

DANCING WITH ELEPHANTS

*Mindfulness Training for Those Living with Dementia,
Chronic Illness or an Aging Brain*

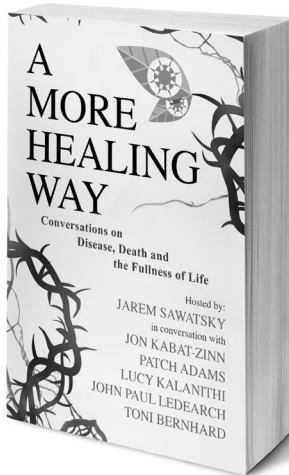


JAREM SAWATSKY

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***A More Healing Way:
Video Conversations on Facing Disease***

featuring Jon Kabat-Zinn, Patch Adams, Lucy Kalanithi,
John Paul Lederach and Toni Bernhard.
Hosted by Jarem Sawatsky (\$200 value).

Details can be found at the end of *Dancing with Elephants*.

Reading Guide for *Dancing With Elephants* (great for individuals and
book clubs) available at:

www.jaremsawatsky.com/dancing-guide

Praise for Dancing With Elephants

In Dancing with Elephants, Sawatsky beautifully models a way to dance in the gale of full catastrophe, to celebrate life, to laugh with it and at himself, even in the face of personal failure and defeat.

- JON KABAT-ZINN, national bestselling author of *Full Catastrophe Living*

In Dancing with Elephants, Jarem Sawatsky offers a powerful example of the art of real happiness. This inspiring story reminds us just how essential it is to bring lovingkindness into every step of life, no matter how difficult the path

-SHARON SALZBERG, *New York Times* bestselling author of *Real Happiness*

... forthright and inspiring... people facing a chronic illness in themselves or in a loved one will learn from his honesty and openness.

-PETER VRABINS, co-author of *The 36-Hour Day*

Life can be tough and it's even tougher without the ability to find humor. You're either going to laugh or cry, so you might as well laugh. When life seems to be falling apart, Jarem Sawatsky's interesting and entertaining

book reminds us that laughter is what we need to not take ourselves too seriously.

-JEN MANN, New York Times bestselling author of People I Want to Punch in the Throat

This is a beautiful and inspiring book. It is full of humor and wisdom about the pain of loss in our life, by a man who is living the severe loss of a debilitating disease. It is a book that we should all read so that loss be not transformed into anger or depression, but into love and radical acceptance.

-JEAN VANIER, national bestselling author of Becoming Human

Chapter 1 - Facing Elephants

Dearest Elephant Dancer,

I know nothing about elephants nor dancing. And yet, this is a training manual and love letter for elephant dancers like yourself.

Facing elephants is something we often avoid. Most of us have elephants hidden in our closets, or hidden in plain sight. These elephants are our big, unacknowledged fears.

What are your elephants? What do you fear? Who gave you these elephants? How can you learn to love and dance with your elephants?

In this book, I serve as your guide in teaching the art of dancing with elephants. One of my big elephants is Huntington's disease—once called the dancing disease! It's an incurable, genetic, progressive, fatal brain disease. It is kind of a combination of Parkinson's, Alzheimer's and Schizophrenia. Just picture an elephant with this combo! That picture makes me laugh now. But I have not always been laughing.

I've never really known life without Huntington's disease lurking somewhere in the corner. Huntington's is genetic and so is passed down from generation to generation. It is a slow train wreck of a disease, sometimes lasting up to 25 years from first

symptoms to death. In the olden days people would say, "Stay away from those families—they go crazy as they age and it is not pretty." When I was a child, my grandmother's generation had Huntington's, as did some of our more distant relatives. Several of them were put in asylums because not much was known about the disease. I was told to not worry because a cure would surely be found by the time I developed it, if I ever did. When I was in my teens, it was mom's generation's turn—my mother had it, as did all her siblings except for two brothers, one of whom was adopted. Huntington's seemed like a massive earthquake that left mostly rubble behind. As a teen, I was part of that rubble. When I started university, I began to focus on conflict and peace studies. I was interested in finding more healing ways to deal with injustice, harm, fear, and violence. By grace, I fell in love with Rhona Hildebrand, an elementary school music teacher. Before we were married, we had to have some careful discussions about Huntington's disease—yes, you can meet my mom but she is not well and can be quite explosive. No, I guess she doesn't treat me like a son... I told Rhona she should consider seriously whether she wanted to marry into a Huntington's disease family. I nervously awaited her response. In hindsight, I learned I had two things working in my favour: 1) She was raised by people who modeled loving through life's ups and downs and 2) I am a very good kisser and Rhona was hooked. So we got married. Rhona said we needed to include "in sickness and in health" in our vows. And so we did. After a couple of years of marriage, we moved to Virginia for a year so that I could earn a master's degree in conflict transformation. During that year, we got pregnant with identical twin girls. We moved back to Canada, where our wonderful daughters, Sara and Koila, were born. I taught conflict studies at two universities in Winnipeg. Teaching turned out to be a great fit, but I knew that if I wanted to continue to teach at the university level, I would need to get my doctorate. So I applied and got a full scholarship to the University of Hull in England. We moved there when the girls were three. It was in England that I started my research into

communities that practiced healing justice. I traveled around the world, visiting Thich Nhat Hanh's Buddhist community in France; Hollow Water, an Indigenous community in Canada; and the Iona Community, a Christian community based in Scotland. These places are living examples of community life where injustices are addressed with healing and love rather than punishment, judgment, and fear. During this time, my mom died from Huntington's disease at the age of fifty-eight. We had to fly back from England for her final days and the funeral. Two years later, I completed my studies and was re-hired as Assistant Professor at Canadian Mennonite University. I published two books—one about research into restorative justice and peace-building that I had written in Virginia and the other about the three communities of healing justice that I had studied in England. My career as a teacher, researcher, and author was going very well. I got a government grant to allow me to continue travelling the world searching for communities of healing justice. The girls were in school and Rhona was back at work half time. Life was good. But we knew that because my mom had Huntington's disease, I had a 50/50 chance of getting it. My mother's main coping mechanism was to deny that she even had the disease. This left too many elephants lurking in the corners. There was a DNA blood test I could take that would tell me if I had inherited the gene for the disease. My mom could have had the test done a decade sooner than she did. While denial may have provided her some comfort, it made it profoundly difficult for any of us to support her on the journey. I wanted to chart a different path. First, I applied for early promotion at work. Once I was approved, both me and my brother had the testing done. I was positive. He was not. I would develop the disease. My daughters now had a 50/50 chance of having the disease.

For me, the news was both shocking and not shocking at all. I had always felt like I would get the disease. That insight provoked me to enjoy life in the present. However, having a doctor tell you that you will get this disease is, of course, different than listening to your own inner voice. The genetic counsellor had to make sure I

wasn't suicidal over the news. When she asked what we were going to do next, I said, "We will throw a Movers & Shakers party with friends to welcome the next part of our journey." She asked if I was kidding. You can read about the party in Chapter 5 – Celebrate Everything.

The same day we learned my diagnosis, we told our girls and went on a short family vacation to process it. The doctors could not give me a timeframe for the onset but I started to visit a neurologist every eight months for a checkup. Four years later, in 2014, I began having symptoms. When it was time to see the neurologist again, I put together a self-assessment, comparing myself to the previous year. Rhona added to the list and we shared it with the neurologist and the social worker from the Huntington Disease Society. Here are some highlights from that list.

Movement (body):

- stiff ankles
- progressively poor typing skills
- involuntary foot and toe movement
- finger movement
- elbow movement, lots of spilling
- decreased spatial awareness – knocking into things
- tingling sensation in the top of head
- painful sensitivity to loud noises
- ringing in my ears
- some swallowing problems
- night-time leg twitches
- more sick days from work than ever before

Cognitive (mind):

- difficulty moving to the next task at work
- inability to multitask
- very distractible, can't keep focus very long
- hard time deciding on priorities
- tend to get an idea in my head, then get fixed on it
- altered sense of time—it seems to move very slowly, and I am more impatient
- hard to remember to follow through on short, easy tasks
- overwhelmed by email, and don't open most of it
- harder time making decisions
- hard to sustain complex research exploration
- slowed mental functioning
- loss of ambition—hard to self-motivate or initiate
- hard time remembering short grocery list
- hard time remembering/accessing the word I am looking for
- tend to take on job assignments at work and then not get work done
- foggy brain

Psychiatric (emotional & relational)

- depression
- don't seem to feel fear in situations I used to feel fear (e.g. heights)
- hard to move out of anger
- tend to be easily irritable
- avoid social settings
- constantly feel like a failure at work
- increasingly tired in the evenings and likelier to stay home and not relate to others
- tend to care less about mistakes
- loss of spontaneity – prefer to know what is coming

Rhona and I met with the neurologist and a social worker. After a bunch of discussion, the neurologist told us that it was time for me to quit work. This was in early July. Again, we went straight on vacation—a road trip across Canada—lots of time to process our new path, again.

On the advice of friends, we added a golden lab puppy named Kobi to our family. Sara and Koila are 15 now. Kobi is two. And I am literally stumbling my way into learning about loving, letting go, and living in the present moment.

I understand the agony, pain, and struggle of having your world turned upside down by disease and aging. I have watched Huntington's move through three generations. I look into the eyes of my daughters with the full knowledge that there's a 50/50 chance that they too have Huntington's, passed on by me. After they turn 18, they will need to wrestle with whether or not to get the DNA test done. It is possible this disease may take another generation, my girls.

This is hard for all of us. In many ways, I have had lots of advantages in life. I have made studying conflict and healing my life's work. I do not want agony to be the main story of my life. I think agony, on its own, is toxic. I do not want to pass agony, fear, or violence onto Sara, Koila, or Rhona. So I have been experimenting on myself to find a healing way to face disease.

I am two years into these experiments and explorations. I will share my results with you. To help you understand the way I am trying to live well with disease, I need to first share the stories and the wisdom of some of the people who have influenced me the most on this journey.

When you find out that you are dying from an incurable disease, a kind of clarity can emerge. It is the clarity to distinguish between what matters and what does not matter. Having four university degrees and having experienced three generations of a debilitating disease, I had a lot of sorting to do. This book chronicles what I see as important. It is my cheat sheet for facing disease and aging in a healing kind of way.

When I had to “retire” at age 41 from my work as a university professor, I had hundreds of books. I gave away almost all of them. I saved the handful I thought might be helpful for me in learning the art of dancing with elephants.

The author with the greatest number in my little library is Zen Buddhist Master Thich Nhat Hanh. While he is not quoted much in this book, Thay—as his students call him—lies at the heart of it. Thay is responsible for bringing a revitalized Engaged Buddhism to the west. He was nominated for a Nobel Peace Prize by Martin Luther King Jr. I had the privilege of spending time at his community, Plum Village, as part of my research on healing justice. Thay is an author of more than one hundred books. I find his writing and speaking deeply valuable. It is inspiring but also very concrete and practical. I was deeply shaped by Thay’s focus on practicing wisdom in everyday life and living that wisdom in a community. In this book, I try to maintain this focus: true wisdom, lived in the everyday, supported in a community. The summer I was at Plum Village with my family, Thay taught the five mindfulness trainings. Each of the five parts of this book reflects one of these trainings.

Each section also includes an interview with a leader in the field of finding more healing ways of living. The featured teachers include the following:

Jon Kabat-Zinn, is the author of 10 books on mindfulness, trauma and health. He is known for mindfulness based stress reduction (MBSR) trainings which more than 16,000 people have successfully completed. MBSR was designed to develop relaxation and calm self-awareness, a reliable foundation for facing the “full catastrophe” of stress, pain, and illness—indeed, of life itself. In Chapter 6 Jon Kabat-Zinn dares us to focus on living now, rather than being paralyzed by the life we cannot live.

Patch Adams, M.D. who was made famous by the hit movie starring Robin Williams. Patch has been working on building a model hospital, modelled as an ecovillage where doctors and patients live together and where the doctor and the janitor get paid the same salary. Patch estimates he has been present at more

than 10,000 deathbeds. In my interview with him in chapter 11, he talks about dying well and living well.

Lucy Kalanithi wrote the bestselling book *When Breath Becomes Air* with her 36-year-old neurosurgeon husband, Paul, as he was dying of stage IV metastatic lung cancer. Lucy, who is also a medical doctor and professor, spoke with me about true love in the face of diseases like cancer.

John Paul Lederach is the author of more than 22 books on conflict transformation, peace-building, and healing. John Paul—my former professor—and I discuss how his professional life and his faith has helped and hindered him in supporting his wife, Wendy, who has Parkinson’s disease.

Toni Bernhard was a law professor at the University of California-Davis for 22 years until some fibromyalgia-like illnesses forced her to retire. In chapter 29, Toni and I discuss the three books she has written since, including *How to Live Well with Chronic Pain and Illness*.

The rest of the book offers glimpses of my wrestling, laughing, and stumbling my way into healing. Not the kind of healing that takes away the disease but the kind of healing that awakens the heart to love. I call this dancing with elephants because dancing is a playful way of engaging that which we fear most. Those who know me well know that playfulness is a major practice for me, as is the intentional use of humor. Suffering is real and must be faced head-on. But suffering alone is not enough. On the other side of suffering can be joy—and also more suffering. We must learn to dance with both.

Our culture offers abundant advice on how to achieve financial and career success, but there are very few books on how to embrace the downward path of losing your mind. We have success tips for leaders, but almost no “success tips” for the billions of us facing disease, dementia, and aging. This book is for those billions. Together we will explore the art of dancing with elephants.

I invite you to join me in this dance.

PART I
REVERENCE FOR LIFE



Chapter 2 - Embracing the Hard Things

On Avoiding the Hard Things

Do prayers ever piss you off? Sometimes they piss me off. In my teens and twenties, I was a wilderness guide, leading group canoe trips. Sometimes participants on these trips would pray that it wouldn't rain. Even in my teens, I knew this made no sense. Sometimes I would prod.

“Do you want the trees and animals to die? They need rain.”

“No,” they would say. “We just don't want it to rain on us.”

“Oh, so you want it to rain on the other groups I take out this summer, but not your group?”

“No,” they would say. “God can make it rain on the trees and animals but not the people.”

I already realized as a teen that it requires substantial mental (and sometimes theological) gymnastics for people to be able to justify a view of the world in which uncomfortable or unpleasant things shouldn't happen.

On the Way We Ride the Wave

This fall, I returned to that same wilderness of Canadian Shield country. It felt like coming full circle. Crossing paths with my younger self, I was reminded of the wisdom I could receive only by listening to the heartbeat of the wild. The temptation to try and insulate oneself from the hard things remains both common and understandable, but I still don't want to run from the storm. I don't want to run from the hard things. Healing is not the absence of the storm. Healing is the way we ride.

Driving alone on the prairies after going to the funeral of a young man, and thinking about my own chronic illness and about rain, I wrote this poem:

Nobody Wants the Rain

Everybody wants green scenery

Nobody wants the rain

Everybody wants food on the table

Nobody wants the rain

Everybody wants the colourful rainbow

Nobody wants the rain

Everybody wants water in their bodies

Nobody wants the rain

I went to the prairie,

The Expander of Horizons

To ask about the rain

I stood on the edge of the world

And watched the rain coming all around

And the prairie proclaimed a vision

Each time the gift of rain was offered

the people ran in fear

Heart's fear perverts darkness into evil

Missing the gift of life hidden in the cloud

Let it rain down, let it rain down

Let it rain down on me

*Everybody wants green scenery
Nobody wants the rain
Everybody wants food on the table
Nobody wants the rain
Everybody wants the colourful rainbow
Nobody wants the rain
Everybody wants water in their bodies
Nobody wants the rain*

*I went to the mountain
The Giver of Wisdom
To ask about the rain
I knelt on ancient rocks
Fifty billion years awake
and the rocks spoke to me
The rain shapes and molds us
and turns us into sand
These rain-shaped rocks
Feed the earth as their dust becomes soil
The mighty mountains are transformed
By but a tiny drop of rain
Let it rain down, let it rain down
Let it rain down on me*

*Everybody wants green scenery
Nobody wants the rain
Everybody wants food on the table
Nobody wants the rain
Everybody wants the colourful rainbow
Nobody wants the rain
Everybody wants water in their bodies
Nobody wants the rain*

*I went to the ocean
The Alpha and Omega
To ask about the rain
I sat on the ocean's edge
As but a tiny grain of sand
And the ocean questioned me
Where is my beginning and
where is my end?
Ocean's edge is hard to find
On shore? In sky? Inside my body?
The ocean's end is its own beginning
Let it rain down, let it rain down
Let it rain down on me*

We cannot learn to revere life if we cannot wrap our hearts around the idea that suffering exists. The art of dancing with elephants is not the elimination of suffering. We don't kill the elephant. We learn to dance with it. All living beings suffer. To revere life, we cannot remain in denial but must understand that suffering and death are inevitable. This truth is not the end of the story but it is a necessary starting point on this journey.

Once we become comfortable with the idea that suffering exists, we need to learn to let go of fear and replace it with love. This is the focus of the next chapter.

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