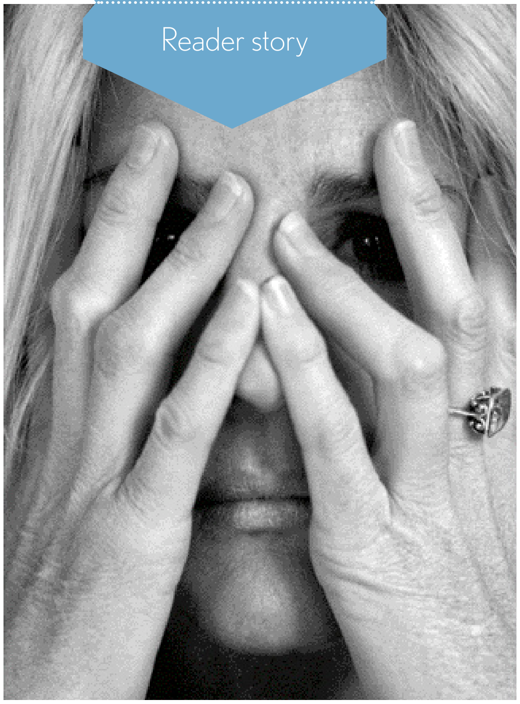


Her hands, above, give Karen Ager's condition away; even though she has lived in New York for ten years, Australia is still home

Fighting spirit

PHOTOS: COURTESY OF HAIK KOCHARIAN/ARTHRITIS FOUNDATION NY CHAPTER

KAREN AGER, NOW 46, WAS DIAGNOSED WITH AN AGGRESSIVE FORM OF RHEUMATOID ARTHRITIS WHEN SHE WAS A TEENAGER. THE JOINT-DESTROYING DISEASE, WHICH AFFECTS MORE THAN 400,000 AUSTRALIANS, HAS SENT HER ON A CHALLENGING JOURNEY

Told her only choice was to live on a disability pension, this adventurous blonde with model looks has instead travelled the world, is married to the love of her life, and is working in her dream job.

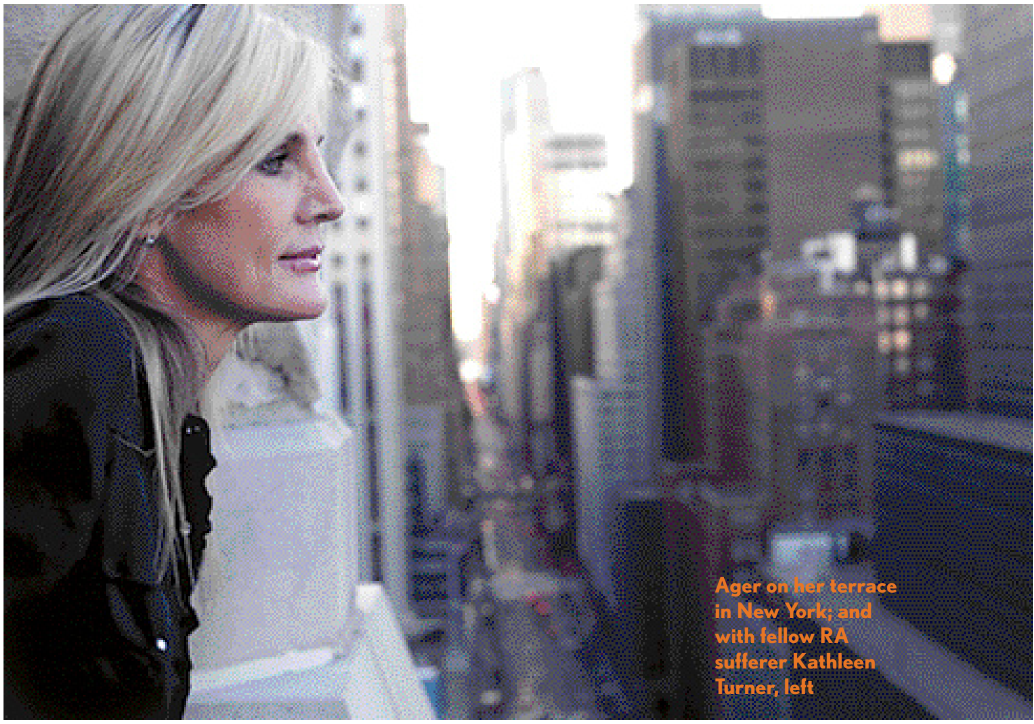
How did the diagnosis make you feel?
I was 17 and had just been told I had a disease with no cure – rheumatoid arthritis (RA) – which would almost certainly cripple me. I was a normal teenager, so I did my best to block it out.

Just out of high school, I was eager to start at a travel industry trade school. I'd passed my final year exams with impressive results, despite a three-month absence due to a bout of glandular fever, and I was living with my father in Melbourne. Mum had flown in from Perth, where she was living, to take me to the rheumatologist. Neither of us really understood the magnitude or the implications of the diagnosis at the time, but as the year progressed, so did my RA.

A few months later, when I began to struggle with day-to-day activities such as showering and getting dressed, my family and I slowly started to understand just how bad the RA diagnosis was. ➡

GOT AN INSPIRING STORY TO TELL?

You could earn up to $500. Submissions must be true, unpublished, original and 800-1000 words in length. See healthsmart.com.au for more details



Ager on her terrace in New York; and with fellow RA sufferer Kathleen Turner, left

What is rheumatoid arthritis?

About four million Australians have arthritis, a joint-stiffening disease usually thought of as an inevitable by-product of the ageing process. RA is its wicked cousin – it's an auto-immune disease that causes your body to attack itself. It's chronic, progressive, deforming and as yet incurable.

RA wreaks havoc with the joints, causing painful flare-ups and loss of mobility. Its primary target is the musculoskeletal system, but it can also damage the heart, lungs and eyes. Researchers don't know if RA's source is viral or bacterial, whether genetics plays a role, or if stress is part of the triggering mechanism.

For many RA sufferers like me, it begins almost invisibly, with occasional flare-ups in joints and other subtle signs of the inner destruction that limits mobility and can lead to disfigurement, joint-replacement surgery and even death.

What would a diagnosis mean for people today?

There is still no cure. However, the good news is that with aggressive treatment using some of the new biologic drugs, further joint damage and loss of mobility is often limited. This means a better quality of life.

Have you ever felt like giving up?

Australians are known for never giving up and I was no exception! I studied to be a teacher, and in the late 1990s I travelled the world as the nanny for a rock'n'roll legend and his supermodel wife. Teaching has always been one of my career dreams and I now have a job at an elite Manhattan private school. I also met the love of my life in 2000 and we live on 42nd Street in New York City with our puppy dog.

What has helped you make it through?

There's the daily grind of feeling isolated and being unable to do the simplest of physical tasks without pain or fatigue, the fear of an unpredictable future, and the burden of disclosing the secret of the illness to colleagues and employers. My hip replacement at 28 and my frequent hospital visits due to infections were among my darkest days.

I got through these moments by telling myself, *This will pass*; by accepting the situation and by trying not to fight it. I don't feel self-pity, and lead myself to a place where I feel empowered. I try to find a way to be enriched by the struggle so that I can put my energy into helping others.

How has RA altered your life?

My diagnosis has been a curse and a blessing. In the past, it stripped me of my independence and dignity, and made me very angry.

But my disease has taught me how to be a better teacher of children with disabilities, to be more compassionate towards others, to laugh at myself, to appreciate life and to reach out to others in need. My RA has mostly been a gift for which I am truly grateful.

What about your teaching?

At first the children and my school didn't know about my disease. This changed eight years ago when a Grade 2 student noticed my crooked hands. I finally disclosed my secret. The student, Joseph, is now 15 and my biggest supporter.

A Grade 1 student with Down syndrome also had a profound effect on me. Amy accepted that her illness was a condition of her living. This helped me to be at peace with mine.

Teaching is a very physical job. I have to be careful the children don't squeeze my hands too hard or run into me when I have sore joints. Fatigue is also a big problem, but I've learnt not to focus on the negative; I think about how lucky I am instead.

Where does your strength come from?

From acceptance and from my husband, Matt, who is always there for me. From my family and my amazing girlfriends who have carried bags for me around the world just so I could be included in the fun. From my mother, my brother Steve, who has been my rock, and my dad, who always has the wisest words. And from finding time to be thankful for everyday moments – and never forgetting that acceptance is one of the most powerful weapons of all.

Through my charity work with the Jeffrey Gottfurcht Children's Arthritis Foundation, I hope to become instrumental in granting wishes and dreams for children with juvenile arthritis in Australia. I want to use this experience to help others in their times of need. ●

To contact Karen, go to karenandarthritis.com or read more in her book Enemy Within *(New Holland, $26.95).*