



# EAT YOUR RICE CAKES

DISCOVERING  
EMPOWERMENT  
AFTER A  
LIFE-CHANGING  
DIAGNOSIS

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# INTRODUCTION

*There I was with the door locked, cocooned in the tiny space of my main floor powder room, on full alert for unwanted observers. I had grabbed an entire unopened sleeve of Oreo cookies from our family “snack closet” and was systematically chewing and then spitting each cookie into the toilet, one after the other, without swallowing. Never one to dunk an Oreo in milk or split one open to scrape the filling off with my teeth, I popped each cookie into my mouth, whole and dry, just the way I like them. They tasted exactly how I remembered, chocolatey and sweet.*

*This was how I ushered in the spring of 1995, about four months after I was diagnosed with celiac disease. I not only had to learn a new diet that excluded a mysterious new vocabulary word, “gluten,” but I also had to retool many logistics in my life, such as cooking, shopping, and traveling.*

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*My favorite warm weather flower plantings, pool openings, barbecues, and kids' team sporting events were unfortunately taking a back seat to the time and effort I needed to make these new adjustments. Happy with and accustomed to the varied, spontaneous lifestyle and eating habits I already had, I was a reluctant student. Reluctant to disrupt what had been working year after year, and reluctant to introduce into the mix what looked like difficult and unexpected struggles. I was the only one in my immediate family going through this transition, and the unhappy feeling that I'd had a "monkey wrench" thrown into my life put me in danger of spiraling into a bad place.*

*I really did spiral down that afternoon, cloistered in the bathroom with the Oreos. Having promised to start their homework after dinner, my two young sons were huddled in the basement, laughing and shouting as they tried to conquer the latest video game. Their father was not due home from work for hours, and I was alone. Alone and hungry. None of the food I had purchased for my new diet seemed appealing, and I was incredibly tempted by the smell of all those now-forbidden, gluten-containing breads, pastas, cookies, and cakes that were in the house.*

*How I loved those smells! The memory of eating those old favorites was still fresh in my mind. The familiar smooth and creamy textures of baked goods and the moist and spongy consistencies of breads were nothing at all like the crumbly,*

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*dry “imitation” versions I was now forced to substitute for these all-time favorites. I hated the changes I saw in front of me, and how they clashed with how I really wanted to live. The habits and patterns that used to be enjoyable and easy were becoming unpleasant and burdened with lots of rules and restriction.*



Things change all the time . . . isn't our world evolving at what feels like a crazy pace? Many of us find ourselves with little choice but to greet changes to our personal circumstances in the name of progress and growth. Our ability to adapt to change is one of those unavoidable yet invaluable skills that are necessary to live on this planet.

But change also has a tendency to shine a stark spotlight on its alter ego: the things that stay the same. When the dueling pair of change and sameness presents itself, we can't help but measure and compare the two. This juxtaposition is a lightning rod for our emotions when we stretch into a new direction or trajectory, as we navigate back and forth between familiar comfort and unwelcome upheaval. And it's also logical that in this atmosphere we cling a bit more to that familiar comfort. I know I do!

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On that day in 1995, I didn't want to focus on the change that came with my diagnosis. In fact, my head was somewhere else entirely. I was absorbed with one of those favorite, familiar constants: the transition from winter to spring in central New Jersey.

Born and raised on the East Coast, I could always count on the predictable lush flourish that comes after the gray winters typical in this part of the country. Just like a birthday or an anniversary, I was celebrating the blooming of daffodils and forsythia common to where I lived. I also loved to keep an eye on fresh sprouts as they gradually appeared on branches in the woods behind our house, savoring my own made-up game of predicting the exact day they would—by some amazing unseen cue—all bloom at once and turn all of the winter bare trees and bushes green for the summer. Plus, I can't forget the predictable appearance of two robin red breasts that I swore to anyone who would listen was the same faithful pair that returned every spring to nest and feed in our backyard. These were happy events—predictable and enjoyable—and I looked forward to them every year. Yet, the spirit of my devoted ode to spring had been broken by the inescapable and unwelcome adjustments brought on by a change in my health.

Did my moment of sheer recklessness and defiance make me feel better? Actually, no it did not. Once I finished

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chewing and spitting out the cookies, I realized that I had added yet another element to the emotions I was already feeling: Guilt! Guilt that took over most of my brain in the moment, leaving me to feel ugly and a bit evil. I had foolishly hoped that my spitting out the cookies after chewing them would remain undetected and do no harm to my body. However, the entire episode did nothing but demonstrate in very stark terms an overview of what was to be my new normal: initially, a desire for forbidden foods, then the internal fight of “should I or shouldn’t I?” and finally, the resulting guilt if I gave in to my temptation and was personally responsible for hurting my own body.

I clearly grasped all of what my diagnosis and dietary changes meant to my health and everyday activities, and it made me feel even worse. I ached for the life I had when I could easily share meals with my family, friends, and colleagues without worrying about ingredient lists or the risk of cross-contamination. Now that I had celiac disease, this free and easy life was taken away and replaced with changes that seemed difficult and frankly unfair. I was beginning what would be a long, firsthand education in what it means to feel deprived, to feel different, and to have the need to plan ahead. I was experiencing what it feels like to “fall off the wagon,” and all of the guilt associated with that. And I was forced to master the reconstruction of parts of my everyday life that would help me stay on my

new regimen.

What a moment in time this diagnosis presented! Nothing would ever be the same. Life was no longer just about freedom and spontaneity. It was now about restriction, precaution, and vigilance too.

Many years later, I ended my stint as a stay-at-home mom, went back to school, and began a new and varied career as a registered dietitian and a diabetes care and education specialist. Now with about fifteen years of counseling individuals behind me, I have served in many different institutions and settings. I worked in the ICU for a large teaching hospital, wrote online articles for a supermarket chain, and counseled patients privately. A large healthcare system in New Jersey gave me the opportunity to start and manage a dedicated center that promoted advocacy, treatment, and education for individuals living with celiac disease. And, most recently, I spent several years as an educator for a major pharmaceutical company, providing diabetes education and training for physicians, office staff, and patients.

In all of these roles, one common element always stood out. No matter where I worked or what clinical prescription or diagnosis I was supporting, I had to promote new lifestyle changes to achieve optimal health. And these changes were usually drastic and required quite a bit of counseling and follow-up with my patients, whether they were

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managing celiac disease, obesity, heart disease, diabetes, or any other significant diagnosis. I could not help but tap into and apply to my work everything that I had personally learned about change and my own forced transition as a patient with celiac disease. I actually felt fortunate that I had had these experiences myself and could connect with patients about their own monumental life changes in such an intimate and sympathetic way. I know my patients felt that connection with me and appreciated it too!

I came to fully appreciate the power that being both a patient and a provider can provide very early on in my career. One of my first patients, an eight-year-old girl, had sadly lost her beloved dog within days of finding out she had celiac disease, doubling her feelings of loss and disorientation. I confessed to her that I had lost my own dog a few months earlier and pointed to her picture on my desk. I could see the wheels turning in her head, and she actually said to me, “You mean you have celiac disease *and* your dog died?” She visibly relaxed, and we then used that picture as a launching pad to explore some of her feelings and allow for some much needed commiseration and compassion. It was a perfect example how shared personal experience can be extremely helpful when talking with someone about adversity. Since then, I have been continually impressed how the mutual understanding that comes from a common experience proves to result in better clinical improvement



and faster emotional acceptance for the individuals I have worked with.

The array of challenges and opportunities both patients and clinicians face are many and complex, and the experiences and insight I have gained in both of these roles inspired me to write *Eat Your Rice Cakes*. Patients and providers each strive to manage change and achieve optimal health by conforming adjustments and new situations to existing lives and activities—although they get to these goals in different ways. I’ve seen a lot of what motivates and what burdens each of these two groups as well. How we treat change can be subjective, such as our emotions and feelings, or it can be more objective, such as the information we find in clinical literature and textbooks. Rather than espousing or applying them individually, I’ve come to know that an approach that *combines* details from both “life” and “textbook” provides the best support to treat patients undergoing change. Because of this, I now embrace a blend of approaches to treatment derived not only from my own history but also from those of the patients and providers with whom I have connected and collaborated over time.

This dual perspective has historically opened the door to an incredible number of positive encounters, substantial growth, and sustainable healing for all involved. Taking this success into account, I wrote *Eat Your Rice Cakes* thinking

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initially about the providers of healthcare—those dedicated, educated professionals who administer health-related treatment and advice to patients everywhere, every day. Providers, through my eyes, I invite you to explore this journey of change that I know so well—a wide spectrum of events, starting with the early, emotional struggles that come with the need to forge a new direction and ending with real-life, time-tested prescriptions for change. You'll receive an inside look into the patient experience that you may not have considered or appreciated before. I've included plenty of helpful data and clues in these pages that will support your own journey to guide and advise others through different experiences, medical conditions, and clinical prescriptions.

I, myself, am always looking for new ways to enhance my counseling chops with alternate language, questioning techniques or supporting data, and I actively “borrow” from peers, speakers, and presentations. Providers, your crucial role gives you far-reaching powers to execute immediate, meaningful change for your patients. The stories and encounters that I relate, both personal and professional, offer an inside view that can certainly help toward that end.

But I can't forget about the patients—I've been there too! Patients, it can feel overwhelming as you navigate change and new territory, and it's easy to wonder, “How

am I ever going to manage this?” You may have happened upon this book on your own, or you may have been asked to read it by your healthcare provider. No matter how you got here, know that *you* are the ultimate benefactor of the work we do to help with understanding change and transition. For you, this book will offer important affirmation for your own feelings and experiences. Plus, even though much of the information is geared toward providers and may get a bit technical at times, you may appreciate having the opportunity to learn different theoretical approaches to clinical treatment and get some ideas about what you might look for and expect from your current or future providers.

*Change. Transition. Adherence that is uncomfortable but necessary.* What exactly do these concepts really mean? And what exactly is the process to handle the disruption characteristic of this kind of change? Significant life changes take us on a journey of personal transformation, starting with initial vulnerability and extending all the way to feeling capable and confident after mastering these changes over time. Once we understand change and our response to it, what then helps adherence and what hinders it? It all comes down to the ultimate goal of acceptance that takes place in our minds and bodies when the need arises. Our efforts would be well purposed toward coming to an understanding not only regarding how we process these concepts internally, but also what helps us move forward

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in the outside world and what tools will help us adapt and continue on the right path going forward.

It's quite an undertaking, this change business. Just that single scene of my "Oreo Escapade," with its elements of concealment, longing, and guilt, underscores how hard and complicated change can be. Understanding this process is intricate and can also feel difficult, as life's circumstances are continually changing, frequently conflicting, and multifaceted. But never say never! I have seen and experienced success and opportunity more often than not. The journey is not easy, but there are many rewards and possibilities that significant change can bring.

*Eat Your Rice Cakes* is here to build on the ideas of change, transition, and acceptance, and suggests a way to navigate it all from a dual perspective. Yet, it's not a textbook. There are plenty of textbooks and technical resources available for patients and providers to turn to, but here we will spend more time acknowledging and incorporating the emotional side of diagnosis and treatment.

Curiously, this less clinical perspective is rarely addressed, although it seems perfectly clear how much our internal reactions impact our decision-making and behavior. From the perspective I've gained, what is offered here are ways to understand why changes make us feel the way we do, with possible actions to take that are different from simple, traditional prescriptions of medication. In

the following pages, I introduce ways to help cope with the negative feelings associated with discomfort and, most importantly, demonstrate forward-looking ways to apply and cope with transitions and adjustments that are productive and healing.

That forward-looking perspective then gives us the ultimate payoff: empowerment. Any life-altering change prompts questions about our place in the world and how to manage it. It is what we *do* with our experiences, how we ultimately emerge from life's curveballs, that is important to our story going forward. Change can be quite a blow and, as a result, we need to figure out how to regain our health, composure, and sense of self. Our reactions don't have to take us on a negative or destructive path, but can instead give us the ammunition to take charge of our lives, to rise up to new and improved opportunities and directions. We need learnings to build us up, to give us resources and inner strengths that steer us away from feeling vulnerable and victimized. This is how we find the power to heal and move forward.

The first gastroenterologist I saw after being diagnosed with celiac disease unwittingly delivered this kind of directive for forward-looking healing, although I don't think he realized or meant to do what he did, and it sure didn't feel helpful at the time. At that time, awareness about celiac disease and its only known treatment, the gluten-free diet,

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was virtually nonexistent. This doctor came right out and said that I was his first celiac patient and that, ha-ha, he vaguely remembered a chapter referring to it in medical school. As for the gluten-free diet, he clearly had no knowledge of or experience with it, either in process or in substance. Despite his admitted weakness, and without any understanding of the enormity of what he was asking of me, he delivered what he thought was an uproariously funny joke, something so unforgettable that it was the impetus for writing about my personal and professional journey: “You’ll be fine, just shut up and eat your rice cakes!” I laughed outwardly along with him, but inside found no humor in the joke or comfort from his manner. The implication, of course, was that rice cakes are probably the least desirable food on the planet, but eating them anyway was—literally—going to be invaluable toward the overall goal of healing and health in my body.

We can look at the sentiment of eating rice cakes “for the greater good” in the figurative sense as well; life changes require incorporating into our lives any number of new and perhaps undesirable thoughts and actions that ultimately are needed to cultivate promotion and healing. It is actually a mandate to all of us when life is drastically altered: first, explore the challenges of change, then learn to “eat” or embrace life’s adjustments on your way to healing and mastery.

## EAT YOUR RICE CAKES

I have carried the metaphor of the command to “eat your rice cakes” throughout this book, and we’ll see how well it works not only with celiac disease but with all sorts of different medical situations and major life-changes, such as diabetes, heart disease, and weight management.

To that end, we will first walk through the bundle of internal reactions I and others experienced when change is introduced: at diagnosis, via emotional expression, through the grief experience, and as a result of a path to accepting change that is frequently called “buy-in.” Then, we will examine how established psychological behavioral theories and applications offer clinical guidance and reliable support for why we behave the way we do. Finally, we will explore how to put it all together into action that honors our needs, expectations, and environment. It’s a combination of the subjective and the objective—an invaluable perspective for handling change.

At the end of each chapter you will find specific concepts, or “Essential Highlights.” Yes, a lot of the information in this book is meant for providers, but I invite every reader to examine this information to reinforce specific ideas and bring helpful input to the table, whether you are confronted with a brand new regimen or have been managing one for a while. We all want to not only mitigate our own discomfort, but I believe we also have a strong desire to inspire and bring joy to others, cultivate

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and enhance relationships, and apply new strategies to our interactions. No matter where you find yourself, I invite you to consider elements of this book that portray how counseling and treatment can occur in practical and humane ways, with approaches that allow development and rebuilding no matter what cards life deals us. By coming to know how “rice cakes” were managed in my personal and professional adventures, you may see patterns and similarities that aren’t meant to promote a “woe-is-me” attitude, but can instead be useful and provide insight into your own journey. What has occurred in my personal and professional life is a portal to this bigger story of transformation as a result of change that I believe will resonate with readers from any perspective.