

# Patients as Drivers: A Prescription for the Future



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**An experienced patient, visionary, and advocate offers insights into the cancer journey.**

It's a different world than when I was diagnosed in 1996 with the incurable cancer multiple myeloma. Today, thanks to advances in sequencing technologies, we have gained unprecedented insights into the genetic drivers of cancer. We now have an arsenal of breakthrough treatments that take into account these genetics and patients' other unique characteristics, personalizing care and giving patients their very best chance of beating the odds. And, with access to information with the click of a mouse or swipe on a smartphone and the increasing availability of digitized health records, patients now find themselves as vital partners not only in their care, but also in the research process itself—a position that has the power to transform the

landscape more than we can even imagine.

Despite this progress, far too many of the estimated 1.7 million people who will be diagnosed with cancer this year still struggle at far too many steps in their cancer journey. I've experienced this firsthand as a patient still in active treatment and as a caregiver to my identical twin sister, who was recently diagnosed with breast cancer, and as a long-term patient advocate. Where do patients get stuck along the way, and what can we as patient advocates do to help?

### **At the moment of diagnosis:**

Patients must get up to speed quickly not only about their disease and its treatment options but also where to go to receive care.

**“Patients must be educated and empowered at critical points in their journey to advocate for themselves.”**

Unfortunately, many people struggle with health literacy challenges that prevent them from understanding health information and making complex health-related decisions. A coordinated effort must be made to improve patients' health literacy, ideally before a cancer diagnosis is made. Teaching them how to use the internet to find reputable, unbiased information from .org versus .com sites—the National Cancer Institute, American Society of Clinical Oncology, or disease-based nonprofits—is a good first step and will go a long way. Patients must also be advised to get second opinions and, when possible, to visit centers and clinicians that specialize in treating their specific cancer.

### **Before starting treatment:**

Choices patients make prior to beginning treatment—from getting certain imaging tests at baseline or banking their tissue for genomic testing—can affect how their disease is managed later. This applies not only to a patient's first line of therapy, but again after relapse(s). Complicating this is that insurers may not routinely cover what they need, and centers may be concerned about reimbursement. Patients must be educated and empowered at these critical points in their journey to advocate for themselves.

### **Choosing the best treatment:**

A growing number of medicines can treat cancer by its genetic mutations, not just by the organ where the cancer was first found. In fact, a recent study found that more than 75 percent had a genetic

mutation or other molecular abnormality; of these, 80 percent had variations that could be targeted by an existing drug. Prior to patients making any treatment decisions, efforts should be made to have their tumors sequenced, know their disease sub-type, know what treatments exist that have worked for others with this sub-type, and how they are likely to respond to specific drugs or combinations of drugs. Patients must be fully aware of potential side effects and whether they are reversible, diminish with dose modifications, and might impact their quality of life or ability to do their jobs.

**Finding clinical trials:** Fewer than 3 percent of adults with cancer participate in a clinical trial. Of those, how many are participating in the very best trial for their disease sub-type or simply a trial that is at their center? Patients should be directed to [clinicaltrials.gov](http://clinicaltrials.gov) and other clinical trials databases. Though hospitals already offer patient navigators throughout the process—and patients should, by all means, use this resource—it is imperative the patients are also able to self-navigate outside of their center if they need to.

**Make the most of health data:** Ninety-five percent of U.S. hospitals have implemented electronic health record systems, and yet only 36 percent of patients are currently using health portals. At the Multiple Myeloma Research Foundation, we've seen that more than 95 percent of newly diagnosed patients

use their portal, allowing them to go online and monitor their disease, to analyze health data to identify important trends and changes over time, and to easily collaborate with their healthcare providers in informed decision-making. Patients everywhere must be empowered to use this vital resource to take charge of their own healthcare and, should they choose, have the ability to share these health data to support research.

## THE GUIDE

What can we as patient advocates to do help?



**Diagnosis**  
Get educated through research



**Before Treatment**  
Map critical decision points



**Treatment**  
Know your options & their ramifications



**Clinical Trials**  
Use public databases to self-navigate



**Health Data**  
Take charge of your information