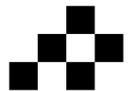


Mark J. Moser

**The art of living  
with chronic illness**



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# Endorsments

## **Prof. Irene Abderhalden**

In the more than twenty years that I've known Mark, he has become a great role model for me. Despite having to endure intense pain for such a long time, he has never given up being a loving and positive person – with a big heart and an open mind – sharing this richness generously with others. The way he has come to live with his illness and its limitations is not only a powerful source of inspiration for people with chronic pain, but for anyone facing recurring challenges. It is a precious gift to all of us that Mark shares his experiences in this book with such depth and lightness.

## **Dr. Christine Jacob**

Knowing Mark as both a friend and colleague, I've come to admire him not only for his insight, but for his rare combination of genuine empathy and fearless honesty. He has a remarkable gift for sharing his experiences in a way that is open, unfiltered, and deeply human, always with the intent to uplift and empower others. Mark doesn't shy away from naming the hard truths, he calls the devil by its name, but he does so with remarkable gentleness and compassion. This quality shines through in his work as a patient advocate, where he uses his own journey to remind others that they are not alone in their experiences of illness or pain. He speaks not just from personal experience, but from a place of deep care and solidarity. In this beautifully written and thoughtful book, Mark brings that same authenticity and strength to the page. If you want to explore what it means to live with pain, and yet live well, with purpose, resilience, and even joy, this book will move, inspire, and stay with you. It is a powerful companion for anyone navigating life with chronic illness or supporting someone who is.

**Dr. Oliver Merz**

The blend of personal experiences, practical advice, and professional insights is highly compelling and makes your book exceptionally credible.

**Alezandra Canteros Russel**

Mark's commitment to vulnerable populations has never faltered despite battling chronic illness and debilitating pain. His personal struggles have only strengthened his advocacy, inspiring all of us in the anti-trafficking field. Through his unwavering service amid profound physical challenges, Mark exemplifies what true resilience and purposeful living look like.

**PD Dr. phil. Helen Koechlin**

Mark's book is essential reading for healthcare providers, people living with chronic illnesses, and relatives and friends of a chronically ill person. It is a strong and moving call for more community and compassion—and it impressively demonstrates the rare ability to truly holding multiple truths simultaneously.

**Gideon Zimmermann**

Mark has cultivated an astonishing perspective on living with chronic illness and enduring pain – a journey that has spanned decades. With remarkable self-compassion, unwavering curiosity, and a deep sense of attentiveness, he has uncovered pathways that foster choice and personal growth. His focus and lived experience serve as a truly inspiring example of resilience and strength.

**Prof. Dr. Peter Sommerfeld**

This book is unique in many respects. From the perspective of personal experience Mark Moser delivers a great description of the complexity of coping with chronic pain and disease. Hardly anyone would think of all these components and their interplay building the trajectories leading to a high quality of life – and by consequence of all the odds that can be discovered,

developed and used. The uniqueness of the book for me mostly derives from the manner it is written. The mentioned valuable description of the complexity of coping processes somehow is just a by-product of the main goal of the book: showing ways, techniques, philosophies, giving practical advice to support people with chronic disease and pain. I think and I hope that many of those affected will experience this support on their trajectory to a 'good life' – only seemingly against all odds.



**Mark J. Moser (1973)** is an intercultural consultant, coach, lecturer and spirited bridge-builder whose roots in Papua New Guinea and seasons spent in Switzerland and Southeast Asia have shaped a life of dialogue and depth. Based in Bern, where he lives with his family, he lectures at the FHNW in Olten and other universities. He draws on over fifteen years of global experience in Europe, Asia and Africa – including leadership of an international health organization – to help individuals and organisations transform conflict, cultivate communication, and nurture mutual understanding. With a postgraduate degree in conflict analysis from the University Basel and coaching credentials from Ashridge, he brings rigor, compassion, and practical insight to cultural encounters and change. He has been living with multiple long-term illnesses and strong pain since the age of nine. This experience deeply informs both his professional work and his writing.

#### **The Year | Living while preparing to die**

A profound 104-page memoir of a year Mark Moser spent in a Jerusalem hotel room, engulfed by pain and facing inner bleeding. Not yet ready to die, he navigates preparing for death while holding on to life – with family, friends, hope, and intentional humanity. His courage shines when despair rises.

<https://buchundnetz.com/werke/the-year/>

#### **Living with pain without going crazy | Reflections on a life marked but not defined by pain**

A focused 48-page book of hardship and hope. Mark Moser bravely opens a window into chronic pain – not as destiny, but as a companion. His reflections invite us to witness the struggle, yet reclaim our own humanity.

<https://buchundnetz.com/werke/living-with-pain-without-going-crazy/>

**I dedicate this book  
to my family and to Dr. H and Dr. C.  
Thank you!**



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Prof. Dr. Sabina Heuss

# Prologue

**F**or those affected by chronic pain, pain is a constant companion – for hours, days, years on end. Outsiders can hardly comprehend what this really means for a person's life. Mark Moser's book is therefore more than just a personal account or a collection of symptoms and instructions for coping with pain. It is an invitation to listen, to learn and to take on the perspective of a person who has been living with chronic pain for over four decades – and yet has become much more than just a 'patient'.

In his book, Mark Moser provides an impressive insight into life with chronic illness. It is not about explaining it in a medical sense, but about making things visible: What does it mean when symptoms can no longer be managed and pain cannot be reduced any further? How does this affect me, my family, my relationships, my work, my friendships? This book's strength lies precisely in this: it builds a bridge between those affected and those who are not, between medical knowledge and lived experience, between language and sensation.

The book is a rare, necessary and powerful voice from the perspective of someone who is personally affected, who is a father, husband, friend, colleague, business man and partner – someone who will not be reduced to the role of patient, but who reflects on his experience with analytical acuity, emotional intelligence and deep empathy. The author does not hold anything back. He openly addresses feelings that are often kept silent: fear, anger, grief, loneliness, loss. He shows how chronic pain changes relationships, how it shifts roles, how it can blur physical and emotional boundaries. And yet, in many passages of this book, one senses something surprising: humour. Some-

times quiet, sometimes sharp, sometimes comforting. Mark Moser shows that people with chronic illnesses are experts on their own reality. And he highlights the power that lies in living your own way of dealing with illness and putting the experience into your own words.

In addition to its narrative power, the book also offers concrete assistance: proven strategies, checklists, digital tools and references to further resources. Furthermore, Mark Moser addresses topics that are often omitted from medical literature on chronic pain: relationships, sexuality, social roles, communication and death. For people with chronic pain, it provides practical and emotional support. For relatives, friends and colleagues, it provides better access to the experiences of those affected. For healthcare professionals, it is a call to reflect on their own role, to treat patients as equals and not to give up on the relationship with the patient – even when there is ‘nothing more to be done’ from the medical perspective. The book shows how important empathy, respect and a holistic view are in the care of people with chronic illnesses.

The book touches, enlightens, accompanies and inspires. It is a gift – for anyone who is willing to listen.

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# Introduction

## Living well with illness and pain

**T**here is hope in living a qualitatively good life even when affected by long-term illness and pain.

Chronic diseases are the world's leading cause of death and disability, affecting millions worldwide. For those facing chronic conditions, the journey is often accompanied by complex emotions - fear, grief, anger, loneliness and more. If you've experienced these feelings, know that you are not alone. Despite the immense challenges, I believe it's still possible to find fulfillment and meaning. This book shares hard-earned strategies for adapting to the realities of an incredible but ill body.

### **My story**

I don't look sick, but I have lived with intense physical pain for most of my life due to various forms of arthritis altered by tropical diseases. Since age 9, I've undergone many surgeries and taken long-term pain medication, leading to severe side effects.

And yet, I am living a captivating, colorful, and fulfilled life as a professional communication expert, husband, father, grandfather and friend. By no means do I wish to sugarcoat the difficulties of chronic illness, but I'm proof that pursuing a good life is possible. There is hope!

### **Who this book is for**

If you are living with a chronic condition, this book is for you. Whether your symptoms are physical, mental, or both, the

pages ahead will offer validation, practical tools, and most importantly, the reminder that you are not defined by your illness. This book is also for the caregivers, loved ones and medical professionals supporting someone with chronic illness. You'll gain insight into the daily realities and complex emotions of life with long-term health challenges. Most importantly, you'll learn tangible ways to offer support while still prioritizing your own well-being.

### **Beyond 'As long as you're healthy'**

I reject the implicit message that health is the most essential thing in life. I know many chronically ill individuals, myself included, living happy and meaningful lives, just as I know many who are healthy yet unfulfilled. It's possible to thrive even without perfect health if other areas of life flourish.

### **Purpose of this book**

As someone who has lived with long-term illness and supported others on this journey, I'm motivated to share the truth about the resilience, creativity and courage of the chronic illness community. Throughout these pages, you'll hear not just from me, but from a diverse chorus of voices living with various conditions. Their vulnerability and wisdom will inspire you, as they've inspired me.

You'll gain practical pain management strategies, insights on navigating relationships and work, and inspiration to live fully despite limitations. Most importantly, you'll learn how to build a fulfilling life around chronic illness, not in spite of it.

I am not a medical professional, so my thoughts should not be taken as medical advice, but rather as hard-earned wisdom from personal experience.

*Some of the most transformative lessons shared include:*

- the power of acceptance and how to get there
- when to push and when to prioritize self-care

- how to rally support and be a good chronic illness advocate
- daily practices to strengthen resilience
- finding purpose and meaning during challenging times

As you make your way through this book, I encourage you to pause and reflect after each chapter. Journal about what resonates with you and discuss key takeaways with loved ones. Putting insight into practice is how transformation happens.

### **Structure of the book**

We'll begin by exploring common emotional experiences and laying the foundation for healing. From there, we'll cover practical strategies for managing symptoms, building support systems and advocating for your needs. You'll gain tools to navigate major life areas like relationships, work and self-identity. The arc of this book will take you from surviving to thriving - not by eliminating chronic illness, but by embracing the fullness of life alongside it.

*Here's a roadmap of the journey ahead:*

- honouring difficult emotions and experiences
- exploring silver linings and sources of hope
- understanding pain and disease
- navigating the path of acceptance
- practical strategies for pain management
- crucial communication skills
- building resilience while managing risks
- utilizing therapies and treatments
- living and working with chronic conditions
- integrating mortality to live more fully

### **An invitation to connect**

I invite you to share your own experiences and insights with our readership community on my website ([markmoser.ch](http://markmoser.ch)) and social media.

**My hope for you**

My deepest wish is that within these pages, you'll find validation, practical guidance and a renewed sense of possibility. May the words here be a comforting companion on your journey, a reminder that you are not alone, and that a meaningful life is possible not despite chronic illness, but through it all.

Viktor Emil Frankl (born March 26, 1905) was an Austrian neurologist, psychiatrist, philosopher and Holocaust survivor. has strongly influenced me. Suffering is not a riddle we solve, but a summons we answer. The question is not «Why me?» but «How shall I respond? For Frankl, suffering is not the end of meaning but the very place where meaning can be forged—by choosing our stance, by responding with courage, and by holding onto the values that make life worth living.

I offer this book in the spirit of Tonglen, a Tibetan Buddhist practice of giving and receiving. As you receive my experiences and those of others brave enough to share their stories, may you be inspired to share your own, creating a compassionate cycle of mutual support.

Let us begin this journey together, embracing the challenges that chronic illness brings, and discovering how to live well through it all. However your path unfolds, know that you have the resilience, courage and wisdom within to meet each step. And you have a community of fellow travellers to remind you of your light on the days it's hard to see.



Onward together,  
Mark Moser

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# An altered Life

## The journey begins

**L**ife has a way of taking unexpected turns, and for those who find themselves on the path of chronic illness and persistent pain, the journey can be as challenging as it is transformative. When pain refuses to leave – when it transforms from a temporary visitor into a permanent resident – everything changes.

My own journey with chronic pain and illness began decades ago, altering the trajectory of my life in ways I could never have anticipated. In these pages, we will explore together how chronic pain and illness reshape our daily experiences, our relationships, and ultimately our sense of self.

### **Chronic pain: The invisible epidemic**

Chronic pain is a silent illness – an invisible epidemic. Of the 50 people shopping in your local supermarket this morning, 10 to 15 were probably in physical pain. Yet they push their carts, select their groceries, and exchange pleasantries at the check-out counter, their suffering hidden behind practised smiles and everyday motions.

### **When life takes a turn**

Sarah, a 45-year-old teacher and mother of two, has been living with fibromyalgia for over a decade. «Most days, I feel like I'm dragging my body through quicksand,» she shares. «But I get up, get dressed, and show up for my students and my kids. They don't see the effort it takes or the pain I'm in. It's an invisible battle.»

### **When life changes course**

Your life may have been interrupted by infirmity and never been the same again. Medical professionals often distinguish between disease – a category of biological malfunction – and illness, which represents the negative impact on lived experience. Disease exists in the body; illness manifests in how life feels.

This distinction matters deeply. With appropriate treatment, someone with rheumatoid arthritis might maintain a life similar to their pre-diagnosis trajectory. Without treatment, even a mild form of this illness may lead to unemployment, social exclusion, and a downward spiral affecting every aspect of life.

This reality underscores a crucial truth: illness is distributed even more inequitably than disease, following lines of wealth, race, and nationality. Our experiences of chronic conditions are inseparable from our access to care, support, and resources.

### **The complexity of chronic pain**

Attempting to capture the essence of chronic pain on paper is more daunting than painting a picture of love, joy, or pleasure. The standard medical definition – pain that persists beyond the average healing time, typically for more than three to six months – fails to convey its reality. Chronic pain is not just a symptom but a condition that affects a person's physical and emotional well-being in profound ways.

Pain is a complex and multifaceted experience influenced by biological, psychological, and social factors. It is often underestimated and misunderstood, with a widespread belief that it is solely a physical sensation. How we perceive and express pain is heavily influenced by cultural background, personal beliefs, and past experiences (Morris, 1993, 'The Culture of Pain').

Chronic pain is an uncontrollable, unpredictable condition that infiltrates all aspects of life. It varies in intensity without warning, making it nearly impossible to plan confidently for the future – whether tomorrow's dinner party or next year's career move. This 'unreliability' profoundly impacts relationships,

leading to a gradual isolation that becomes another burden to bear.

### **My journey with pain**

Every experience of chronic pain is uniquely personal. In my life, chronic pain means that I can hardly remember an hour of a day without some form of pain or the consequences of pain management – medication, baths, heating pads, and most of all, resting in bed when I would rather be elsewhere. My personal definition of chronic pain: thousands of hours of not being able to do what I would like to do. It means submitting to a reality in which pain and my responses to it dominate my decisions.

Living with chronic illness has meant enduring more than 30 MRIs, over 100 shoulder interventions with anesthesia, dozens of surgeries, and countless physical therapy sessions. It means having 50 or more doctor's appointments yearly. It means travelling with bags of medication and permits from ministries of health that allow me to enter countries legally with particular medications.

It means leaving parties early or not going at all. It means working but skipping nearly all social events with my colleagues. And importantly, it means living with profound unpredictability. I may plan to join friends for brunch, but depending on my pain level that morning, I may not make it.

Throughout my years navigating this landscape, I have met countless others whose lives have been similarly transformed. I have witnessed people confronted with financial insecurity and all its cascading effects due to lost careers. I have seen individuals dismissed by insurance companies and treated with little respect by systems designed to help them. Despite enduring pain and countless setbacks, they continue showing up for their commitments with remarkable determination.

Amid darkness, I have encountered people who cling to hope, refusing to let it slip away. The common thread that connects all our stories: loss. Loss of independence, of friends, of

financial security, of mobility, of energy, and of the futures we once imagined for ourselves.

### **Beyond 'Good vibes'**

Our culture places enormous emphasis on well-being, positivity, and the pursuit of happiness. Philosopher Shelly Kagan coined the term 'ill-being' for 'the elements that directly constitute of a life going badly'. In a society that promotes a 'no bad vibes' mindset and an Instagram-perfect life portraying only highlights, the reality of 'ill-being' receives little attention.

Yet suffering and illness requires an unblinking gaze. Only the courageous do not deny or flee from suffering. This means taking a deep breath and acknowledging, «I am scared. I am overwhelmed. But I won't run from reality. I will face this suffering.»

### **Being prepared**

#### **A message to those new to chronic illness**

I wish I had been better prepared for this journey. Illness is an identity changer. Looking at a picture of myself at age 20, I see someone who exercised regularly, possessed abundant energy, and maintained a large social network. Now, 30 years older, I have experienced not just the natural effects of aging but the cumulative impact of limited mobility, medications, decades of pain, and countless medical procedures.

Illness makes our bodies crumble. My outer self has deteriorated, but my inner self has blossomed and developed in ways I could never have anticipated. It is important to acknowledge that it is okay – necessary, even – to grieve the loss of strength and health, and the many other losses illness brings. We often must let go of cherished goals and dreams. Our worlds become smaller due to diminished financial resources and mobility.

This is an involuntary journey we face. Being prepared does not eliminate the difficulty, but it can provide tools to navigate the terrain with greater resilience.