

# THE DECISION TREE

TAKING CONTROL OF YOUR HEALTH  
IN THE NEW ERA OF PERSONALIZED MEDICINE



THOMAS GOETZ

# THE DECISION TREE

TAKING CONTROL OF YOUR HEALTH  
IN THE NEW ERA OF PERSONALIZED MEDICINE

THOMAS GOETZ



This book is intended as a reference volume only, not as a medical manual. The information given here is designed to help you make informed decisions about your health. It is not intended as a substitute for any treatment that may have been prescribed by your doctor. If you suspect that you have a medical problem, we urge you to seek competent medical help.

Mention of specific companies, organizations, or authorities in this book does not imply endorsement by the author or publisher, nor does mention of specific companies, organizations, or authorities imply that they endorse this book, its author, or the publisher.

Internet addresses and telephone numbers given in this book were accurate at the time it went to press.

Portions of some chapters have appeared, in different form, in *Wired* and the *New York Times Magazine*.

© 2010 by Thomas Goetz

All rights reserved. No part of this publication may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopying, recording, or any other information storage and retrieval system, without the written permission of the publisher.

Rodale books may be purchased for business or promotional use or for special sales.

For information, please write to:

Special Markets Department, Rodale Inc., 733 Third Avenue, New York, NY 10017

Printed in the United States of America

Rodale Inc. makes every effort to use acid-free ♻️, recycled paper ♻️.

Illustrations by Victor Krummenacher

Book design by Chris Rhoads

### Library of Congress Cataloging-in-Publication Data

Goetz, Thomas.

The decision tree : taking control of your health in the new era of personalized medicine / Thomas Goetz.

p. cm.

Includes bibliographical references and index.

ISBN-13: 978-1-60529-729-3 hardcover

ISBN-10: 1-60529-729-1 hardcover

1. Self-care, Health. 2. Medicine, Preventive. 3. Medical screening.  
4. Medical technology. I. Title.

RA776.95.G64 2010

613—dc22

2009038550

Distributed to the trade by Macmillan

2 4 6 8 10 9 7 5 3 1 hardcover



We inspire and enable people to improve their lives and the world around them

For more of our products visit [rodalestore.com](http://rodalestore.com) or call 800-848-4735

# THE DECISION TREE

**FOR WHITNEY,  
REX, AND BUCK**

## Introduction

Every night, Laurie Fournier looks at a chart of the human body and makes a decision: where to stick the needle.

Like 400,000 other Americans, Laurie, a 48-year-old massage therapist living in a suburb of Minneapolis, has multiple sclerosis (MS), a disease classified as an autoimmune disorder, meaning one in which the body turns against itself. In the case of MS, the immune system targets the central nervous system, in particular the fatty sheath that covers each neuron. In someone with MS the immune system, which normally assaults damaged cells or invaders, perceives this sheath—known as myelin—as an antigen that must be destroyed. Alas, these myelin sheaths are not ordinary fat; they have the essential task of carrying electrical signals from nerve to nerve throughout the body. And so, as the immune system's T cells begin their attack, a person with MS may notice certain things starting to go wrong. His eyes might begin to twitch, he might have trouble pronouncing words, or he might simply feel off-balance. These symptoms can come and go in episodes, randomly enough that it typically takes years for someone to assemble the various symptoms into a pattern that leads to a diagnosis of MS.

There is no cure for MS, but there are treatments—drugs to slow

down the immune system or distract the body from its self-destruction. In Laurie's case, a drug called Copaxone (glatiramer acetate) seems to act as a decoy to the T cells, drawing them away from the myelin and thus impeding the disease's progress. Like insulin for diabetics, Copaxone is delivered by regular self-administered injections. Learning the technique takes a certain amount of practice, particularly since Copaxone can cause some annoying side effects at the injection site, such as itching, swelling, lumps, and redness.

This is why Copaxone users like Laurie plan their shots using a chart that marks the body into a grid. This "shot journal" notes about 60 potential injection sites on the abdomen, arms, and legs. It's important, Laurie says, to follow a sequence and avoid putting today's shot too close to yesterday's or the day before's. "If you keep hitting the same spot, the tissue becomes fibrotic," she explains, making it difficult to flex the muscle. So before she goes to bed, she consults the chart, delivers the injection, and marks a box in the body grid with an X.

Laurie, who describes herself as an "information junkie," deals with these details with a blasé precision. MS can be an exhausting disease that weighs on people throughout the decades that they must live with it. But Laurie doesn't consider herself much different from anybody else. "Pretty much everybody I know over 45 has some kind of medical condition," she says. "Some people have had cataract surgery, or they have high cholesterol or diabetes. Everyone has something. And if everyone has something, that really levels the playing field."

Laurie is exactly right. When it comes to our health, we all have something we need to heed. Maybe it's a bum knee or a sore back, or perhaps it's something more serious, like cancer. It could be we've been diagnosed with a risk-based condition like high blood pressure that puts us in jeopardy of developing a more dangerous disease. Sure, some people are exceptions, those few who are in 100 percent perfect health today—in which case, well, something certainly looms for them in the future. The fact is that past a certain age, every one of us is made aware that his or her health is a variable, not a constant. At some point, health becomes complicated, something we must tend to, and often something scary.

And we learn that health demands that we make choices and compromises. But even before that happens, we need to be paying attention.

Laurie Fournier's circumstances—the gravity of her choices—might seem a world away from our own health concerns. Yes, we should exercise more, and we should eat better (and less). But by and large we may not think of health as an issue. We visit the doctor regularly and deal with the results when they come. We're doing fine. From this perspective, we'd define health as freedom from disease or illness. But that binary definition misses the subtle way we actually *experience* our health. It misses the multitude of other considerations, from our quality of life to our ability to meet a specific goal—be it to run a marathon or simply walk to the car—that go into caring for ourselves. And it misses the opportunity we all have to actually better our health, to improve the quality of our lives and pursue more ambitious goals. And in this regard, our health is very much like hers.

In truth, we are constantly making a series of decisions, some unconsciously, some with great intent, that combine to create our health. Some of these decisions can be easy: remembering to go to the dentist for an annual checkup, or opting to take a statin drug if we have high cholesterol. Others are exceedingly difficult and apt to provoke anxiety. Women with a high genetic risk of breast cancer, for instance, face a choice of whether to have a preemptive surgery or to begin drug treatment. Men diagnosed with prostate cancer typically choose between surgery or radiation treatment—both of which carry significant side effects—or decide to do nothing, hoping the cancer remains quiescent. Health is a constant negotiation between what we *want* to happen and what *may* happen. In health as in life, uncertainty is always part of the equation.

Medical science has made stupendous progress over the past 100 years. In 1910, polio and smallpox were common around the globe, crippling or killing millions of people. Today, vaccines have made the first almost unheard of and the second alive only in a few laboratories. In 1910, diabetes was a horrible disease that was treated with starvation, baths, and amputation; 30 percent of people with diabetes died from it.



Today, insulin injections and careful blood-sugar management have made it an entirely manageable disease. We are all infinitely better off for these innovations, and they are rightly hailed as miracles of science.

By and large, though, medical knowledge has been accessible only through an inefficient and cloistered health care system; our only entry point has been through the expertise of a physician. The education and training required to be a doctor is staggering, and physicians are rightly esteemed as an expert class of stature and influence. But the patient's role in his or her own care, ironically, has been an afterthought at best and a distraction at worst. Making medical decisions has been the physician's job, never our own. When we seek treatment, we often find ourselves lost, adrift in a poorly designed system that pushes us along quickly and officiously from the silo of one specialist to the next. We're told to always ask our doctors, but then we're consigned to less than 15 minutes of face time in an office visit. When we seek out information, we get lost in a muddle of contradictory studies and imprecise advice. Too often, we come to realize that the best opportunity for action is already gone, having come before we even thought about our health. All in all, this is not the way to stay healthy. And it's not the way a 21st-century society, with a health care system steeped in science, should treat its citizens.

THIS BOOK IS ABOUT HOW we can make better choices for our health. Today, we have the opportunity to engage with our health more prudently, more strategically, and more effectively. We can engage through new science and technologies, tapping the best practices of genetics, behavioral science, information technology, and even each other. We can make sense of the babel of data to craft a personal strategy for making the best choices that lead to the best outcomes. We can take a central role in our health and be the better for it.

The central organizing principle of this approach is a *Decision Tree*, a system that maps out our options, factors in all the relevant information and our backgrounds and statuses, and guides us toward the best possible decision, whether the choice is to take a screening test or not,

how to best respond to a diagnosis, or whether to try a new drug. A Decision Tree is a simple idea—many of us, after all, learned to draw them in the form of flowcharts in fourth or fifth grade. But in an age of too much information and too little guidance, they're a handy way to think about our options and take some control over our health. On a basic level, a Decision Tree is simply a tool that nudges us to think through our options, to act consciously and with consideration. And it puts us in the central role as decision makers—not the doctor, the insurance company, or a hospital administrator. By factoring in our family histories, our good and bad habits, and, ultimately, the conditions we need to ward off or treat, using a Decision Tree approach can maximize our efforts to push ill health, and ultimately death, as far into the future as possible. It's a powerful way to think about our health.

Decision Trees are already all around us. They're common in engineering and industry, where they're known as algorithms. The pharmaceutical industry uses them to predict drug safety in clinical trials. Computer scientists use them to root out patterns of credit card fraud. They're even used by civil engineers to plan streetlight patterns and map out school bus routes. And over the past decade or so, they've become a common tool in medicine, used by doctors to weigh the effects of different interventions and factor in various probabilities for various treatments. In these cases, Decision Trees can be complicated structures laden with mathematics and computer science. But they needn't be only for the experts. A Decision Tree can be as straightforward as writing down the pros and cons and noting the risks and benefits *before* we act.

Think of it this way: Health is, in many respects, a system of inputs and outputs. The inputs start with the huge number of choices we make every day that have a great influence on our health: what we choose to eat, whether or not we exercise, how much we sleep, whether we heed our doctors' orders. These choices combine with other inputs, things that we may not even consider to be medical information and that we probably know much more about than our doctors—like our family history, where we live, our jobs, our stress levels, and so on. All of these inputs together create one primary output that is unique to us alone: our health, for good or for ill. This is our Decision Tree. This is the opportunity

before us. The more we're conscious of these inputs, the more often we take the time to think them through and maybe even write them down, the better are our chances of making the best decisions and having the best lives. The ideas and science and stories inside this book are meant to help each of us grasp that opportunity.

So what does a Decision Tree look like? Throughout this book, I'll present different people's Decision Trees as a way to make explicit the choices they face and how they're weighing their situations. Sometimes actually putting pen to paper and sketching out a Decision Tree can be helpful. But chiefly, a Decision Tree is a concept, a frame of mind that helps us think about our health, a process that should begin years before it typically does.

THERE ARE THREE FUNDAMENTAL PRINCIPLES of making smart health choices. They are common rules that can make a decision about whether to have a screening test or undergo surgery or begin a new diet more likely to result in a good outcome.

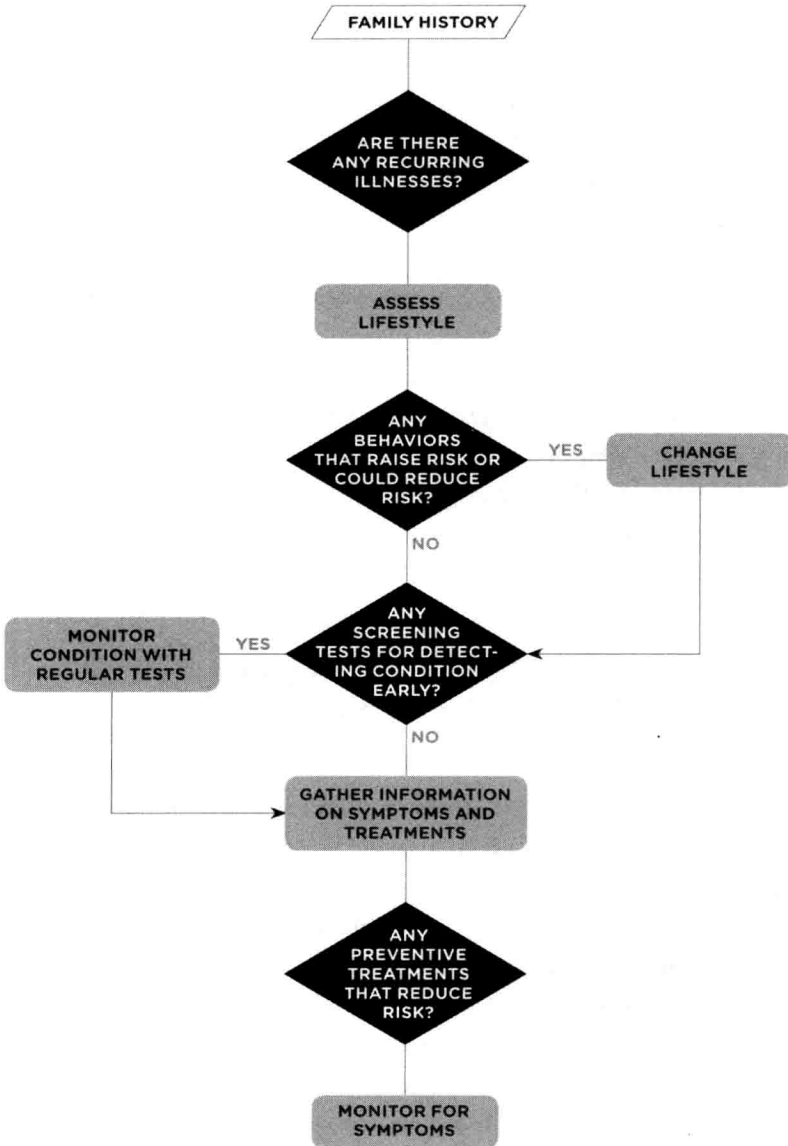
## **THE FIRST RULE: EARLY IS BETTER THAN LATE**

It's well known that the earlier medicine begins to treat disease, the better the outcome. And when we treat disease before it happens—by going after risks rather than symptoms—we can do even better. These days, “acting early” means that by learning our genetic predispositions—starting, when possible, at birth (or even before)—we can modify our choices in life. “Acting early” means that when we're at a higher-than-average risk for something like colon cancer, we'll go ahead and have a colonoscopy regularly (screening, after all, is better than surgery). And if something is found, treatment will be a much simpler and less invasive process, with far better odds of success.

Acting early sounds like the obvious path to take, but it's far from the norm in health care today. Indeed, more than 70 percent of the

## A Decision Tree for Health

Thinking actively about our health concerns and choices not only improves our decision making—it can improve our well-being. Here's a sample of how a Decision Tree can start with some basic family history.



\$2 trillion spent on health care in the United States goes to chronic disease treatments and late-stage interventions. This is the status quo of health care today, and, like any status quo, it won't be easy to change. Most doctors, as I'll explain, are compensated for exactly the wrong things: diagnosing and treating disease, rather than preventing and warding off illness. Often, if there's nothing wrong, there's nothing a physician can bill for. Some screening procedures are covered by insurance, but not enough—and don't even think about trying to get a genetic test covered without an exceptional reason.

Acting early is hard for individuals as well. We Americans have proven ourselves to be awfully slow about engaging with our health before something goes wrong. Screening rates for simple procedures that are known to improve outcomes—regular testing for colon cancer for example—are consistently low. And the rising obesity rate—two-thirds of Americans are now overweight, with 30 percent of that number qualifying as obese—shows that we're not good at taking preemptive action on health matters. Obesity can open the door to many worse conditions, such as type 2 diabetes, heart disease, and stroke. Acting early, in other words, can be more difficult than it sounds.

## THE SECOND RULE: LET DATA DO THE WORK

*Data* can be a scary word. It brings to mind statistics, formulas, and lots and lots of numbers, the stuff we thought we left behind back in calculus class. But data is very much the foundation of medical science, where fealty to scientific rigor has made possible so many of the treatments and cures we count on today. In the past decade or so, this faith in data has spread to the doctor's office with the rise of evidence-based medicine, which insists that a caregiver's every decision be based on clinically valid research. And, as we'll see, now there are even opportunities for individuals to heed more complicated data as well, to be guided by statistics and true probabilities to make better-informed, smarter decisions.

There's another sense in which data can play a part in our health

decisions: the data that we generate ourselves. More than just the workup from a hospital or doctor's office, we generate a constant stream of information. It's in our diets, our exercising, our moods, our DNA. And just as the recommendation engines at Amazon.com and Netflix.com use our customer histories to help us choose the right book or movie (or, at eHarmony, the right spouse), this data constitutes powerful information that can help inform our health decisions. This data can create a feedback loop for better health. Knowing our personal data gives us a baseline from which to evaluate our future health, revealing whether we're improving or slacking off. It can also be used to fine-tune the risks for disease, augmenting the population-level numbers we're all given (the 36 percent risk of developing heart disease in America, or the 8 percent risk of developing type 2 diabetes) to create personalized risk models that tell us what each of us should prioritize.

This drive toward data, of course, means that each of us must become more comfortable with predictions and probabilities, more at ease with weighing our options based on statistical risk rather than symptoms. Navigating our way through the data can challenge the best of us. But as I'll explain in Chapter 1, research shows that, when numbers are properly framed, ordinary people are more capable of handling them than many medical professionals assume. What's more, research has shown that in many of the medical decisions we're faced with—how to interpret a test, how to decide upon a treatment, or when to move to a different treatment—trusting data can improve our decision making and our outcomes.

## THE THIRD RULE: TRUST IN OPENNESS

In the technology world, *openness* and *transparency* have become the new buzzwords as the principles of collaboration and sharing have spread from open-source software to Wikipedia to Yelp.com. Bringing openness to health care, on the other hand, sounds like a less obvious proposition. Sharing our personal information with strangers sounds downright risky. After all, doesn't more openness mean less privacy?

The answer is both no (not necessarily) and yes (but it's nothing to worry about). The truth is that our personal information, including our health information, is a currency, something we can exchange with others to create new, more powerful information. Facebook and Twitter have changed the notion of privacy and fostered a much more open display of personal information that has yielded all sorts of benefits in terms of friendship, entertainment, and even political change. The same sort of structure, sharing, and cooperation can benefit health care as well.

At the very least, bringing more openness to our decision making means demanding more transparency from our physicians. We shouldn't have to ask for copies of our medical records or test results, and when we do, they should be provided without hesitation. Our doctors should be urged and, indeed, expected to fully integrate patients into making decisions on medical care. Openness, not paternalism or isolation, should be the default mode in health care.

Openness can offer even more in the form of collaborative research. Individuals are now able to share information about their genomes to create new bodies of information about genetic risk, and they're contributing information about their drug dosages and symptoms to build information banks that can help everyone maintain their health or treat disease. This is how Laurie Fournier became such an expert about Copaxone injections—by sharing her information and experiences and learning from others at a Web site called PatientsLikeMe (I discuss the company at length in Chapter 10). Yes, this means contributing private information, but only with full knowledge of what we're giving up and what it's being used for. Anonymity is always an option. But openness can have another powerful benefit for individuals facing health decisions. Openness reduces isolation. It helps to know that someone else has faced the same quandary we have. That can be a powerful medicine all its own.

THESE THREE PRINCIPLES aren't just smart ideas or vogue philosophies. They have all been scientifically associated with better health. Early detection of ovarian cancer, for instance, can boost the odds of

survival to upwards of 90 percent, a huge leap from the mere 15 percent survival rate for a cancer found in the last stages (I get into this in Chapter 7). Tracking and monitoring our own data has been strongly associated with good health, not only because it makes it easier to lose weight or lower our cholesterol levels, but also because it seems to offer us a sense of control that contributes to better health and well-being (I'll explain more about this notion of control in Chapter 1). And openness has become a resonant topic in medical research: Having strong social networks has been linked to success in quitting smoking, losing weight, and modifying other behaviors (as I'll discuss in Chapter 4).

What's more, there's also ample evidence that using a Decision Tree approach can, in general, have a positive impact on health. Research has demonstrated that individuals who are actively involved in making their own medical decisions have significantly better outcomes than those who rely only on their doctors to make the calls. In other words, simply by participating in the process, we're more likely to have better results. The more we mind our health, the more we take charge of it (rather than being subject to it), the better our outcomes. This is the power of the Decision Tree.

THE IDEA FOR THIS BOOK came to me a few years ago, during a hectic period when I was simultaneously working as an editor at *Wired* magazine in San Francisco and studying for a master's degree in public health at the University of California, Berkeley. Early every morning, I would drive across the Bay Bridge to the campus, where I'd wrestle with epidemiology, biostatistics, and health economics. I was captivated by the discipline of public health, its deference to data, and its mandate to think in the largest possible scale—populations, not individuals. Public health, I learned, had been preaching the mantra of prevention long before it became fashionable. After all, the cheapest, most efficient way to improve the public health is to keep the public healthy in the first place.

This approach was best described to me by S. Leonard Syme, PhD, a legendary figure at Berkeley who pioneered the study of social causes



of disease. In a lecture one morning, Dr. Syme challenged his students with a scenario: People are traveling in their cars along a highway, only to find that the road heads directly off a cliff. Not surprisingly, this creates a pileup at the cliff's bottom, with all sorts of injuries and fatalities. "So where do you put the hospital?" Dr. Syme asked the class. It was, of course, a trick question. Conventional medicine tends to build its hospitals at the base of the cliff, where the bodies are. But the answer from a public health perspective would be to avoid building a hospital at all. Better to move the highway, or build a bridge, or somehow intervene *before* people plunge into the abyss. Sure, it sounds obvious, but then again, if it's obvious, why does preventive medicine get such short shrift? It's a simple lesson, but a profound one.

After attending my classes each morning, I'd race back across the bridge to San Francisco and shift my attention to my job at *Wired*, where we chronicle the profound impact technology is having throughout business and culture. At the time, Silicon Valley was in the early throes of what's called Web 2.0—a new generation of Internet tools that draw on an individual's own participation and collaboration to create a highly personalized online experience. Facebook, MySpace, and Twitter are all spawn of the Web 2.0 boom. The power of personalization was taking off.

As months of this back-and-forth went by, I was struck by the unfortunate disconnect between the public health world and the technology world. After all, technology and public health both share an appetite for scale—the idea that an innovation becomes more powerful as its cost drops and accessibility increases. In technology, this is known as Moore's law, and it's what makes digital cameras and high-definition TVs and so many other digital gadgets cost half as much this year as they did last year. Public health is all about scale, too—vaccines are the perfect cheap technology, as are simple, cheap screening tests like mammography and blood tests. But many corners of the public health world harbor a suspicion of technology, a worry that bells and whistles distract from the goal of bringing health to the maximum number of people. In part, there's good reason for doubt. Modern medicine has too often gotten technology wrong, letting it drive costs up rather than down. A major factor in