Why We Need to Stop Calling it Rheumatoid Arthritis

by KELLY O'NEILL YOUNG

Why Use the Term Rheumatoid Disease?

A Disease Beyond Inflamed Joints

The simplest name for something is what it is. An apple is a fruit. A Ford is a truck. And RA is a disease.

The phrase rheumatoid disease is not new, and I didn't create it. It has actually been used many times in medical studies. So, I'm neither first to use the term nor the first to advocate for it. I sometimes say, I didn't invent the ball; I just picked it up and ran with it.

The problem is that many people are unaware of aspects of the disease beyond inflamed joints (arthritis). I became conscious of them for three reasons:

- I live with the disease
- People in the RA Warrior community have shared their experiences
- I've read the research

Why the Book *Rheumatoid Arthritis Unmasked: 10 Dangers of Rheumatoid Disease*?

When I first started writing it, I thought RA Unmasked would be a brief ebook with a massive amount of footnotes – about a hundred. I wanted to expose the true nature of the disease, and show that it's much more than a type of arthritis.

However, as I continued to investigate rheumatoid disease (RD), I read increasing evidence that I knew patients and doctors needed.

Ultimately, I'd read hundreds of studies and research articles and written a 240-page book with over 500 footnotes.

Are There Really "10 Dangers of RD" as the Title Suggests?

Experts have shown the disease can affect almost any part of the body. The disease doesn't start in the joints, and it doesn't end there.

In the book, I cover the dangers one by one, showing how the disease affects the eyes, lungs, or skin, for example. I investigate the latest research about how frequently various extra-articular aspects of the disease occur. Most are much more common than people think.

Closing the RD Mortality Gap

For years, I’ve advocated earlier diagnosis of RA/RD, improved preventive care, and treating the whole disease.

The evidence in RA Unmasked makes those goals more achievable. The result will be reducing what Mayo Clinic calls the “mortality gap” for people with RD who have not experienced the same mortally reduction as the wider population in recent decades.

For individual people with rheumatoid disease, a greater awareness of extra-articular disease could mean better outcomes as their concerns like fatigue or shortness of breath will not be overlooked.

Eventually, awareness of the true nature of the disease could improve the research-funding disparities described by the American College of Rheumatology. And, turning attention in research to the whole disease, instead of just joints, could bring a cure nearer sooner.

Living With RD Is Hard

Except for the mildest forms of the disease, people with RD face progressing disability and frequent health problems. Work disability levels are high, in part because accommodations are inadequate.

Many people assume that “rheumatoid arthritis” is the same as the arthritis in their knees. Greater awareness that RD is not the same thing as arthritis (osteoarthritis) could improve accommodations. Some people with RD might be able to work longer.

Inappropriate expectations and insufficient accommodations also create problems in the personal lives of people with RD. Patients often talk about friends or family who cannot understand their complaints of severe pain, suddenly being unable to do things or frequent medical problems associated with having RD.

The divorce rates are much higher. All of these contribute to loneliness and depression that can strike anyone with a chronic disease or recurrent severe pain.

Consequences of Misunderstanding

People with RD often have so many health problems that doctors or others may label them as hypochondriacs. Confusion about the nature of the disease has contributed to such stereotypes in medical settings.

Of course, this can contribute to inadequate medical care and the mortality problem.

Over the years, I’ve decried the research dollars spent trying to show that people with RD amplify pain or other symptoms. Instead, I want every possible dollar spent on finding ways to stop the disease and its destruction.

How Can Changing the Name Be Accomplished?

RA Unmasked discusses what can be learned other successful disease name changes. The book also outlines simple steps people can take to make progress in the adoption of the term “rheumatoid disease.”

I plan to do all I can to help the community take these steps. But the easiest step anyone can take right now to help patients is to call it what it is: a disease.

Working Together for Lasting Change

People diagnosed with RD need to get the information in this book as early as possible. But they are not the only ones who need it. To truly help patients, doctors need to be more educated about the extra-articular features of RD.

It was difficult to write a book for patients that would also be compelling to doctors and researchers. But people with RD deserve to have the facts in their hands. And medical professionals need to know the reality of the whole disease.

I plan to do everything I possibly can to make sure the next generation does not suffer in the same way from rheumatoid disease.