

Mark J. Moser

The Year

Living while
preparing to die

The Year

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Publisher: buch & netz, Kölliken (Switzerland), buchundnetz.com

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ISBN: 978-3-03805-237-1 (Print – Softcover)

978-3-03805-238-8 (Print – Hardcover)

978-3-03805-265-4 (PDF)

978-3-03805-266-1 (ePub)

978-3-03805-267-8 (mobi/Kindle)

For Laurence, Jael and Chris.

For all who dare to love and forgive.

Endorsements

I have read «The Year» in one sitting. I am lost for words, and yet full of feeling and expression. This has been a «pain-full» read that is also strangely hope-filled and uplifting.

Through this intimate narrative I have lived Mark's Year with him, and in doing so come closer to understanding his deepest experiences and also nearer to uncovering my own denied realities. Mark has lived with all kinds of pain – but has never been defined by them. His courage and care-full humanity shine through the distress and moments of despair he has endured.

This book, like his life, is a testimony of hope in the face of difficulty and uncertainty. If our not-so-well-hidden quest is to live lives with love, hope and meaning, then this book, like Mark himself, is a loving, meaningful and hope building contribution to this ongoing essential endeavor.

Anthony Kasozi

«I choose to live, but more importantly, I want to be alive. I won't settle for living at any cost and without a certain influence on the quality» – this sentence from «The Year» summarizes the essence of the book. What is the consequence thereof? Challenging for me as occidental doctor and reformed Christian – neither university nor the church pew have been able to prepare for this line of thinking. Nonetheless, I am familiar with these statements, as I have been in constant contact with them for years now. In innumerable conversations with spiritually and physically suffering people I am faced with the essence of «The Year»: an open and honest quest to find a way that is endurable in the face of a restricting starting point. Mark shares this quest with us in a very authentic way.

I have the greatest of respect for this. I regard this book as a hugely beneficial read for us all and especially a must-read for those of us who are professionally involved in medicine and theology.

Dr. Manuela Wälchi

«The Year» is a beautifully relaxed yet serious preparation for life. It is a book for everyone. Although I have not experienced the unbelievable pains Mark has to endure, neither have I had to face the kind of obstacles he has, I wrestle with the same questions raised in this book.

I admire Marks' courage to approach answers in such a rigorous way. We may be grateful that he shares his experiences and thoughts with us.

Mark openly presents his personal experiences with us, giving us a taste of a liberating concept of life wherein we smell the trees of the forest in which life happens.

Pascal Sieber

The reader of this book is taken on a journey of searching and finding. The immense effort to overcome pain, hardship and loss and to transform this into gain and forgiveness becomes tangible. I marvel as I see the faith in an inexhaustible source of life. Mark hits the mark. It's my privilege to be his friend.

Tanja Flückiger-Rentsch

Mark dedicates his text to the curious, the searching and to those who dare to love. Be ready to develop, listen and feel.

I have the honour of travelling with him through parts of his experience, history and thoughts. Mark's voice is and will be most important to me as I try to find out more about the truly big things in life. You might want to try it as well?

It is a challenge to understand, but it easy to develop, listen and feel.

Sabine Künzi

Introduction

The clue to who I am lies in my heart's desires. Shaped by the desires I dare to unleash and the lessons I learn from failure and success. How I deal with pleasure and pain points towards the essence and mystery of life. One of the most important lessons has been not to abandon the journey of desire.

Over the last years I have had the privilege of discovering many facets of myself. This process was accelerated, deepened and enriched through many inspiring encounters in many cultures. My sincere gratitude to all the friends who have been such a valuable part of my journey and made it so rich and meaningful. I mean it. I learnt from you how to navigate the wild waters, how to climb mountains and swim across rivers and not to give up when I row weary. The community of friends in my life, including my family, has been the most precious gift life offered me.

Simon, you were a wonderful partner in dialogue and exploration as we set out to write this book. You are a courageous man who dares to look beyond the obvious, to question and to hold on to values that are dear to you. To the others who have worked with me on this book and given input, thought and much more: Anthony, Irene, Manuela, Sonja, Chris, Tanja, Jael, Laurence, Pascal, Sabine, a heartfelt thankful hug.

My profoundest thank you goes to my wonderful partner and friend Laurence who has shared the journey of my life with me. You are the most generous person I know. To Chris and Jael I extend a big hug, my love and my thanks. My desire for you is that you never cease to be connected with the source of love.

Eknath Easwaran writes: «We can spend the better part of our lives attempting to construct the perfect personal environment, a kind of bubble that will insulate us against everything that is unpleasant. But sorrow is woven into the very texture of life. Pain, disappointment, depression, illness, bereavement, a sense of inadequacy in our work or our relationships ... the list could go on and on.»

My desire is that this book inspires you to nurture your curious mind, to believe in mystery and to love.

It's the generous, the daring, the compassionate, those who believe in mystery and justice, the doubters and the lovers, the unbelieving believers and hardworking dreamers that give me the fuel to keep going.

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Prologue

The air is humid and hot after a heavy downpour. Only few cars are driving down Soi Langsuan in central Bangkok as I exit Hotel Muse and cross the road in the wee hours of the morning to go and buy a Pad Ka-Práo in the nearby 7Eleven. Bangkok never sleeps, but in the early hours of the morning the pace is slower, gentler. I greet the rubbish collectors and buy them a beer as I enjoy the well-spiced dish on the sidewalk.

I am awakening after a ten-hour intense pain phase, which had me bound to bed. The pain waves caused nausea, cramping in my legs and arms, and I felt intense heat in my hands and feet, pinning me to bed for many hours. Dehydration and exhaustion accompany me as I walk unsteadily down the road. During periods of pain I discipline myself not to engage with my thoughts, as the pain often tends to bring out my most hopeless and gloomy thoughts.

«The Year» doesn't start here in Bangkok. The storm swells in my life started crashing down on me with intensity long ago and can no longer be overheard.

I could start by telling you the story of who I am and of those people in my life that swim the oceans with me. Or I can share about my professional engagements, the travels and working in many nations and cultures, which have enriched my life. And then there is the story of pain and illness, which weaves into all recesses of my life.

I invite you to board this train and travel through a year with me. On this journey, you will get a glimpse of what it means to live with excruciating pain and how I chose to live with what I

didn't choose to have. In «The Year» I regain influence over my life and find freedom. This book is as much about preparing to die as it is about getting ready to live.

During the past three weeks, I've been based in my second home, Bangkok. I worked for a few days with a social organisation active in poverty-stricken areas on the outskirts of Dhaka, Bangladesh, providing medical services to persons in need. In Chiang Mai I worked with up! international and Urban Light on a new programme focusing on vulnerable street-living boys. My family lives in Bern, Switzerland where we just celebrated Christmas together. I feel immensely thankful for my life, privileged to be among such loving, caring, intelligent, humorous, adventure-searching friends and family. Working in many countries all over the world has opened my eyes in awe to the diversity of humanity.

Now, I am scared. I'm bleeding somewhere in the depths of my body. I have lost weight and I struggle to eat. The side effects of various chemical treatments leave me dizzy, weak and marked by poison, which ought to somehow bring health to my body. I sit at the entrance of Hotel Muse and speak with the night concierge, eating slowly, trying to ignore the stinging pain in my stomach as food and ulcers interact.

Tomorrow I'm flying back to Switzerland to start teaching a course on intercultural communication at the University of Applied Sciences and to work with other clients on multi-cultural competence. The thought of a twenty-hour journey is daunting. I try to master the immediate challenge of walking back up to my room. My left ankle is swollen after spraining it and tearing a ligament a few days ago.

Let me take you on a journey through the year.

01

Crisis

It's 2am and I am trying to sleep in room 425 of the YMCA hotel in Jerusalem. People are partying outside and the air coming in through the open window is crisp. I hear sirens and birds from my tiny, cold, somewhat shabby room.

We, my colleagues and I, are on a field and study trip as part of the studies on conflict analysis and transformation, offered by the University of Basel. Many of us have been studying together for several years and are now finishing a stimulating process with this tour of Israel, before completing our MAS course.

This is my first visit to Israel and I'm alert and thankful to get a glimpse of life in this complex reality. We want to observe, learn, reflect and attempt to understand how the different perspectives, realities and interests of so many stakeholders interact, nurture each other, contradict and clash.

I didn't think I would be able to take this trip. Continuous inner bleeding, ulcers and nausea make it difficult to eat and keep food. The chemical treatment I've been receiving for more than a year has weakened me and is taking its toll. Walking stairs has become a major challenge. Dizziness and double vision affect me and make it challenging to navigate safely. I take morphine and other pain medication on a daily basis to keep pains on a bearable level.

When I discussed the attendance of this module with the professor in charge, Ueli Mäder, he encouraged me to participate and to do as much or little as possible, and to allow

the group to support me as he knew they were open to do.

Now, aggressive pains have been flooding my body for many hours, forcing me to excuse myself from the ongoing lecture, and to retreat to my room. After another fierce jab of pain, I crawl over the dirty carpet to the toilet and throw up.

The next thing I recall is waking up with my face on the floor in a pool of blood. I am cold and too weak to stand on my feet, so I crawl back to bed. This isn't my first hotel crawling – the root of my deep dislike of carpets in all things hotel! Looking at the clock I see that I was unconscious for quite some time.

I will not die in a crappy hotel in Jerusalem with a smelly carpet floor! This is my resolve as I endure being knocked around by rough and relentless pain for the rest of the night. I can't continue like this. I am at a point where my strategy of how to live with my pain and illness is failing me. If I don't change my approach to living immediately, I will die.

Pain has been my companion for as long as I can remember. My life has been a wonderful, breathtaking, thrilling – but also painful ride. I have had pneumonia, malaria more than a dozen times, torn ligaments, broken fingers, mumps and encephalitis in my twenties. I have experienced the torturous pains of dengue fever, migraines which made me wish I could evaporate and escape to the stars, and I have lived through tropical diseases that doctors didn't even have names for.

My chronic pains are caused by a genetic disorder bringing forth calcification in soft tissue and strong inflammation in the joints. The illness broke out as a form of juvenile polyarthritis when I was nine years old, and then came in waves with increasing intensity and frequency as the years went by. After more than a dozen operations in my shoulder and feet, I decided to stop invasive medical techniques. Now the pain waves occur daily and the waves of inflammation return every few days. Symptoms include swelling of fingers, hands and joints, spontaneous rips of tissue, sprained or torn ligaments and mind-numbing headaches.

In order for you to understand what my life looks like and to understand this account, I'd like to take you on a regular day of pain and explain my vocabulary and use of a pain classification:

I measure pain on a scale of one to ten. Zero virtually never occurs so I don't include it on my pain scale. One is a magnificent day with very mild reminders of pains. Level two to three pains take my attention and energy and can be annoying but I can assimilate them into my current on-going activities. Level four to five is disturbing, it's hard to focus, one can see it in my eyes that I'm in pain. I try and focus, but it's difficult. I can assimilate the pain for some time, but I will later pay a price, as the pains often re-bound even harder when I stop focusing, for example, on work.

A level six pain means I need to devote my attention more or less fully to the pain. I can't assimilate it into other activities anymore. It requires attention and usually the first stronger pain killer. Level seven means I begin to struggle to walk – or even lie. I'm in strong suffering with pains crashing down on me. I need peace and isolation. All my focus is on breathing. With level eight I am in serious trouble, despair and extreme suffering, and

require high amounts of morphine or more potent stuff. A nine means «please shoot me» or just somehow let this torture end. A ten has never happened. I am still here.

I classify and name my pains. «Reminder» pains just keep telling me «I am here» but I must not respond. «Alerts» are pains insisting I take notice of them, otherwise they will start calling for my attention louder and more persistently. «Threats» are the pains that will turn very ugly if I don't heed to their warning and do something for or against them. «Escalation» are those pains that give me the opportunity to try and appease and work with them, but they require a lot of attention, like massages, movement, food, focussed breathing etc. «Motherf*** of all pains» are the pains that make me surrender in the face of their sheer power.

The first sensation I usually feel when I wake up is a cold stiffness in my hips and back. My eyes open and I notice a sharp, tingling hot sensation in my ankles, normally a level three to four. When I move, the tingling lessens and I feel the beautiful absence of «sharpness». My hands are stiff and moving feels like moving them across sandpaper.

My neck is only minimally uneasy, but when I try and sit up my shoulder slips into a position where it does not belong. I momentarily see dark flashes and stop breathing. My first steps are among the worst. Dizziness hits me as the pain awakens in my elbows, fingers, ankles, shoulders and my hips where I have some small broken bones. I keep taking my first slow steps, my eyes fixed on the reward of a first coffee.

Once my body is on normal operating temperature, the sharpness of pains eases and I feel a dull, constant throbbing in my ankles, toes and feet. This pain is like a constant, ceaseless knocking on an apartment door. It's not threatening

and I can learn to ignore it.

Sitting and working at a computer I virtually always have a cold, tuned down high-frequency pain in my hands and particularly my right shoulder. The pain in my shoulder tends to sit in the shoulder scapular for most of the waking day. Every move sends a wave of pain down my arm into my elbow, sometimes flowing into my hands. Another wave goes up my neck, over my ear into my front temple lobe.

While sitting I often feel irregular jabs like small knives in my hips, which I can't control. These too are just reminders of an energy that usually doesn't have a warning signal other than to call for my tender attention.

When I go out into temperatures beneath 15 degrees Celsius or colder, I am hit by a strong pain that takes my breath away. I become dizzy. My eyes tear up.

I go silent when I'm together with others because I lose my breath. This usually goes unnoticed. I feel strong stabs from thousands of needles. Some of them are just for milliseconds but it's their number that takes my breath. After twenty to sixty seconds, the first wave subsides and I can catch my breath, do a mental check and let oxygen flow through my body, and as I exhale I try and let the pains flow out. The following twenty to sixty minutes in the cold, or warming up, are accompanied by a cold stiffness, dull throbbing of pains which wander.

During a wave of inflammation, which currently happens every three to five days, my hands and feet feel like a first or second-degree burn. These pains are amongst the hardest to touch lovingly. Heat triggers a fear in me. I am learning to condition myself, training myself that heat must not always

be fled from. But my hands are a part of the body I use to connect with others or with things. Seeing my hands and fingers red and swollen and increasingly stiff triggers a fear I must learn to cope with.

Depending on the trigger of pains – it can be stiffness, a sudden change of temperature, inner pressure or stress, a wave of inflammation or one of many unknown factors – the stinging pains come with increasing frequency. I usually refer to this as a pain wave. My coping strategies fall apart and I can't ride the waves of pain anymore. I become helpless, eventually thrown off the boat and pulled along by an incredible force of energy ripping through my body, creating spasms, flashes of light and darkness, taking me into a pit of non-stop severe pains, flowing from my toes over my back with an accumulation of presence in my neck, shoulders and head.

Towards the evening I feel painful energy getting jammed in my knees and ankles. I must consider it in whatever I am doing. Its presence cannot be overheard. It is constant and it demands a lot of energy I'd rather use for other things. But by giving it attention and the energy it requires, I can often partner with it and whatever it is I'm doing.

That's a good, a normal day.

Here in Jerusalem, I'm dealing with aggressive pains combined with low energy, nausea, dizziness and numbness in my arms.

Several friends had advised against doing this trip. But somehow my feeling was that if I could pace myself and accept some support where needed, I would be fine.

Against all odds, it turned out to be an amazing experience to see the response of most in the group. In the two weeks to come, I would sometimes ask for a helping hand to guide me, when I followed a tour lecture, half blind from pain and medication, or when I asked for another form of support. The generosity and compassion of the students offering to carry my bag, give me a hand or massage my hurting muscles is overwhelming.

I had told a few colleagues that I'd skip a visit to Neve Shalom, as I knew I would feel nauseous and weak after my regular injection of a strong medication. I didn't want to create a scene. However, several colleagues urged me to join anyway and to accept more support. After lunch in the village, I went aside to a spot in the garden overlooking the beautiful landscape. As I prepared the injection, one friend asked if she might give me company whilst administering the treatment. Wordlessly, we sat as I injected and awaited the first round of nausea and illness to hit me. During the afternoon programme, I had to leave the lecture room several times and each time colleagues went along with me to support me, as I threw up and overcame the side-effects.

A few days later, during an evening session, I had a very sudden and strong pain wave. Within minutes, my body went into shock and spasms of violent pain, leaving me gasping for air. Three colleagues carried me to my room and lovingly accompanied, massaged, helped me through the awful hours as I cramped in agony, vomited and gasped for air till the morphine finally kicked in and gave me some relief.

Despite the valuable moments on this trip, now I feel, hear and taste it clearly: it's enough! I can't continue like this. In the city of conflict, I come face to face with a personal adversary I cannot conquer. I am urged to make a decision. I can't hold onto how I used to live my life. If I don't decide to follow a clear-set path, I will become subject to the consequences of taking no decision, and these consequences will be driven by forces other than my own free will.

02

Decision

I feel like a swimmer in the vast ocean, during an ultra-long swim with no shore in sight. I am tired, very tired. I didn't set out to prove to others how long I can swim in pain. But I feel that if I stop swimming, I am giving up. Giving up isn't what I am used to doing.

For many years I referred to my relationship with my illness using combative words. I «fought pain», had a «pain attack» and said «pain is winning». I worked as if I was healthy and only accepted illness and pain but pushed myself hard to keep performing, working, living, challenging and often forcing my body to go way beyond a reasonable measure given that I was in pain. I would go to pain treatment, have anaesthesia injected in my shoulders and then head straight back to the office to work. I performed in public and suffered in private.

Over the years, this «strategy», which had allowed me to experience a rich, full and wonderful life in spite of pains and suffering, became increasingly more difficult to execute. In the years of collaboration with Irene as Secretary General of the International Blue Cross I became aware of these patterns. Irene often pointed out how demanding I was on myself. With her help and the support of a therapist I chose to be-friend pain and learn to be more loving with myself. As long as I was fighting a part of me, how could I truly love myself if I was rejecting such a powerful part of me? And now here I am. The medical team around me has tried every thinkable action to find a way to respond to my illness and – as there is no known cure – at least to minimise the symptoms. The only medical interventions that have helped are pain medication and