THE MYELOMA SURVIVAL GUIDE

SECOND EDITION

JIM TAMKIN, MD
DAVE VISEL

ESSENTIAL ADVICE FOR PATIENTS AND THEIR LOVED ONES
Praise for *The Myeloma Survival Guide*

“Dr. Jim Tamkin has turned his own illness into a benefit for patients with myeloma worldwide. Together with Dave Visel, they have developed a literal GPS system, an invaluable guide to patients with newly diagnosed multiple myeloma. Not only have they provided clear information on the disease and its treatment, but most importantly also conveyed critical guidance on how to deal with the very personal life-impacting effects of this disease for patients and family members alike. In this era of great excitement in myeloma where novel therapies are changing the treatment paradigm and improving patient outcome, this book assures awareness and access to patients and caregivers of these advances, so that patients can enjoy longer and higher quality lives with their loved ones. There simply is no greater gift than this.”

Kenneth C. Anderson, MD
*Kraft Family Professor of Medicine, Harvard Medical School*
*Chief, Division of Hematologic Neoplasia*
*Director, Jerome Lipper Multiple Myeloma Center and LeBow Institute for Myeloma Therapeutics*
*Dana-Farber Cancer Institute*
*Boston, Massachusetts*

“*The Myeloma Survival Guide* is filled with facts, factoids, tidbits, and anecdotal descriptions that would help anyone starting on their myeloma adventure. We have come a long way since the advent of transplants with the discovery of new novel agents and combination therapies. There is much to learn and much to do. I was pleased that Dr. Tamkin takes into account the vast differences in approach to the disease, its treatment, and whether or not cure is real. I would definitely recommend the book to my patients and their caregivers.”

Bart Barlogie, MD, PhD
*Director of Myeloma Research, Icahn School of Medicine at Mount Sinai*
*Founder, Myeloma Institute for Research and Therapy*
*Winthrop Rockefeller Cancer Institute*
*University of Arkansas*
“It’s tremendous for new patients to have this book. A myeloma diagnosis is overwhelming. Even as a physician, I did almost nothing but read for a month after my myeloma was confirmed. One of this book’s greatest values is that it covers everything in one place.”

Burton Dickey, MD
Myeloma Patient
Professor and Chair, Department of Pulmonary Medicine
MD Anderson Cancer Center
Houston, Texas

“This is the ultimate guide for all patients and caregivers as they navigate through the rapidly changing landscape of the myeloma diagnosis and treatment process. The authors have poignantly written The Myeloma Survival Guide from the unique perspectives of the patient and caregiver. The intimate knowledge of living with cancer allowed the authors to highlight common health and psychosocial concerns as patients are living longer than ever.”

Beth Faiman, PhD, MSN, APN-BC
Multiple Myeloma Nurse Practitioner
Taussig Cancer Institute
Cleveland Clinic
Cleveland, Ohio

“This is a wonderful primer for myeloma patients and their caregivers. It provides up-to-date knowledge while at the same time providing practical pointers for patients and caregivers to deal with this horrible disease. Since knowledge is power, this book will provide essential tools to allow patients and caregivers weather the ‘myeloma storm’ more prepared. I wholeheartedly recommend it.”

Sergio A. Giralt, MD
Chief, Adult Bone Marrow Transplant Service
Memorial Sloan Kettering Cancer Center
New York, New York

“As a patient, I understand how difficult it is for patients and their families to manage the uncertainties of a multiple myeloma diagnosis. Dave Visel and Dr. Jim Tamkin have collaborated to develop a detailed resource for approaching this situation, which will undoubtedly help newly diagnosed myeloma patients and their caregivers attain the information that they need to empower themselves throughout their journey with myeloma.”

Kathy Giusti
Founder and CEO
Multiple Myeloma Research Foundation
“This book is very good! It is direct and comprehensive and features just about anything and everything new myeloma patients, caregivers, and family members need to know.”

Pat Killingsworth
Multiple Myeloma Patient
Medical Journalist and Freelance Medical Writer

“I will hand this book to new myeloma patients, knowing that it will give them tools and a confidence that they would not have gotten without it. The teaching is clear, complete, accurate, easy to follow, memorable, and occasionally very funny. It produces better prepared patients for their oncologists to treat. When I learned that I had myeloma in 2007, I looked for this book. It was not there. Even though I had access to the medical faculty of a great university, my pathway to survival followed a much tougher road than you will be shown here. If you are a myeloma patient, or a caregiver, the key to the future is in your hands. Don’t put it down.”

John W. Killip, DDS
Myeloma Patient
Clinical Professor Emeritus
University of Missouri School of Dentistry
Kansas City, Missouri

“We have needed this authoritative, comprehensive, encouraging reinforcement for myeloma patients for at least 15 years. A copy should be placed in the hands of every new myeloma patient at the time of diagnosis.”

Robert A. Kyle, MD
Professor of Medicine, Laboratory Medicine and Pathology
Mayo Clinic Cancer Center
Rochester, Minnesota

“In a word, it’s fabulous! I can find nothing lacking in style or substance in this treatise on myeloma. I have been studying the literature on myeloma since my diagnosis in 2006. I have interviewed eight different doctors (five oncologists) relative to my treatment. Almost all of what I’ve discovered is in the first 90 pages and I’ve still got some reading to do! I’ve received written “what to expect” documents from both the City of Hope and the Veteran’s Administration—neither of which is this complete, enlightening, or well written. The authors have produced a well-documented . . . [and] wonderful tool for oncologists treating myeloma and their patients, caregivers, and other interested parties.”

Duke Rohlffs
Myeloma Patient
Mesquite, Nevada
The Myeloma Survival Guide
Also by Dave Visel

Living with Cancer: A Practical Guide

Also by Jim Tamkin

Manual of Ambulatory Medicine
(with Alan S. Robbins, MD)
We thank the Vasek and Anna Maria Polak Charitable Foundation and its Director, Soterios F. Menzelos, for the wise counsel and generous financial support that underpinned this project from its inception.
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You’ve been mugged. They didn’t steal your wallet. They stole your life. And there’s nobody you can call to get it back.

You did nothing wrong. At least nothing either you or the medical world can figure out. Your number just came up.

Multiply the U.S. population times .000094. That’s your number.

Thought of another way, your disease strikes one in 10,650.

You could have won a lottery beating odds like that. Instead you’re stuck with an incurable disease called myeloma.

Myeloma. As a name, it doesn’t even have the decency to be catchy.

Or famous. Nobody’s heard of it. When you tell people what’s wrong with you, they say, “Huh?”

That’s what you said when the doc first introduced it to you, isn’t it?

The other thing that’s really irritating is the unpredictability. There are at least half a dozen different ways myeloma can make you sick or bring you pain or give you some weird side effect like double vision or numb hands or back pain. It chooses one or all of them without warning. You shuttle from doctor to doctor for help. Sometimes it’s worth it. Sometimes not.
I’m pretty sure that the moment of your diagnosis was unlike any experience before or since. When you heard, *I’m terribly sorry to tell you* . . . the shock hit like a ton of bricks. You felt like you’d fallen into a dark, lonely place with nothing but questions and fears. Abandoned. Vulnerable.

I called it *no man’s land* when I first got there.

If you haven’t realized it yet, please know that soon, out of this confusion, darkness and fear, sanity will reappear. Yes, you have cancer. Yes, the situation is bad. But you have company. There are lifeguards on duty and ways for you to get to safety.

All sorts of help is coming, including people who intend to do things for you that you didn’t know needed doing and won’t be thrilled about.

Over 100,000 Americans have been plunged into this awful illness ahead of you and are still here. A lot’s going on in research. We’ve benefited, and so will you.

This sharing of life with an obscure incurable illness is no five-star accommodation. But the assembled experts in these pages offer you the best available ways to maximize damage control and—perhaps—to extend life.

Hang in and hold on.

Jim Tamkin, MD
Introduction

This is the myeloma patient’s guide to survival.

While a cure is yet to come, it may not be necessary. Several avenues to prolonged, high-quality coexistence with this cancer are being demonstrated and continuously improved.

With proper disease management, over 120,000 myeloma patients, who would have died, will credit normal or near normal lives to recent events in the few years just ahead.

**HOW COME NOBODY’S HEARD OF MYELOMA?**

In a world of practical limitations, the cancers that attack millions receive far more attention than the cancers that attack thousands. Out of a total U.S. annual expenditure north of $300 billion for cancer treatment and research in 2016, a pittance went into fighting myeloma and other rare afflictions.

Nobody's marching for myeloma. There's no symbol that everyone recognizes.

Many confuse it with melanoma, a dangerous but wholly unrelated skin cancer.

Meanwhile, dramatic medical progress is being made. This is a new day for both myeloma patients and their physicians.
BACKGROUND

In 1845, a patient with excruciating broken-bone-like pain and heat-soluble animal matter in the urine was studied. The disease responsible came to be known as *multiple myeloma* because of tumors spreading through the bones of legs, pelvis, back, and skull. Though treatments to ease pain and to slow its advance have been developed over the past 150 years, no definitive cause is known, or cure.

European cultures experience moderate rates of the disease while Black descendants of African races are two to three times more likely to be afflicted. Asians suffer it least often. Statistics for Native Americans are unreliable. We also know that 60% of its victims will be men and that it usually emerges in mid to late life. A usually harmless condition called *monoclonal gammopathy of undetermined significance (MGUS)* always occurs first. About 3% of those with MGUS, as it is universally known, eventually get myeloma. How either disease selects those it strikes or why others escape them are also mysteries.

Whatever ethnicity or age—or length of time with MGUS—death usually followed the onset of myeloma within 2 or 3 years, until recently.

**HOW THIS BOOK WAS WRITTEN**

Jim Tamkin, MD, FACP, FACE, a Los Angeles internist and endocrinologist, was diagnosed with multiple myeloma in 1999. At the time, life expectancy after the appearance of the cancer averaged 33 months.

Shortly thereafter, Dr. Tamkin visited the five leading myeloma oncologists in the United States and adopted a therapy program based on a composite of their recommendations. Though his disease remained aggressive, he was able to successfully manage it through a series of innovative chemotherapy protocols, until
a sudden turn for the worse in December 2010, 11 years after diagnosis.

Dave Visel met and interviewed Dr. Tamkin in 2001 as part of another book Visel was writing, *Living with Cancer*. Their meetings were candid and intense, with neither expecting to see the other again—at least not in this world.

So it was a pleasant surprise for them to meet again in March 2009. They discussed Tamkin’s survival at length, realizing that what was coming to be known about managing this still incurable disease would be of great importance to new myeloma patients.

The next 18 months were given to co-development of this project. Though Dr. Tamkin died in March 2011, the amount of time he had focused on myeloma therapies and disease management strategies may exceed that of anyone else in the world.

A general book outline, interviews, points of view, voluminous notes, and several chapters were in place before Dr. Tamkin’s passing, which Visel finished in the name of the partnership.

In addition, well over a hundred other distinguished men and women of medicine, other sciences, the law, education, health insurance, and public service have contributed their expertise to this book.
The Myeloma Survival Guide
Share
Part One

FIRST STEPS
TAKE CHARGE: YOU DON’T GET TO JUST SIT THERE

*Supervise your case.*

THE NUT OF IT

Your health care team wants you to understand the situation. It knows that if you do understand, and if you actively participate in the discussion of your treatment program, you will be a more successful patient.

CAN I DO THIS?

So here you are. Not feeling your best. Angry. Scared. Being presented with scientific jargon (see the Glossary for myeloma-specific explanations of the words and terms you don’t understand) and machines and decisions that would confound a PhD—and you’ve just started reading a chapter that says that this is your ship to steer.

The situation is actually worse than that. Research indicates that more than half of those who get multiple myeloma don’t know what’s happening or why. The result for them is catastrophic.

This is not just a ship—it is a ship in crisis. You are not just steering, you are directing both boat and crew. Your sailors are reporting awful things like boiler room failure and holes in the hull. They are recommending which to fix, and how—to you.
Decide to step up to this task and, together, we will make sure that you succeed.

**USE IT OR LOSE IT**

“I was a mile into my treadmill workout when coverage began to air of a healthcare forum at the White House. As I watched, I found myself gradually gaining speed, growing more and more upset.”

At this point in her essay published in the *Los Angeles Times*, Valerie Ulene, MD, a preventive medicine specialist, reveals a long-simmering frustration: “The plan demanded fundamental change from insurance companies, hospitals, and healthcare providers, and failed to address what patients have to do.”

We aren’t holding people accountable for their unhealthful behaviors, she says. Particularly after you discover that you have a serious illness, you must take care of yourself. If you don’t know what to do—and no one does on day 1—find out. Then take responsibility for getting the tests, seeing the specialists, doing the fact-finding, and reorganizing your life; whatever is necessary.

Find out what to do—that’s why this book is open before you—and get’er done.

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**Your Take-Charge Tools:**

- Don’t expect the government or anybody else to run this treatment program for you.
- Don’t do it alone. Get a partner–caregiver.
- See the Glossary in the back of this book for definitions of myeloma-specific terms.
- Keep good records.
- Know the goal you are working toward.
FIRST THING: GET A PARTNER–CAREGIVER

As a myeloma patient, you are beginning a long, complicated, physically and mentally taxing journey. There will be doctors and insurance people and hospital and lab people—also bankers and lawyers and your friends to deal with. On top of that, all the demands and responsibilities you had before you got sick are still there.

You may think you can handle this mess by yourself. Don’t try it. You will screw up in ways that you will deeply regret. Get someone by your side, helping you keep your house in order.

Everybody needs somebody. The Lone Ranger had Tonto. DeBakey had Ochsner.

PARTNER–CAREGIVER CANDIDATES

If you are married, consider reading this chapter and the next two with your spouse beside you. Think about the pros and cons of using your marriage partnership as the springboard for caregiving. There are a dozen reasons why a spouse should take on this job. There may be strong arguments against it. Only the two of you can sort this matter out.

Next option: Recruit another family member or a friend. This sort of team often works well, even if this person has no qualifications beyond friendship and a willingness to try.

Before exploring this choice, be warned that yours will become a very personal relationship. You will need somebody with maturity and staying power.

You may also elect to hire a professional caregiver. While paid help is financially draining, a person who knows how to give a shot, has a driver’s license, and is strong enough to help you get about may be a wise investment.
A variation on this theme is to reserve paid assistance for the times that you and your partner–caregiver need peaking power.

**CAREGIVERS NOT TO HIRE**

If you employ a paid helper, look for daily evidence that your caregiver cares about you. You will see plenty of the other kind helping the halt and the lame in the offices of the doctors you visit. These obviously bored helpmates, providing dissolute service, make thoughtless, and dangerous mistakes.

Even if you hire a personal nurse from one of the medical concierge services that prowl high-rent districts, be certain that you have put yourself into enthusiastic helping hands.

A candidate caregiver who comes out of the hospice industry may not be a good choice. We will all approach that great gettin’ up morning one day. Let’s not make it a day next week. Work with someone who thinks more about remission and your bucket list than about the kicking of the darn thing.

**KEEP THOROUGH, WELL-ORGANIZED TREATMENT RECORDS**

One of the benefits of being in charge is that you will make a point of noticing what’s going on in the offices and laboratories you visit.

Each office you visit keeps its own records. Some are scanty. Some are voluminous. None includes all the records from all the other places you go for help. You are the only one who can do that.

**Illnesses and Treatments**

A simple history, including date, the reason you went to the doctor, the doctor’s name and specialty, and medical tests and treatments, could look like this:
Illness and Treatment History
(From the date myeloma was discovered to the present)

Name: ____________
Year: ____________

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<tr>
<th>Date</th>
<th>Condition</th>
<th>Physician</th>
<th>Treatment</th>
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<tr>
<td>1/3/14</td>
<td>Fell. May have fractured a rib.</td>
<td>Jane Doe, MD, our long-time family doctor</td>
<td>X-ray revealed</td>
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<tr>
<td>1/6/14</td>
<td>Fracture and other conditions need to be diagnosed.</td>
<td>Dr. Doe</td>
<td>Ribs taped. Blood samples taken. MRI.</td>
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This simple table can be created with a pencil and ruler on notepaper. If you have access to a computer, a table like this one can be created in Word, in Excel, or in any of many other programs. Keep the information short, legible, and current. Be careful to spell medical terminology accurately.

“I have found that since I began keeping careful records of my treatments and side effects, I have better conversations with my doctor.”

—Doug B.

Drugs, Herbs, Vitamins, and Supplements

You should also carry a record of all of your drugs, herbs, vitamins, and supplements: name, size of the dose (often in “mg” or milligrams), and how frequently you take them. Keep the list
current and simple. Do not forget to include any chemotherapy
drugs, blood infusions, or other serum products. List any allergies
and allergic reactions or side effects you experience.

These data will help many of the healers you visit. Your record
is also a safety measure. “Oh, you’ve taken dexamethasone. Then
we should . . .”

Sample:

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<th>Date</th>
<th>Medication</th>
<th>Dosage (mg)</th>
<th>Frequency</th>
<th>Notes</th>
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<th>Date</th>
<th>Vitamins/Herbs/Supplements</th>
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Prescriptions, Receipts, and Test Results

You will also need file folders to keep all of your prescriptions, receipts, and test results. If you’re told to do something, get a prescription or written order. Try to never leave the office of someone who has told you to get something without the prescription for it. Always keep a copy of the prescription in your files.

Also save phone numbers, addresses, patient ID numbers, and names of key contacts.

Myeloma Manager Software

If you or your partner is computer savvy, the International Myeloma Foundation sponsored the creation of disease management software, *Myeloma Manager, Personal Care Assistant*, which is offered as a free download at its website, www.myeloma.org. It is thorough and myeloma-treatment specific. It is easy to use. However, entries must be made almost daily, which can make it become an insistent chore. Some find that keeping file folders and maybe a three-ring binder are a sufficient alternative.

Either way, you will be quickly lost if you don’t establish a good record-keeping system and maintain it.

**LONG-RANGE GOALS**

One cannot leave a discussion of taking charge without deciding, *Of what?* What are your goals?

The physicians treating your disease seem to have one of two objectives in mind for you. Some want to find a cure. Others
will guide you into any port that shelters you from the present storm.

“\textit{I think the focus on curing myeloma has been distracting for both my colleagues and their patients,}” says Sergio A. Giralt, MD, Chief, Adult Bone Marrow Transplant Service, Memorial Sloan Kettering Cancer Center, New York City. Patients do a lot better when treatment decisions are based on a balance of estimations.

First, patient and medical team should look at how a proposed new treatment may affect patient longevity, then at how it may affect quality of life.

If these two questions seem simple to you, reconsider. Each can be multilayered and quite complex. Each deserves input from your myeloma specialists.

If the answers for longevity and life quality encourage it, evaluate how burdensome the treatment will be for you. Is it worth it? What are you buying? What are you giving up?

Some medical procedures may only be effective once. Others only work if your kidney health or some other specific condition meets criteria that could change. Is this the time to chamber your silver bullet?

Dr. Giralt explains that treatment innovations and drug developments have brought us into an era in which many myeloma patients will outlive current four- or five-year estimations—maybe by decades. Though probably not cured, their disease will be controlled, become indolent—detectable but not aggressive—or go into remission, no longer detectable.

The goal of Dr. Giralt's treatment strategy is a tie, not a win. Given the finality of losing, and the so far unsuccessful search for a cure, it is a third alternative to seriously consider.

If you adopt this goal, you should share it with your caregiver, family, and friends. Your selection of a medical team will be influenced. There are treatments and clinics your goal will steer you toward and others you will be directed away from.
When You Hear Hoofbeats, Think Horses Not Zebras

The worst thing about being in charge is that you have to accept responsibility for what’s decided. Here are a few travel rules for the decision-maker’s road:

- When diagnosing, first consider the obvious. (Sutton’s Law\(^1\))
- Does it pass the giggle test? (Can you seriously consider the idea?)
- Sometimes the hardest thing in life is to know which bridge to cross and which to burn. (Eric Warren Singer)
- To know little and to be proud of knowing little is disrespectful. (Peggy Noonan)
- Battles are fought by scared men who’d rather be someplace else. (James Bassett)
- Any fool can make a rule, and any fool will mind it. (Henry David Thoreau)

\(^1\)Not Dr. Sutton, Willie Sutton, the Chicago gangster, who, when asked, “Why do you rob banks?” Snorted, “Because that’s where the money is.”