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A weapon of last resort

Crippled and pained by arthritis, one woman finds relief after using a controversial drug

BY JENNIFER FRIEDLIN

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Karen Ager is willow thin and model pretty. As she walks down the streets of Manhattan it is impossible to discern that anything ails her. But that was not always the case.

Until a few years ago, Ager, 40, was practically immobilized by rheumatoid arthritis, a disease in which the body's immune system rebels against its own tissue, destroying joints and cartilage. She was in chronic pain as she watched her body become increasingly deformed. Though she tried a number of different drugs and remedies, no treatment put a halt to the disease's progression.

All this changed, however, a few years ago when a doctor informed Ager about a host of powerful new drugs that were giving renewed life to sufferers of severe arthritis.

"It was like a virtual cure," said Ager.

Ager is one of millions of people worldwide who suffer from arthritis. In the U.S., an estimated 70 million people, or one quarter of the population, have some form of the disease.

Arthritis comes in about 100 forms, the most common of which is osteoarthritis, a degenerative joint disease, common in the elderly, that causes the cartilage covering the ends of bones to deteriorate, resulting in pain and loss of movement. Other types of arthritis, including rheumatoid arthritis and psoriatic arthritis, can strike people in the prime of their lives. Arthritis disproportionately affects women.

Yet, the disease, one of the most prevalent chronic health issues and the leading cause of disability among Americans over age 15, has not garnered a commensurate amount of public attention. Doctors say that's largely because up until now there were so few effective treatments.

"Arthritis really isn't taken seriously," said Dr. John Klippel, president and CEO of the Arthritis Foundation. "People with arthritis think there is nothing that can be done about it. But we're sort of in the midst of a revolution. Suddenly, we have new drugs that are changing people's lives."

Twenty-five years ago Ager was a typical 15-year-old living in her native Melbourne, Australia. One day, she was at the beach when a searing pain gripped her body. Her cousin carried her home, gave her an aspirin and put her to bed. When she woke, she felt okay and dismissed the incident.

The next year, just as Ager was about to graduate from high school, she had

Karen Ager's rheumatoid arthritis had her confined to a wheelchair before doctors tried an intravenous infusion procedure.

another flare up in which she was unable to move her wrists, shoulders, jaw or knees.

"Every part of my body was red and inflamed," she said.

Ager was diagnosed with rheumatoid arthritis, but at the time there was little that could be done to treat the disease. She took pain medication and carried on with her life, taking a job as a travel consultant.

At the age of 20, however, her condition worsened and Ager could no longer work. She was on massive doses of anti-inflammatory drugs, including large doses of cortisone, but the medications did little to treat the disease.

The medications "masked the pain, but my joints were degenerating before my eyes," she said, lifting her hands to show several deformed fingers.

Ager went back to school and took a position teaching kindergarten. Afraid that she might lose her job, Ager never told her boss about the disease. Instead, she stoically stood out in the winter cold playing with the kids while the pain gripped her feet, ankles and wrists.

As the disease ravaged her body, it also took a toll on her self-confidence. Ager said it made her feel so badly about herself that she stayed in a "destructive relationship" for several years.

"I was going into relationships in my 20s that were co-dependent because I was too scared to be on my own," Ager said. In an effort to take control of the disease, Ager tried alternative treatments that proved dangerous. At one clinic in England, she was given treatments that consisted of apple cider and molasses. After 3 1/2 months of such homeopathic remedies, Ager returned to Australia and was confined to a wheelchair.

"I was wheelchair-bound because I went off the meds to do the 'natural thing,'" she said.

By 24, Ager was housebound. She lived in a fourth-floor walk up and could not move on her own. She would shimmy off the couch on her behind to get across the apartment and used satin sheets because they helped her to roll over more easily in bed.

The Australian government evaluated Ager for disability and determined that she was an invalid who would never work again. This devastating diagnosis served as a catalyst for change.

Ager went to a rheumatologist and was put back on cortisone, which enabled her to at least get back on her feet. She had a hip replacement and went to

work part-time. Most importantly, she began to realize that the disease was something she was going to have to come to terms with.

"By this stage, I started to realize my illness was something I had to accept," said Ager. Up until that point she had fought the disease by refusing to accept it.

Although her disease remained out of control, Ager spent the next few years globetrotting. She worked as a teacher in Toronto and spent three months working as a nanny.

Ager continued to work throughout her early 30s and in 2000, at 36, she moved to New York City to teach second grade at the United Nations school. Despite various treatments, the pain and shame continued. Even the short walk from her apartment to the school was a burden.

"I'd get to work and I'd be exhausted. I would have to face the kids and their

parents and pretend to be ready for the day."

In 2001, a visit to a local rheumatologist signaled the start of a new beginning. Dr. Paula Marchetta told Ager about a new intravenous drug known as Remicade that was having amazing results in some patients. At first, Ager balked because she was afraid of taking a medication intravenously.

"Dr. Marchetta said, 'You can continue as you are and in 20 years you'll be in a wheelchair, severely, severely restricted, or you can try the unknown and overcome your fears,'" Ager recalled.

That was enough to make Ager try out the treatment.

After the very first infusion of Remicade, which has caused life-threatening adverse reactions in some patients, Ager was a new person. For the first time in more than a decade, she could walk without pain and, her joint degeneration stopped. "I'm in clinical remission," Ager said with a big smile.

In order to keep the disease at bay, Ager goes to a local clinic every five to six weeks for an intravenous drip of Remicade, and supplements the treatment with a cocktail of several other medications. The painless sessions take about 1 1/2 hours.

During a recent visit to the clinic, Ager sat in a blue recliner leafing through a magazine as the Remicade dripped into her right arm. She said she now looks forward to the sessions.

"It's forced relaxation," Ager said. "I come in, get the infusion, pay my co-pay and go. After this I'm off to a party as if nothing ever happened."

Doctors say that for the first time, new treatments, including Remicade and two other drugs, Enbrel and Humira, offer real relief to people suffering from various types of arthritis. These biologic agents work by blocking a molecule called tumor necrosis factor, an inflammation-regulating protein believed to lie at the heart of rheumatoid arthritis and other autoimmune disorders.

"All three drugs are gene engineered proteins that act like a sponge to pull TNF out of the bloodstream," Dr. Jay Adlersberg, a rheumatologist whose clinic Ager visits for the Remicade treatment.

Adlersberg said that of the three TNF treatments, Remicade is the most flexible, meaning dosages can be fine-tuned for each patient. Enbrel and Humira do not work better at higher doses than they are indicated for, he said. And, unlike Remicade, Enbrel and Humira are also self-administered.

Yet, there are possible downsides (see box). Before going on a TNF-inhibiting drug, patients should test for tuberculosis since the drugs can reactivate a dormant case of the illness. And some studies indicate that there may be a correlation between drugs like Remicade and a type of cancer known as lymphoma, particularly non-Hodgkins lymphoma, the disease that killed Jackie Onassis.

But autoimmune diseases increase a person's chances of getting lymphoma, so researchers say it is hard to determine if TNF inhibitors or the underlying illness are to blame for the higher rates of the disease.

Even if there is a correlation, Ager, who has a new relish for life and married a "wonderful man" last summer, said the rewards of Remicade far outweigh any potential risks.

"I don't want to go back to how I was living, so I would still take the risk,

she said.

Weighing the risks

Last December, the FDA notified healthcare professionals about serious complications that arose in some patients who take Remicade and revised their patient-package insert to include that information. The drug, indicated for the treatment of rheumatoid arthritis, Crohn's disease and ankylosing spondylitis, has caused severe hepatic reactions, including acute liver failure, jaundice, hepatitis and cholestasis in some patients. Autoimmune hepatitis has been diagnosed in some of these cases. Severe hepatic reactions occurred between two weeks to more than a year after initiation of Remicade. Some of these cases were fatal or necessitated liver transplantation.

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