A Resilient Life

Learning to thrive, not just survive, with rheumatoid arthritis



A Resilient Life:

Learning to Thrive, not just survive, with rheumatoid arthritis

Written by Kat Elton, OTR

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A Resilient Life: Learning to Thrive, not just survive with rheumatoid arthritis.

By Kat Elton, OTR

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The author has taken care to ensure the information in this book is accurate and up to date, however, as knowledge in medicine is constantly changing and new information discovered changes in treatment occur. The reader is encouraged to acknowledge his/her unique situation when considering any recommendation in this book.

Ordering information:

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To the Elton clan And to all the amazing healers who, over the years, have given me back my life

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Introduction:

A Resilient Life

Mae West once said, "Old age isn't for sissies," I say neither is arthritis. People with arthritis are some of the toughest people I know. Put a bunch of people with arthritis in a room with professional athletes and they'd have a lot to talk about: how to push through and go beyond a pain threshold that would stop most people in their tracks, how to ignore discomfort, how the snap, crackle, and popping joints between them could create a chorus, how to pick yourself up after a fall, what it's like to be alone out there. Professional athletes will brush off injuries because those injuries jeopardize their ability to participate in the next game. People with arthritis will brush off their pain because it jeopardizes their ability to participate, period.

When you are diagnosed with a chronic disease you soon confront one of the most humbling experiences of being human. In large part we are completely alone in our experience. The people around you can go on with their lives, yet you have to deal with this 24/7. Sometimes it may feel like you are treading water, other times that you are sinking and occasionally you get to swim. Your whole world has narrowed and widened at the same time. Narrowed, because you have this entity to constantly keep track of which can feel stifling. Widened, because you have been introduced to a whole new world-being a patient.

There is so much decision-making that you alone must make from what medications to take, how much to spend on things to ease your discomfort, and the limits you place on yourself and others so that you have enough energy to make it through the day. The internal dialogue can get very busy. Explaining it all to others may seem so difficult you don't even know where to begin. You alone end up juggling the busyness in your head. The fact is that having a chronic disease can isolate you from others both emotionally and physically. All of this is important to confront as early as possible in your process of living with chronic disease.

And then it's important to remember that for a penny to be a penny it has to have two sides. In life, for something to exist there must be an opposite to even it out. Night/day, love/hate, fear/trust, isolation/togetherness, and disease/ease. It is possible to thrive with rheumatoid arthritis as contradictory as this may seem at first. The road that leads there embraces both sides of the coin. The alone part can lead you toward taking responsibility, seeking out others to be on your healing team, which leads you to togetherness. You learn to live in both. You learn to see the opportunity that life has brought you; the opportunity to slow down, really look at yourself, and experience who you truly are.

Thriving with arthritis means you wake up every day and decide to thrive. In doing so you see that your greatest tool is your perspective, and attitude really is everything. You learn to be patient. You learn to transform your suffering into compassion, which literally means "to suffer with." You're humbled, time and time again, and then you're grateful. You work hard to do your homework but then you allow yourself to live in the

unknown. At times all you can do is laugh at the absurdity of it all. Eventually you realize how truly resilient and strong you are.

There is richness in a life of thriving with chronic disease I doubt can be gained anywhere else. Through it all you must reach into the depths of your soul, be strong, savor the experience, and be grateful. It will transform you and I guarantee it will make you a better person. How you

do this is up to you. The Golden Rule in this game is to keep trying, if you are doing that you are doing everything.

I didn't write this book because there is a lack of information about rheumatoid arthritis available. Actually, the amount of information we have today is mind-boggling. One trip to Barnes & Noble's, Amazon.com or Google will confirm this. I've been to them all, and guess what, I've found so many ways to beat this disease it's amazing any of us still have it!

How many of you would take 10,000 mg of vitamin C every day if it took away the pain? How many of you would stop eating wheat? Sleep on magnets? To those people who've cured their arthritis through any of these means I applaud you. The problem is, for 99.5% of us, it's not that simple and when we read about "Grandma's Arthritis Cures," or "The Cure For All Diseases," we are bound to get our hopes up.

I'm the type of person who can wear rose colored glasses. I'm grateful for this; they work for me most of the time. But they can also get me into trouble. Trouble, because time after time I've convinced myself that this will be it. I'll tell myself, "Of course, humans can't produce vitamin C and because I don't like orange juice I've let the arthritis run rampant in my body! BIG mistake." And then the rose colored glasses come off. Time after time, high hopes, hopes dashed, until I can't help but wonder, "Why me?"

At that point, I will inevitably hear from my Aunt Matilda, who has a friend with a son, whose cousin went to Mexico and came back in glowing health. "Well, shoot," I have to wonder, "Why is everyone coming up here from south of the border if they have the cure for one of the nemesis of our time?"

This is about the time I turn back to the doctors to learn more about the chronic, progressive, disabling illness that not only attacks my joints but also my eyes, skin, organs, and most horribly my sense of humor. To top it off it's all because my immune system is defective and has decided to attack my own tissues. So it's all my fault, just as I suspected, and I go back to the books.

According to the experts, in order to best manage this disabling disease I need to think positive, do range of motion exercises every day, protect my joints, swim, watch what I eat, do visualization, get good sleep every night, take medications as prescribed, avoid

stress... wait a second, do I get to live a life here? And then the realization hits me that this is my life, this is my chance to create a life that I can be proud of.

The reason I'm writing this book for you is precisely because you don't need to be told what to do. As someone who has spent every moment since age two with arthritis and has worked as an occupational therapist I consider myself more than a little qualified. But for these reasons I know wholeheartedly that when it comes to rheumatoid arthritis and chronic disease in general there are no absolutes.

When I was young I learned very quickly that when an adult said "This won't hurt" they were lying. So I decided that before anyone did anything to me they had to explain what they were going to do in detail. I remember going to the dentist to get a bunch of teeth pulled and being forewarned that I would bleed a lot because of the aspirin I was taking for the arthritis. Just that little bit of information allowed me to prepare myself for what was to come and helped me to feel like I was part of the process. I never lost the need to feel that way. When you have rheumatoid arthritis there are many times when things happen to you and you can easily feel as if your life is spiraling out of your control. I've always felt strongly that knowledge is power and that you never run out of options. These two ideas have kept me going when the going got tough.

My goal is to have this book give you the knowledge and the options you will need to live well with rheumatoid arthritis. Each chapter addresses a different issue or area of concern that I've encountered numerous times throughout my life. Inside each chapter you will find personal experiences, knowledge I've gained, and tools to use. Use this book like a toolbox. Use the tools when you need them and when you don't be assured that they are there. The best tools won't be the one's I'll give you though; they will be the ones you discover within yourself.



Being a patient has always been a part of my life and as a kid my parents always made the experience a special one. I'd get dressed up, drive across the George Washington Bridge to Columbia Presbyterian Hospital which was an exciting experience. After all I was going to New York City! My Mom and I would arrive at Dr. Jacob's office where I'd feel very grown up reading magazines while I waited to see the doctor. Okay, they were Highlight magazines for kids but I still felt very mature reading them. Once I was in the office Dr. Jacobs would examine my joints and talk to my Mom about how I was doing. When I was in Dr. Jacob's office I was the center of attention. My needs were being addressed and I felt cared for. Even getting my blood taken wasn't so bad. I'd feel very brave by not making a fuss when they poked me with the needle and I still remember the stuffed animals and pictures on the wall to take my mind off the pain.

Looking back with what I know now about healing, Columbia Presbyterian, and Dr. Jacobs, did everything right. Being a patient there did not go hand in hand with fear, apprehension, anxiety, or frustration but instead gave me the experience of feeling good.

I wish I could say it was always that way but given my long history as a patient it was inevitable that at some point I'd eventually experience less compassionate care. The first and probably most dramatic example of this happened before my first hand surgery. Weeks earlier I had learned that I had ruptured one of the tendons that lifted my ring finger and I knew I was in deep trouble.

I was in the office of one of the top hand surgeons in the country and was being examined by a Fellow, a young doctor who was receiving training to specialize in hand surgery. This young doctor had swooped into the room, grabbed my painful hand, and started measuring my range of motion, blissfully unaware of my winces as he pushed and pulled on my joints. Abruptly, he looked down at my arm and dropped it. "What is that!" he said, and I looked down. I had suddenly started breaking out in angry red welts. "Looks like hives to me," I said. At the time I was not very aware of my emotional reactions and I still thought stoicism was the best way to approach my situation. However, it was apparent to me that anxious response to this guy's utter disrespect and disregard were causing me to break out in hives.

He left the room and I tried to calm my body. Minutes later he came back with my x-rays. He took one look at them and exclaimed in an excited voice, "Wow, look at this, I've never seen anything like it, not even in a textbook!" and then ran out of the room to fetch the other Fellows. Here I was, breaking out in hives because one of my worst fears, surgery, was coming to fruition and I had five doctors crammed into my tiny exam room "oohing" and "ahhing" at the horrible state of my wrist joint.

All I can say now is that it's a good thing this guy had decided to be a surgeon. Ninety percent of the time his rudeness would be irrelevant because his patients would be unconscious. And luckily for me, my hand surgeon, Dr. Melone, turned out to be a star. To this day he is one of my heroes.

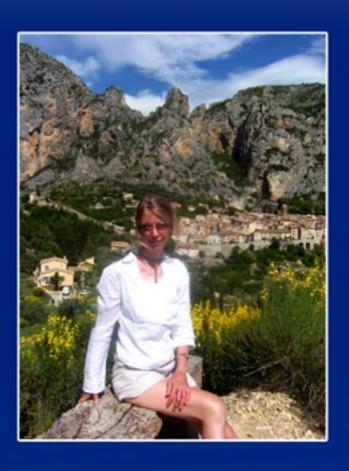
I've learned a lot throughout my years as a patient, and also as an occupational therapist who has been on the other side of the exam table. And I've decided that for me, if a healthcare provider wants to keep me as a patient they have to meet a high standard. I've decided this because, in varying degrees, they have my life in their hands. And my precious life is not to be taken lightly.



Chapter One:

The Art and Science of Being a Patient

"The good physician treats the disease; the great physician treats the person who has the disease."
-- Sir William Osler



ABOUT THE AUTHOR

Kat Elton, OTR has a master's degree in occupational therapy and fifteen years experience in health care. She has lived with rheumatoid arthritis for forty years. Her latest book, A Resilient Life: Learning to Thrive, Not Just Survive, with Rheumatoid Arthritis, won the "Best Books 2010" Award from USA Book News and the 2010 Bronze Medal from the League of Utah Writers. She wrote A Resilient Life because she knows that, although it isn't easy, moving beyond disease and into a well-lived life is important for everybody, regardless of their circumstance. Kat currently resides in Salt Lake City, Utah where she keeps busy as an, author, speaker occupational therapist, and health coach. She enjoys being in the outdoors every day with her dog Jasper who provides the comic relief.

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Too often, people faced with a disease such as rheumatoid arthritis hear words like, "disabling," "chronic," "progressive," "crippling," or "tragic." "Tragic" may be what people are saying but the real tragedy is that these often repeated words do nothing but harm to those who hear them. They completely ignore a very real truth: physical issues can absolutely lead to positive transformation, action, challenge, inner strength, deep courage, and compassion.

No one chooses rheumatoid arthritis as a way to become a better person: there are MUCH less painful ways to get there. However, this is an opportunity you can choose to take.

This unique book is written by someone who knows her subject well. Kat Elton, an occupational therapist and woman who's had rheumatoid arthritis since age two, knows that people with RA don't need false hope or to be told what to do. What they do need is to be led toward believing in themselves and improving their reality no matter what it is.

Part practical guide, part workbook, part memoir, this book demonstrates that although there is no magic bullet or cure for rheumatoid arthritis, there is a way to live well with this disease.

The way there is through practical knowledge, hope, perspective, inspiration, and real choices.

You can thrive with rheumatoid arthritis. Let this book show the way.