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Arthritis

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**"My triumph
over RA"**

Finding the right treatment let
KAREN AGER leave her wheelchair
behind to pursue a dream life in NYC

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“My secret for BEATING RA”



Karen Ager has battled RA for 30 years—and she kept it a secret while chasing her dreams. Her strategy for eventually conquering the “enemy within”? Making peace with it.

Karen Ager, 47, has traveled the world, from the shores of her native Australia, to a stint as a rock star’s nanny, to her current home in New York City, where she teaches at the renowned United Nations International School. Not only

has Karen fulfilled her travel and teaching dreams, she’s also witnessed another wish come true: An RA treatment regimen that has allowed the happily married Aussie to keep up with her busy work and social life.

But to truly understand how far Karen has come, you have to know how it all started more than 30 years ago, long before the advent of today’s effective RA treatment options.

The sun was shining on the Melbourne beach where Karen, then 15, and her cousin were putting the school year behind them. As they were basking in the sun, Karen noticed the first symptoms of what would eventually be diagnosed as RA. “I just couldn’t get up off my towel,” she recalls. “My cousin had to carry me home. We chalked it up to overdoing it in the heat, and my symptoms went away.” Unfortunately, it was only a temporary respite.

“The following year, the pressure of school exams caused my body to fall into a heap, and I had severe swelling in my knees and right hip,” she says. “I was diagnosed with RA after that, but the word *arthritis* didn’t register with me and I didn’t know what it

meant.” In retrospect, it signaled the beginning of a long journey. “Within five years, I became confined to a wheelchair; my mom had to help me do everything, including get dressed, which put a strain on our relationship. I was angry and depressed.”

Making matters even worse, she had a particularly aggressive form of RA; treatments would work for only a short time before her symptoms returned “with a vengeance.” At 27, she hit rock bottom: “I was diagnosed with pneumonia and was in the ICU for two weeks. I nearly lost my life; the hospital was about to call the priest in.”

“I vowed to fight”

“I saw my mother’s eyes in that hospital room—how afraid she was—and in that moment, I started to will myself to live. It was a pivotal moment in the long process of change for me,” she says. After recovering from pneumonia, Karen refused to go on permanent disability and vowed to fight everything from depression to her mobility problems. “I had always dreamed of becoming a teacher and wanted to see the world—and nothing was going to stop me,” she says.

The promise she made to herself in that hospital room signaled a turning point—a renewed fighting spirit that meant she wouldn’t give up until she found the treatment that would work for her. But at one point, she went looking in the wrong place—an alternative treatment clinic in England that encouraged her to stop her pre-



Karen takes comfort in the support she gets from her husband, Matt—and some pet therapy from her dog, Willy!

scription meds and try a “natural” cure of apple cider and molasses. In less than four months she returned to Australia in a wheelchair and became housebound. Karen’s doctor had to put her on massive doses of cortisone, which enabled her to walk and eventually begin working again.

Back on her feet, Karen kept traveling and teaching, eventually landing a job in Manhattan. It was there, in 2001, that a rheumatologist put her on a new RA drug, a biologic. It became “a virtual cure for me,” she says. With her body more of an ally than an enemy, Karen was able to focus on fixing the emotional and psychological toll her condition had taken.

Today, Karen’s more confident than ever—she’s now on another biologic, along with prednisone and anti-inflammatories—and has become a vocal advocate for arthritis awareness. Here, she shares tips from her autobi-

ography, *Enemy Within*, about how to move from a place of pain and anger toward acceptance and happiness.

THE ENEMY: Taking it out on loved ones

“When I was first diagnosed, I felt depressed and angry at the world,” Karen admits. “And I took a lot of frustration out on my mom, who was the closest person to me. She has been an unbelievable support, but when you’re in your 20s and your mom has to help you do everything—from bathe you to help carry you up a fourth floor walk-up—it’s really hard on your relationship.”

HOW TO CALL A TRUCE: Feel the frustration—then do the opposite

“I had to give myself permission to feel the anger, pain and sadness,” she says. “Once you give yourself the time and space to feel those emo-



[COVER story]

“When an 8-year-old in my classroom sees that my hands are swollen and asks about it, I can tell him I have RA. It makes me feel great to show children that you really can do anything with this condition—I don’t like to call it an illness.”

tions, you’ll no longer feel hijacked by them—and you won’t take them out on the people closest to you.” What does Karen do instead? “Now, I hug them and let them hug me. That’s key: to let people in.”

THE ENEMY: Letting negative self-talk prevail

When she was depressed, Karen often turned her negative feelings inward. “I would think, *This can’t possibly be happening to me*, and I’d feel like a failure.”

HOW TO CALL A TRUCE: Revel in your resiliency

“RA doesn’t mean I can’t do things—it just means I need to do them differently. I started to recognize my own strength. It takes bravery and courage to go through this; once I recognized that in myself—that I *am* resilient—I became more confident and all my relationships flourished.”

THE ENEMY: Deferring your dreams

Karen says it’s easy to give up on your dreams when you’re dealt an unexpected blow. “When you’re facing adversity, it affects your confidence and self-esteem. I almost gave up on my future—at least on how magical I once thought it would be.”

HOW TO CALL A TRUCE: Set small goals

Dreams don’t drop into your lap; they have to be achieved piece by piece, she notes. “I realized I had to set small goals and that no matter what happens, trying is important—it gives you a sense of pride.” The huge goal she tackled through baby steps? “I always knew I wanted to write a book about my experiences. So I started writing a journal—parts of which inspired the structure of *Enemy Within*.”

THE ENEMY: Keeping RA hush-hush

For a long time, talking about RA was difficult for her. “I didn’t like asking for help or sharing too much about what I was going through.”

HOW TO CALL A TRUCE: Make a connection

“Connecting with people at support groups and online has made a huge difference,” says Karen, who now runs her own support group. “It opened my eyes to the fact that people *want* to help. The burden of 20 years of not telling my story has lifted.”

THE ENEMY: Staying cooped up

It’s tempting to stay indoors when you’re depressed or your joints are

hurting, she concedes. “There were times I didn’t want to look at another person, let alone go outside.”

HOW TO CALL A TRUCE: Get some pet therapy!

What changed things for Karen? “Willy, my healing dog,” she says, smiling. The cute morkie (a Maltese and Yorkie mix) has proven to be an essential part of dealing with RA. “Walking him is not only good exercise, it’s so therapeutic—I leave my phone at home, go to the park and just relax,” she laughs.

THE ENEMY: Dwelling on the pain

The stress of RA could be so overwhelming, Karen says, “It tested me every day and I would dwell on my fatigue and pain; I just didn’t have an outlet for my stress.”

HOW TO CALL A TRUCE: Find a way to engage

“Now, I try to stay in the moment and relax whenever I can.” Her favorite stress melter? “Music—I never appreciated it before, but my husband really got me into it. I also try to do one small thing for someone else every day. It helps shift the focus off myself and makes me feel great.”

—Kristina Mastrocola

Manage your RA.



Eating something cold relaxes the muscles in your jaw and neck, which can help relieve stress.

Enjoying the little pleasures in life can help you take your mind off the pain and stress of RA.

Natural fruit ice pops, such as strawberry or blueberry, can be an easy way to get antioxidants, which may reduce inflammation. Try making your own at home.

Join RISE, and we’ll show you how to see things a little differently.

RISE is a network of resources specifically for people with rheumatoid arthritis (RA). As a member, you’ll learn how things from your everyday life—like a healthy diet—could help you manage your disease. You’ll also learn about advances in treatment and meet some community experts.



Join today and get a DVD with RA exercises. Send in the card, call 1-877-474-8892, or visit www.RISEsupport.com.

departments

- 7** In step
 - The truth about soy
 - Splash your way back to health ...and more!
- 17** Questions for your doctor
- 21** Little lifesavers
Make every day with RA easier
- 31** Ask the experts
 - How can I get better sleep?
 - Does aspirin cause gout? ...and more!



42

These yummy comfort foods will fill you up without filling you out—and they have **bone-building calcium** to boot!

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WIN A COPY OF KAREN AGER'S BOOK, ENEMY WITHIN

In *Enemy Within*, Karen reveals how she triumphed over RA and shares her tips. For example, here's how she makes it easier to walk her dog, Willy:

"I've got a leash with a padded handle—it really saves my hands! Plus, I use a harness rather than a collar so I can easily lift him with one hand." Another tip: "I have a carabiner—a small rock-climbing clip—on the handle of Willy's leash. If I'm having a flare in my hands, I just clip it onto my belt loop so he can't take off!"



What's your favorite tip for making every day with arthritis easier? Just email it to Talktous@healthmonitor.com by March 30. The top five entries will win a signed copy of Karen's autobiography (see page 26 for her story).

Activity reminder!



Aim for about 150 minutes of moderate-intensity, low-impact activity each week (about 20 minutes a day), such as brisk walking or water aerobics. Physical activity can ease pain, improve flexibility and even boost your mood. Yet a study of osteoarthritis sufferers in *Arthritis & Rheumatism* found that more than half of women and 40% of men are "inactive"—doing less than 10 minutes of moderate-to-vigorous activity per week. If you're one of them, remember that it's okay to start small. As long as your healthcare provider says it's okay for you to move, any effort is better than none.

Stand tall to soothe pain

Having a bad arthritis day? Check your posture. When you stand tall, you assume a dominant pose—and that helps you feel in control and better able to withstand pain, according to a study in the *Journal of Experimental Social Psychology*. Slumping, on the other hand, can lower your pain threshold. Worst of all is curling up into a ball, which intensifies pain by making you feel as if you have no control.