhone, iPod, iPad) or the Google Play Store on Android devices to find more complete information on these and other medication reminders. (Use "medication reminder" as your search term.)



▲ **Educate before you medicate + Keep track of your meds**

▲ **Organize your pills + Create a schedule**

KEEP TRACK OF YOUR MEDS

Complicated drug names, difficult schedules and the realities of everyday life make adherence difficult. Don't try to remember everything! Instead, make a list of all medications and medicines – prescription and over-the-counter – to help keep you and your treatment team organized. Be sure to include the name and contact information of the doctor who prescribed each drug in case you have any questions. Provide a copy of this list to everyone on your health care team so they can help you manage your medications and avoid drug interactions. Keep a copy at home, give one to a family member or caregiver, and keep another copy with you, especially when you travel. Make sure to update all copies if your treatment changes, and redistribute them accordingly.

CREATE A CALENDAR OR SCHEDULE

Patients can benefit from creating a calendar that helps them adhere to their anti-cancer medication, especially if their treatment regimen is complicated. Include the exact days and times you're supposed to take your medication, and keep your calendar in a visible location. The easier it is to read and follow, the better. You can also take notes to help keep track of your side effects or to record important dosing information (missed or skipped doses) so that you can keep your doctor informed when necessary.

SET UP REMINDERS

Forgetfulness is one of the most common causes of non-adherence, which is why setting reminders can be the best way for many patients to adhere to their treatment plan. Take your medication at the same time as something that's already part of your daily routine, such as brushing your teeth or going to bed. This can help you take your meds at the same time every day and establish a routine that's easy to follow. Set an alarm to keep yourself on track, or try another helpful tool, such as a pocket pill box that vibrates, a watch with reminder alerts or a voice alarm. There are also many apps that can help you manage your medication with your smartphone or tablet (see sidebar). Many of these apps are multi-functional, allowing you to create alarms for multiple medications, research drug interactions, keep track of refills and more.

ORGANIZE YOUR PILLS

Weekly pill organizers are an effective way to keep track of your medications. Organizers come in different sizes and are especially helpful when you have multiple pills. Make sure





▲ Set up reminders + Plan ahead for refills

▲ Communication is key + Follow-up check-ups

▲ Manage side effects

you understand how to store your medications properly, as some drugs may have strict storage requirements, such as remaining in their original containers, being kept in the refrigerator or stored away from moisture.

PLAN AHEAD FOR REFILLS

Planning is necessary to make sure you always have your medication when necessary. When you fill each prescription, check the bottle for the number of remaining refills. Call your doctor for a new prescription when one refill is left, or sign up for automatic refills through your pharmacy. If you plan to travel, count your pills to make sure you have enough medication while you're away and in case you have unexpected travel delays. It's best to take your medications in their original containers, and when flying, keep them with you in your carry-on luggage. Be sure to take your list of medications with you in case you need to refill a prescription while away.

TALK WITH FAMILY AND FRIENDS

Family and friends can play an important role in helping loved ones adhere to treatments. Give them access to your medication list and treatment calendar or schedule. They can also help you look for the most appropriate and effective reminder tools, or help you pick up refills of your prescription. Having others give you a gentle nudge when it's time to take your medications can keep you consistent and let them feel helpful. Friends and family might also offer to help with transportation to your follow-up appointments, take notes about your side effects, or search for financial assistance options. Don't be afraid to ask for help; adherence is always easier when you have support from others.

MANAGE YOUR SIDE EFFECTS

Patients sometimes cut back or stop taking their oral anti-cancer medications in an effort to avoid side effects. Many side effects associated with anti-cancer treatments, such as fatigue or skin reactions, may be easily managed if treated early. You should tell your doctor immediately about any side effects you experience so your health care team can help you work through them without reducing or stopping your treatment. This will allow you to get the full benefit of the drug while maintaining a better quality of life throughout your treatment regimen. See page 9 for more information about common

treatment-related side effects and how to manage them.

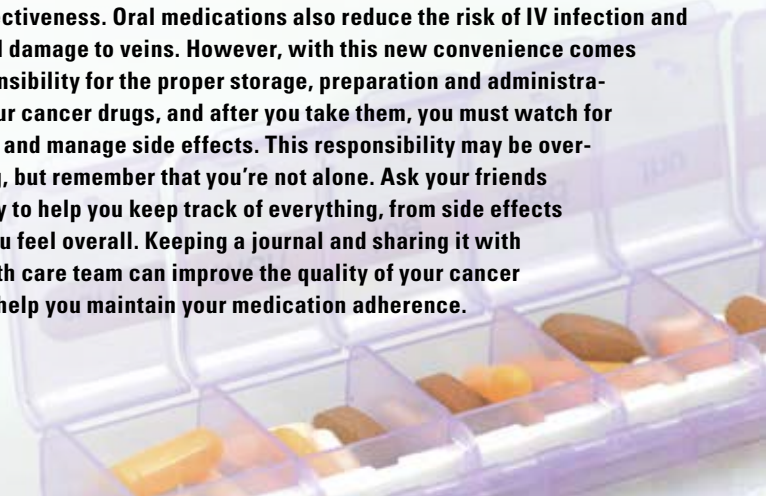
KEEP FOLLOW-UP VISITS

Being open and honest with your health care team is another proven method of improving adherence. Keep all of your appointments for follow-up testing, as your doctor will need to monitor your response to prescribed medications. These appointments should also be used as an opportunity to talk with your doctor about your medication, any side effects you've experienced or any trouble you've had with adherence. ■



ADJUSTING TO AN ORAL ANTI-CANCER TREATMENT REGIMEN

→ **Switching to an oral anti-cancer treatment regimen can be a difficult adjustment. Many believe that IV medications are "stronger" or work better than their oral counterparts. This is simply not true. The oral drugs are designed to provide more convenience and control for the patient, while maintaining the same effectiveness. Oral medications also reduce the risk of IV infection and continued damage to veins. However, with this new convenience comes the responsibility for the proper storage, preparation and administration of your cancer drugs, and after you take them, you must watch for reactions and manage side effects. This responsibility may be overwhelming, but remember that you're not alone. Ask your friends and family to help you keep track of everything, from side effects to how you feel overall. Keeping a journal and sharing it with your health care team can improve the quality of your cancer care and help you maintain your medication adherence.**



How to help patients stick to the schedule

▲ **A big part of your job as a caregiver** is making life easier for your loved one going through treatment. One of your most important daily duties is ensuring they're taking their anti-cancer medications correctly. While this may be complicated at times, open communication between you, your loved one and the health care team will ensure that you have the necessary skills and knowledge to properly care for the patient while at home. Because cancer and cancer treatments are often difficult to cope with, any help you're able to offer the patient will make a significant difference.

FACTORS THAT CAN LEAD TO NON-ADHERENCE



- ▶ **Signs of depression**
- ▶ **Cost concerns** (financial burden)
- ▶ **Cognitive impairment** (difficulty understanding instructions)
- ▶ **Not going to follow-up appointments and/or not refilling prescriptions**
- ▶ **Multiple or painful side effects that don't improve**
- ▶ **Lack of faith in treatment**
- ▶ **Lack of knowledge about disease and/or treatment**
- ▶ **Poor communication with doctors and/or caregivers**
- ▶ **Complicated treatment plans requiring multiple medications**
- ▶ **Language barriers and/or literacy problems**
- ▶ **Lack of support from friends and family**



HOW YOU CAN HELP

Take the patient to appointments, pick up prescriptions, fill the weekly pill box—anything you can do to lighten the load will be helpful. Also, ask what your loved one needs help with so you're not doing anything as a caregiver that the patient is capable of doing alone. Evaluate your loved one's ability and willingness to participate in daily self-care and go from there. Do your best to keep life as normal as possible, and let your loved one decide when help is needed.

Many oral medications can be given at multiple times of the day under different circumstances. Be aware of the dose and administration information for each of the drugs so that they're taken safely. Know whether medications should be taken with food or on an empty stomach, how often they should be taken and the side effects that may occur. All of these are essential aspects of helping the patient adhere to the treatment plan.

Report any side effects as soon as possible to help the patient find relief and avoid serious complications. Be sure to communicate this information to the health care team as well, so the doctor will know when it's time to switch to a different treatment if the current plan isn't working.

Certain side effects (such as nausea and vomiting) are usually more easily prevented than treated. Adherence to anti-nausea drugs can help patients effectively manage their side effects without having to switch to another type of treatment that might be less effective.

RESPONSIBILITIES OF THE CAREGIVER

Some days you might face an uphill battle. You may have to coax your loved one into taking the medication by reminding him or her that these drugs will only work if taken correctly. Get creative and do what you can to ensure the patient is staying adherent, while also allowing your loved one to stay independent during this difficult time.

Friends and family members also serve as much-needed cheerleaders, whose enthusiasm and support will encourage and comfort the patient throughout treatment. Make sure your loved one knows you're on the same team, and communicate often so you both know how the other person feels. Fear, frustration, irritation and relief are all shared emotions that the patient and caregiver can express together, strengthening your bond.

Another role of the caregiver is to serve as the patient's advocate. This might mean speaking with the doctors if the patient is unhappy with the current treatment plan. Ask about alternative medication options, too, as many cancer treatments can be administered through an injection, IV or implant, making it easier for the patient to adhere.

MENTALLY PREPARE TO BE THERE

It's extremely helpful for the patient and the doctors when caregivers monitor for side effects, anxiety or depression, which can all contribute to medical non-adherence. If you notice these symptoms and they affect the patient's daily life, seek help from the doctor. Your loved one might benefit from talking with a counselor or mental health professional. Also monitor yourself and speak to someone if you need help processing your emotions.

According to experts, many caregivers falsely believe that if they just do enough, they can keep their loved one alive. That is a heavy and unnecessary burden to bear. Caregivers do not have the power to keep a loved one alive; a more realistic goal may be to keep a loved one comfortable. A confident caregiver is one who can identify, build and use his or her strengths to be of service to the patient.

All of these responsibilities mean that caregivers need to hone their management and coping skills, as this role can be as challenging as it is rewarding. Remember, it's OK to ask for help, and you should never feel guilty for taking much-needed time for yourself.

By keeping yourself physically and mentally healthy, you're much more beneficial to your loved one and will be a much better caregiver. ■

ADDITIONAL RESOURCES

- ▶ **American Cancer Society:** www.cancer.org
Caring for the Patient with Cancer at Home
- ▶ **American Society of Clinical Oncology (ASCO):** www.cancer.net
Caregiving Tips
- ▶ **Help for Cancer Caregivers:** www.helpforcancer.org
Medication Management

Cate Edwards helped her mom, Elizabeth Edwards, through two battles with breast cancer



A CAREGIVER'S PERSPECTIVE

➤ **According to a recent survey**, there are more than 44 million caregivers who provide care for a short period or a longer one. Four out of 10 caregivers provide support for at least five years. Cate Edwards was just 22 years old when her mother, Elizabeth, was first diagnosed with breast cancer in November 2004. After getting over the initial shock, Cate, who had just graduated from Princeton, returned home to help her mom figure out the next steps.

"We decided to gear up and fight this thing," Cate said. "We figured it was going to be a short-term experience that would hopefully end with her being cured."

After undergoing treatment, Elizabeth's cancer went into remission in 2006, but a follow-up scan a year later revealed that the cancer had returned. The official diagnosis was Stage IV metastatic breast cancer.

"The mentality in terms of her life and living was very different because it wasn't like we were going to stop everything to deal with this cancer, which it was in the initial diagnosis period," Cate said. "Instead it was like we're going to continue to live and live life actually to its fullest. It was her goal to make every single day count, so that was a different mentality in a lot of ways."

Cate was one of her mom's primary caregivers while she was undergoing treatment with chemotherapy, hormone therapy and radiation therapy—as well as fighting side effects such as fatigue and back pain.

"There were days where she had trouble moving around a lot, and that just meant I had to be a support for her in a different way," Cate said. "So I'd crawl into bed with her and watch HGTV or a 'House' marathon—that was one of her favorite shows. We did a lot of just cozing up and being lazy together, and that was really meaningful in its own way."

Elizabeth also suffered from extreme skin dryness and flaking on her hands and feet.

"She used to do this thing where she would rub her feet with Udder Cream, and then wrap them in Saran Wrap and put on

socks to help moisturize them," Cate said. "So we did that together a few times. And my husband actually came to stay with her, and she made him do it, too. I walked in one day and saw him with his Udder Cream and his socks on the couch with my mom. So sometimes it was little things that made a difference and sort of made her feel more normal."

While Cate's focus was solely on taking care of her mom, she later realized it was just as important to take care of herself.

"It's difficult when your loved one is going through cancer to say, 'What about me?'" Cate said. "But the reality is that's not the right mentality. It's also hard on us as family members and loved ones, and that's okay. To be there the best I could for her, I think it would have been smarter of me to try to take better care of myself."

Fortunately, Cate did receive a lot of support from her husband, family and friends even when she didn't ask for it. As for knowing what to expect as a caregiver, Cate says it's hard to predict.

"Every patient is different. Their needs are different. So keeping the line of communication open and being willing to talk about the disease, how the patient is feeling on a day-to-day basis and what their needs are is vital," Cate said. "Even if it's something like mowing the lawn; even if it's making a grocery store run; even if it's picking up prescriptions. Those things make a big difference. But every patient is different, so talking to them about their needs I think is a really important aspect of being a good caregiver." ■

▲ **Cate Edwards is the daughter of author and health care activist Elizabeth Edwards and former U.S. Senator John Edwards. She graduated with honors with a degree in political economics from Princeton University and later received a law degree from Harvard Law School. Cate is currently practicing law and serves as president of the Elizabeth Edwards Foundation, which she started in her mother's honor.**

Cate says, "My mom always said that the best thing you can give your children is wings, because you won't always be there to bring food back to the nest. At the Elizabeth Edwards Foundation, we're continuing my mom's work – to try to give more children the wings they need and deserve."

Financial and emotional resources

▲ **Don't let the price of medications** add to your stress or influence your treatment decisions. Regardless of your financial situation or your health insurance plan, cost shouldn't rank higher than effectiveness when it comes to choosing a treatment.

It's no secret that the cost of fighting cancer can be overwhelming. Fortunately, multiple foundations and organizations have been created to help patients manage the financial and emotional aspects of this disease.

No one should be confused or feel alone while going through treatment. Explore resources online or look for cancer-specific organizations and advocacy groups in your area. (See pages 15 and 16 for a full list of advocacy and financial resources.)

THE COST OF CONVENIENCE

Although oral anti-cancer medications are usually more convenient and effective – and may come with fewer side effects – than their intravenous counterparts, they also may be more expensive. Oral medications are usually covered as prescription drugs rather than as medical expenses by your insurance, which is why they generally require a higher copay or deductible.

If the cost of treatment becomes a financial burden, don't skip or cut back on your prescriptions to save money. Reach out for help so you can fight this disease as efficiently and

effectively as possible. Other cancer patients, survivors and caregivers often have excellent advice about how to manage the costs.

■ **Patient assistance programs (PAPs)** – These programs provide free or low-cost medications to those who are unable to pay themselves. Ask them for guidance on copays, deductibles, reimbursement and insurance premiums. While some programs are intended for uninsured or underinsured patients, insured patients who still need help paying for their medications are also welcome to apply. An estimated 9.5 million Americans have already received free or lower-cost prescriptions through Partnership for Prescription Assistance (PAP).

■ **Discount coupons, vouchers and drug cards** – These valuable tools are available to those who qualify. Keep in mind that not all discount cards are free; some have an annual fee while others charge shipping and handling fees. Some insurance companies reduce the cost of medications if you get them through the mail or order in bulk.

■ **Generic drugs** – Generics are typically less expensive than the brand-name versions, even though both contain the same active ingredients. (See page 6 for more information.)

■ **Patient Advocate Foundation (PAF)** – This organization helps patients deal with financial difficulties and maintain employment during treatment. Copay relief programs help qualified and insured patients pay for prescriptions and/or treatments, and locate other sources to cover additional medical costs. Learn more by calling 866-512-3861 or visiting www.copays.org and www.patientadvocate.org.

■ **Pharmaceutical companies** – The drug makers themselves can often assist with the reimbursement process for their prescrip-



QUICK TIPS FINANCIAL MANAGEMENT

» **Cancer patients are two-and-a-half times more likely to declare bankruptcy than those without cancer, according to a 2013 study.**

» **To avoid becoming a statistic, ask questions until you understand your insurance policy and how your treatment plan will work, then plan your budget accordingly and apply for financial assistance whenever possible.**

» **Learn how to manage the financial aspect of this disease early so you can focus on fighting cancer right from the start.**

tions, but coverage will vary by insurance carrier and individual. It's important to fill out all of the reimbursement request forms carefully, and include all required information for them to be effective. Some companies also offer online support with financial assistance, side effect management and nutritional advice.

KNOWLEDGEABLE GUIDANCE

Hospitals and clinics that treat people with cancer know there's a growing need for staff members who are specially trained to help patients adhere to their drug regimens. Oncology nurses, doctors, patient care advocates and social workers should be able to provide support and guide you to helpful resources. Some health care facilities may even designate a nurse or patient navigator to regularly check on patients, talk about side effects and help monitor adherence. In addition, contact your oncology nurse navigator or oncology social worker for assistance in learning what prescriptions may be available through a drug assistance program offered by some pharmaceutical companies. See page 16 for a list of reimbursement assistance programs.

Talk to your doctor or a member of your health care team if you have any questions; communicating your needs is an important part of your treatment and is essential to your cancer care. Listen to the advice you get from other cancer patients who've already conquered this challenge themselves. From how they managed side effects to how they made treatment decisions, cancer survivors are often happy to help and can provide you with priceless information about their medications. ■

SURVIVOR VOICE | » Heather Snyder | Stage IV Melanoma Survivor



“**Chemo is expensive! Luckily we have great insurance and it has been a lifesaver. We also applied for the copay assistance program that gives us a huge discount. We only pay \$16 a month for chemo now.**”

“**I have a lot more meds in the morning so I've found that using a pill container saves me a ton of time and there's no guessing as to whether or not I took all my medications.**”

ADVOCACY & ASSISTANCE RESOURCES

CANCER EDUCATION

Academy of Oncology Nurse Navigators.....	www.aononline.org
Alex's Lemonade Stand Foundation for Childhood Cancer.....	www.alexlemonade.org
American Cancer Society.....	www.cancer.org
American Society of Clinical Oncology (patient website).....	www.cancer.net
CANCER101.....	www.cancer101.org
CancerCare.....	www.cancercares.org
CancerGuide.....	www.cancerguide.org
CancerQuest.....	www.cancerquest.org
Centers for Disease Control and Prevention (CDC).....	www.cdc.gov
The Gathering Place, A Caring Community for Those Touched by Cancer.....	www.touchedbycancer.org
GetPalliativeCare.org.....	www.getpalliativecare.org
Global Resource for Advancing Cancer Education (GRACE).....	www.cancergrace.org
The Hope Light Foundation.....	www.hopelightproject.com
LIVESTRONG Foundation.....	www.livestrong.org
National Cancer Institute.....	www.cancer.gov
National Comprehensive Cancer Network (NCCN).....	www.nccn.org
National LGBT Cancer Network.....	http://cancer-network.org
OncoLink.....	www.oncolink.org
Oncology Nursing Society.....	www.ons.org
PearlPoint Cancer Support.....	www.pearlpoint.org
Pine Street Foundation.....	www.pinestreetfoundation.org
R.A. Bloch Cancer Foundation, Inc.....	www.blochcancer.org
Scott Hamilton CARES Initiative.....	www.scottcares.org
U.S. National Library of Medicine.....	www.nlm.nih.gov
Wellness Place.....	www.wellnessplace.org

CAREGIVERS & SUPPORT

4th Angel Mentoring Program.....	www.4thangel.org
American Self-Help Group Clearinghouse.....	www.selfhelpgroups.org
Bloch Cancer Hotline.....	800-433-0464
Buddy Kemp Cancer Support Center.....	www.novanthealth.org/home/services/cancer/support-advocacy/buddy-kemp-cancer-support-center.aspx
CANCER101.....	www.cancer101.org
Cancer Action.....	www.canceractionkc.org
Cancer and Careers.....	www.cancerandcareers.org
CancerCare.....	www.cancercares.org
Cancer Connection.....	www.thecancerconnection.org
Cancer Hope Network.....	www.cancerhopenetwork.org
Cancer Information and Counseling Line.....	800-525-3777
Cancer Really Sucks!.....	www.cancerrealsucks.org
Cancer Support Community.....	www.cancersupportcommunity.org
Cancer Support Community Open to Options counseling program.....	888-793-9355
Cancer Survivors Network.....	http://csn.cancer.org
Cancer Wellness Center.....	www.cancerwellness.org
Caregiver Action Network.....	www.caregiveraction.org
CaringBridge.....	www.caringbridge.org
Center to Advance Palliative Care.....	www.capc.org
The Children's Treehouse Foundation.....	www.childrenstreehousefdn.org
Cleaning For A Reason.....	www.cleaningforareason.org
Colorectal CareLine (Patient Advocate Foundation).....	www.colorectalcareline.org
Cooking with Cancer.....	www.cookingwithcancer.org
Cuddle My Kids.....	www.cuddlemykids.org
Family Caregiver Alliance.....	www.caregiver.org
Fighting Chance.....	www.fightingchance.org
Friend for Life Cancer Support Network.....	www.friend4life.org
The Gathering Place, A Caring Community for Those Touched by Cancer.....	www.touchedbycancer.org
Guam Cancer Care.....	http://guamcancercares.org
Guide Posts of Strength Inc.....	www.cancergps.org
The Hope Light Foundation.....	www.hopelightproject.com
I Can Cope.....	www.cancer.org/treatment/supportprograms/services/onlinecommunities/participateinacancereducationclass/icancopeonline/index
Imerman Angels.....	www.imermanangels.org
The LGBT Cancer Project - Out With Cancer.....	www.lgbtcancer.org
LIVESTRONG Foundation.....	www.livestrong.org

LivingWell Cancer Resource Center.....	www.livingwellccr.org
Lotsa Helping Hands.....	www.lotsahelpinghands.com
MyLifeLine.org Cancer Foundation.....	www.mylifeline.org
PearlPoint Cancer Support.....	www.pearlpoint.org
SHARE Caregiver Circle for Family and Friends.....	www.sharecancersupport.org/share-new/support/for_partners_and_caregivers
Strike Out Cancer.....	www.strikeoutcancer.com
SupportGroups.com.....	www.supportgroups.com
Turning Point.....	www.turningpointkc.org
Visiting Nurse Associations of America.....	www.vnaa.org
Vital Options International.....	www.vitaloptions.org
Walk With Sally.....	www.walkwithsally.org
Well Spouse Association.....	www.wellspouse.org
Wellness Place.....	www.wellnessplace.org
weSPARK (Cancer Support Center).....	www.wespark.org
Wonders & Worries.....	www.wondersandworries.org

CLINICAL TRIALS

ACT (About Clinical Trials).....	www.learnaboutclinicaltrials.org
CenterWatch.....	www.centerwatch.com
Coalition of Cancer Cooperative Groups.....	www.cancertrialshelp.org
LIVESTRONG Foundation.....	www.livestrong.org/we-can-help/planning-medical-care/considering-clinical-trials
MolecularMatch.....	www.molecularmatch.com
My Clinical Trial Locator.....	http://myclinicaltriallocator.com
National Cancer Institute.....	www.cancer.gov/clinicaltrials
National Institutes of Health.....	www.clinicaltrials.gov
TrialCheck.....	www.trialcheck.org

COMMUNICATION SUPPORT

American Psychosocial Oncology Society Helpline.....	866-276-7443
Cancer Survivors Network.....	http://csn.cancer.org
CaringBridge.....	www.caringbridge.org
LIVESTRONG Foundation.....	www.livestrong.org
MyLifeLine.org Cancer Foundation.....	www.mylifeline.org
Vital Options International.....	www.vitaloptions.org

COMPLEMENTARY PROGRAMS & ALTERNATIVE MEDICINE

Believe Big.....	www.believebig.org
The Center for Mind-Body Medicine.....	www.cmbm.org
Kansas City Healing Touch.....	www.kansascityhealingproject.org
National Center for Complementary and Alternative Medicine.....	www.nccam.nih.gov
Office of Cancer Complementary and Alternative Medicine.....	www.cancer.gov/cam
Society for Oncology Massage.....	www.s4om.org
Stewart's Caring Place: Cancer Wellness Center.....	www.stewartscaringplace.org
Touch, Caring and Cancer.....	www.partnersinhealing.net

DRUG RESEARCH UPDATES

LIVESTRONG Foundation.....	www.livestrong.org
Marti Nelson Cancer Foundation.....	www.canceractionnow.org
Pharmaceutical Research & Manufacturers of America.....	www.phrma.org
U.S. Food & Drug Administration.....	www.fda.gov

ELDERLY

Assisted Living Facilities.....	www.assistedlivingfacilities.org
BenefitsCheckUp.....	www.benefitscheckup.com
Eldercare Locator.....	www.eldercare.gov
MatchNursingHomes.org.....	www.matchnursinghomes.org
National Council on the Aging.....	www.ncoa.org
Skilled Nursing Facilities.....	www.skillednursingfacilities.org

FINANCIAL ASSISTANCE

American Cancer Society.....	www.cancer.org
American Kidney Fund.....	www.kidneyfund.org
BenefitsCheckUp.....	www.benefitscheckup.com
Bringing Hope Home.....	www.bringinghopehome.org
CancerCare.....	www.cancercares.org/financial
Cancer Financial Assistance Coalition.....	www.cancerfac.org
The CHAIN Fund.....	www.thechainfund.com

HealthWell Foundation	www.healthwellfoundation.org
Hope Lodge	www.cancer.org/treatment/supportprogramsservices/hopelodge/index
LIVESTRONG Foundation	www.livestrong.org
Medicare	www.medicare.gov
NeedyMeds	www.needyeds.com
Partnership for Prescription Assistance	www.pparx.org
Patient Access Network Foundation	www.panfoundation.org
Patient Advocate Foundation	www.patientadvocate.org
Patient Services Inc.	www.patientservicesinc.org
The Pins for Pauly Foundation Inc.	www.pinsforpauly.org
RxAssist	www.rxassist.org
RxHope	www.rxhope.com
Social Security Administration	www.ssa.gov
The Social Security and Disability Resource Center	www.ssdrc.com
State Health Insurance Assistance Programs	www.shiptacenter.org
Stupid Cancer	www.stupidcancer.org

HOSPICE & HOME CARE

American Hospice Foundation	www.americanhospice.org
Caring Connections	www.caringinfo.org
Hospice Education Institute Inc	www.hospiceworld.org
Hospice Foundation of America	www.hospicefoundation.org
International Association for Hospice and Palliative Care	www.hospicecare.com
Kansas City Hospice & Palliative Care	www.kansascityhospice.org
National Association for Home Care & Hospice	www.nahc.org
National Hospice and Palliative Care Organization	www.nhpco.org
The Oley Foundation	www.oley.org
Visiting Nurse Associations of America	www.vnaa.org

PAIN MANAGEMENT

American Chronic Pain Association	www.theacpa.org
Cancer Pain Research Consortium	http://cancerpainresearchconsortium.org
LIVESTRONG Foundation	www.livestrong.org
The Resource Center of the Alliance of State Pain Initiatives	www.trc.wisc.edu
U.S. Pain Foundation	http://uspainfoundation.org

PATIENT ADVOCACY

Academy of Oncology Nurse Navigators	www.aononline.org
American Cancer Society Cancer Action Network Inc	www.acscan.org
Cancer Legal Resource Center	www.disabilityrightslegalcenter.org/cancer-legal-resource-center
Dream Foundation	www.dreamfoundation.org
Firefighter Cancer Support Network	www.firefightercancersupport.org
For Pete's Sake Cancer Respite Foundation	www.takeabreakfromcancer.org
Foundation for Health Coverage Education	www.coverageforall.org
Friend for Life Cancer Support Network	www.friend4life.org
The Gathering Place A Caring Community for Those Touched by Cancer	www.touchedbycancer.org
Gems of Hope Inc	www.gemsofhope.com
Health Connections Network	www.healthconnectionsnetwork.org
LIVESTRONG Foundation	www.livestrong.org
The Mautner Project	www.whitman-walker.org/mautnerproject
National Coalition for Cancer Survivorship	www.canceradvocacy.org
Office of Cancer Survivorship	http://cancercontrol.cancer.gov/ocs
Patient Advocate Foundation	www.patientadvocate.org
Research Advocacy Network	www.researchadvocacy.org
Vital Options International and The Group Room Interviews and Advocacy in Action Videos	www.vitaloptions.org

PRESCRIPTION EXPENSES

American Cancer Society	www.cancer.org
American Kidney Fund (dialysis patients)	www.kidneyfund.org
The Bone Marrow Foundation	www.bonemarrow.org
Brenda Mehling Cancer Fund (patients 18-40)	www.bmcf.net
CancerCare	www.cancercare.org
The CHAIN Fund Inc	www.thechainfund.com
Children's Leukemia Research Association	www.childrensleukemia.org
Chronic Disease Fund	www.cdfund.org
Foundation for Health Coverage Education	www.coverageforall.org
HealthWell Foundation	www.healthwellfoundation.org

Leukemia & Lymphoma Society	www.lls.org
Linking ARMS Program (breast cancer)	www.cancercare.org
Mission4Maureen (brain cancer)	www.mission4maureen.org
National Organization for Rare Disorders	www.rarediseases.org
NeedyMeds (links to assistance programs)	www.needyeds.org
Partnership for Prescription Assistance	www.pparx.org
Patient Access Network Foundation	www.panfoundation.org
Patient Advocate Foundation Co-Pay Relief	www.copays.org
Patient Services Inc.	www.patientservicesinc.org
Rise Above It (youth, young adults)	www.raibenefit.org
RxAssist	www.rxassist.org
RxHope	www.rxhope.com
Stupid Cancer	www.stupidcancer.org
Together Rx Access	www.togetherxaccess.com

REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS

AbbVie Patient Assistance Foundation	www.abbviepaf.org
Amgen Assist	www.amgenassist.com
Astellas Pharma Support Solutions	www.astellaspharmasupportsolutions.com
AstraZeneca Patient Assistance Programs	www.astrazeneca-us.com/help-affording-your-medicines
Bayer Healthcare Pharmaceuticals REACH Co-Pay Assistance Program	www.reachpatientsupport.com
Boehringer Ingelheim Cares Foundation Patient Assistance Program	http://us.boehringer-ingelheim.com
Bristol-Myers Squibb	www.bms.com/products/Pages/programs.aspx
Celgene Patient Support	www.celgenepatientsupport.com
Dendreon On Call	www.dendreononcall.com
Eisai Reimbursement Resources	www.eisaireimbursement.com
Genentech Access Solutions	www.gene.com/patients/patient-access
Genzyme Patient Support Services	www.genzyme.com/patients/patient-support-services.aspx
Gilead Patient Access	www.gilead.com/responsibility/us-patient-access
GSK Access	www.gsk-access.com
Janssen Prescription Assistance	www.janssenprescriptionassistance.com
Johnson & Johnson Patient Assistance	www.jjpac.org
Lilly PatientOne	www.lillypatientone.com
Merck Patient Assistance Program	www.merck.com/merckhelps
Millennium Pharmaceuticals Inc. (Velcade Patient Assistance Program)	www.velcade.com/paying-for-treatment
Novartis Patient Assistance Now	www.patientassistancenow.com
Onyx 360	https://enrollment.onyx360.com
Pfizer RxPathways	www.pfizerxpathways.com
Sanofi Patient Connection	www.visitsponline.com
Searle Pharmaceutical Company	800-542-2526
Spectrum Therapy Access Resources	www.getasapinfo.com
Teva Oncology Core Reimbursement Assistance & Support	www.tevacore.com
Xofigo Access Services	www.xofigo-us.com/hcp/patient-support
Xtandi Support Solutions	www.xtandi.com/support-solutions
ZytigaOne Support	www.zytigahcp.com/zytigaone-support

RESEARCH

American Association for Cancer Research	www.aacr.org
American Institute for Cancer Research	www.aicr.org
Cancer Research Institute	www.cancerresearch.org
The Chemotherapy Foundation	www.chemotherapyfoundation.org
Expedition Inspiration Fund	www.expeditioninspiration.org
Friends of Cancer Research	www.focr.org
International Cancer Advocacy Network	www.askican.org/nccr.html
International Cancer Alliance for Research and Education	www.icare.org
Pine Street Foundation	www.pinestreeffoundation.org
Prevent Cancer Foundation	www.preventcancer.org
Research Advocacy Network	www.researchadvocacy.org
Scott Hamilton CARES Initiative	www.scottcares.org

VETERANS' ASSISTANCE

CancerCare	www.cancercare.org
Family Caregiver Alliance	www.caregiver.org
Fisher House	www.fisherhouse.org
Lung Cancer Alliance	www.lungcanceralliance.org
National Hospice and Palliative Care Organization	www.nhpco.org
U.S. Pain Foundation	http://uspainfoundation.org



YOUR PERSONAL

MEDICAL JOURNAL

→ For additional copies go to: www.PatientResource.com/MAMedicalJournal.pdf

DOCTOR APPOINTMENTS

Date	Doctor	Reason for visit

MY MEDICATIONS

Medication	Dose	Directions	Purpose	Next refill
<i>Drug name</i>	<i>350mg</i>	<i>Once every 4 hrs.</i>	<i>Pain management</i>	<i>1/12/2016</i>

MEDICAL TEAM CONTACTS

Physician _____ Address _____ City _____ State _____ Zip _____ Phone _____ Fax _____	Physician _____ Address _____ City _____ State _____ Zip _____ Phone _____ Fax _____
Physician _____ Address _____ City _____ State _____ Zip _____ Phone _____ Fax _____	Physician _____ Address _____ City _____ State _____ Zip _____ Phone _____ Fax _____
Physician _____ Address _____ City _____ State _____ Zip _____ Phone _____ Fax _____	Physician _____ Address _____ City _____ State _____ Zip _____ Phone _____ Fax _____

P A T I E N T
R E S O U R C E

Where information equals hope