

LEILA JASIM

BEYOND
SURVIVAL

READING SAMPLE

Your guide to ME/CFS and Long Covid

INTRODUCTION AND PRESENTATION

There were days when brushing my teeth was my biggest challenge.

In a body I could barely feel anymore. In a life I no longer recognized. Months in a darkened room, awake, trapped inside my own body, motionless, filled with pain. My heart raced, the nights were endless and sleepless. I felt lonely, helpless, out of control.

Perhaps you know this feeling. Perhaps you're at this point yourself, or just at the very beginning, trying to understand what's happening.

Or you are accompanying someone who is facing this great challenge.

This book is not a self-help guide. It is a companion. An orientation in the middle of the labyrinth.

I'm not writing this from a safe distance, but right in the middle of the process. Because I believe it's needed now. Because I would have needed it back then. And because I hope you find something in it that strengthens you.

Thank you for holding this book in your hands. I didn't write it because I know the one and only way, but because I believe that knowledge, clarity, and small steps can make a difference.

This book will help you better understand your body, find stability, and finally regain a sense of security in your actions.

In August 2020, I contracted SARS-CoV-2 and simply never recovered. Long Covid became Post-Covid, later ME/CFS. I was severely affected, officially classified as needing level 5 care. I wasn't just bedridden, but in a condition I can only describe as a waking coma.

I wasn't always this unwell. But a lack of information, incorrect medical treatment, unsuitable rehabilitation programs, and disastrous recommendations led step by step to a progressively worsening condition.

Over the years came knowledge, experience, and clarity. And today I know: Had I known all this earlier, it very likely wouldn't have come to this.

However, much of this remains difficult to access to this day, sometimes even mixed with half-truths, misjudgments and trivializing statements.

And let's be honest: where are we supposed to get the energy to research all of this ourselves?

As with my first two books and my podcast "Tidal Faces", my thought was:

If we don't do it ourselves, it doesn't exist.

I asked myself: What do I want to share? With whom? And why? This book is for everyone living with ME/CFS, Long Covid, Post-Covid, Post-Vac or a dysregulated nervous system.

For ease of reading, I use the term ME/CFS as an umbrella term throughout the book, but each section is equally relevant to all these groups. Furthermore, this book is also aimed at families and caregivers, medical professionals, doctors, rehabilitation teams, and expert witnesses.

I hope that this insight will enable a deeper understanding and help to dispel common misconceptions.

I designed the book so that you can use it on your own journey, whether you've only recently been affected or have been living with the illness for many years. You can read it from cover to cover or delve deeply into specific chapters.

I really recommend reading chapter 13 at the very end, because expanding the baseline requires some internal preparation.

There are many of us, yet only a few are truly visible. I feel deeply connected to every person who shares this path with me. I have never met stronger, braver, more resilient, and more helpful people than in this community.

I thank you from the bottom of my heart for placing your trust in me right now.

I sincerely wish you a good journey on your path to healing and recovery, and I hope that this book can be a helpful companion to you.

With love, Leila

PURPOSE AND FUNCTION OF THIS BOOK

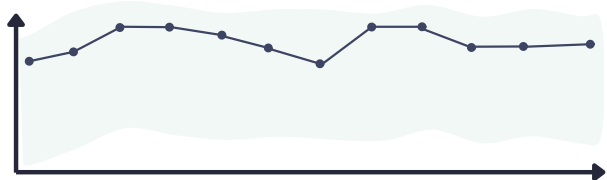
This book guides you step by step towards greater stability, self-regulation and confidence in your actions, at your own pace.

The diagrams illustrate the point: The top image depicts a typical day with frequent stress peaks exceeding the limit. The consequences are crashes, unpredictability, and deterioration. The baseline, or safe stress range, is narrow and relatively low.



The image below shows what becomes possible when you stay within your baseline for a longer period: Fluctuations decrease, recovery phases are more effective, and your system calms down. This allows the baseline to gradually expand, and previous overloads become manageable again.

That is the goal of this book: to help you determine your baseline, to work with calculated stress and targeted recovery, and to support your nervous system so that you can act more confidently and freely again.

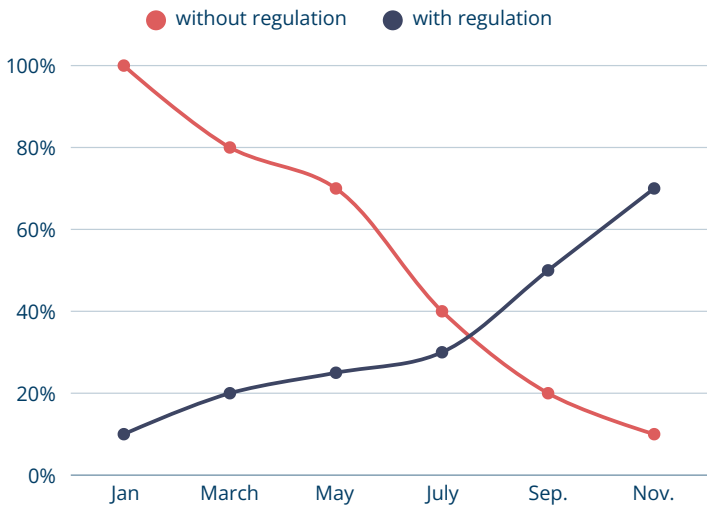


NOTE ON THE DISPLAY

The graphic does not constitute a promise of healing, but shows a possible course of events under different conditions.

If pacing is attempted without a baseline and without targeted regulation, it can lead to increasing stress intolerance and permanent deterioration in the long term (red line). This means that activities that were initially possible, such as brushing one's teeth, increasingly lead to a crash due to persistent overexertion. Everyday resilience decreases, which can also be reflected in a lower score on the Bell Scale.

However, if work is carried out with calculated stress within the baseline and active regulation is achieved, the condition can gradually stabilize or improve (dark blue line).



The lines serve as a guide and are intended to show development potential; they are not a guarantee or a firm forecast.

STRUCTURE OF THE BOOK

This book is divided into six parts. Each part fulfills a specific function, tailored to the course of many recovery processes and to what is truly needed in the different phases.

PART 1

helps you to better understand and classify the disease.

PART 2

focuses on stabilization and regulation.

PART 3

invites you to build upon and deepen your understanding.

PART 4

opens the space for inner work, acceptance, and orientation.

PART 5

is dedicated to expanding your possibilities in everyday life.

PART 6

contains supplementary knowledge for difficult days, as a glossary with understandable explanations of key terms.

Within the six parts you will find individual chapters, each structured according to the same principle:

It begins with a short, golden introductory text, a personal invitation to engage with the topic. This is followed by a clearly structured main section with information, inspiration, and numerous practical instructions.

At the end of each chapter, you'll find a summary page. It presents the most important information in a concise format, written in a way that makes it easily accessible even on days when you have little concentration. You can also read it independently if you're short on energy or just need a quick overview.

The book includes visual aids: colored boxes, routine cards, location symbols, and graphically marked healing stations. These make it easier to find your way around, help you grasp the content more quickly, and offer structure and support even on difficult days.

Feel free to read this book in one sitting. However, for deeper integration, I recommend rereading the individual chapters later at your leisure. Take your time; not everything needs to be implemented immediately. Healing is not a destination, but a process. And that's precisely how this book is intended: as a long-term companion.



Knowledge



Exercise



Overview



Building Block



Note



Important



In-depth

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Part 1



Understanding and classifying

Sometimes knowledge helps to reduce uncertainty. This section is about gaining a better understanding of the processes in the body and nervous system.

When you recognize what is happening inside you, you can categorize your experiences more clearly; this is your first step on the path to greater security and self-efficacy.

1

FUNDAMENTALS OF THE NERVOUS SYSTEM

Let's take a look at the nervous system together and understand what's happening in our bodies.

For people living with ME/CFS (Myalgic Encephalomyelitis / Chronic Fatigue Syndrome), a good understanding of the nervous system is particularly important.

It's a system that controls many processes in the background without our conscious awareness. It influences how we feel, how much energy we have available, and how we can react to stress.

We often quickly find ourselves in a state of over-excitation, overload, and exhaustion without actually having "done anything." This can be due, among other things, to the nervous system being trapped in a state of constant activation and no longer able to find its own balance or return to recovery phases.

Understanding these fundamentals of the nervous system allows us to find ways to calm this system and, in turn, calm ourselves.

We can prevent crashes and better understand, classify, and learn to deal with low points.

This chapter shows you how these processes work and what you can do to influence them.

THIS IS WHERE THE READING SAMPLE ENDS

What you have just read is the beginning of chapter 1. Fourteen more follow.



The best book on ME/CFS

"My neurologist pointed me to your book. Over the past months I have read many books on ME/CFS. Your book is a brilliant compilation of everything that really matters. For me it is the best book on ME/CFS I have read so far."

— LISA

(translated from German)

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