

7 MISTAKES THE MEDIA MAKES WITH RA

1. Not considering Rheumatoid Disease as a serious illness, *viewing it as a type of arthritis.*

Rheumatoid Disease is a serious systemic immune disease that is similar to Type 1 diabetes in that the disease can damage many different bodily systems.¹⁻³ PRD are twice as likely to experience unrecognized heart attacks and sudden cardiac deaths, and have a severely increased risk of cardiovascular disease that is unrelated to traditional heart disease risk factors.⁴ The disease also leads to risk of infections other major problems with lungs, circulatory or nervous systems, eyes, skin, and more.⁵ Poorly functioning PRD have a survival rate comparable to stage IV Hodgkin's disease and three-vessel coronary artery disease.⁶

2. Reproducing outdated information from routine sources because they are frequently quoted, whether or not they are accurate.

Repeating erroneous information about RA contributes to general confusion about Rheumatoid Disease. The result is often the suggestion that the disease is experienced as a few minor aches and pains, with serious or systemic symptoms being non-existent or rare; treatment is regarded as a panacea.

Accurate reporting about RA is challenging in part because web pages with obsolete or inaccurate material related to RA may remain in place since they are already popular in search engines and profitable to the owners, while recent articles in medical journals are less likely to perform well in searches. For a good start to avoid writing an incomplete or misleading story on RA, see [10 Common Rheumatoid Arthritis Myths](#).

3. Assuming currently available treatments work well for most patients.

A minority of people with Rheumatoid Disease (PRD) have an exceptional response to treatment. The well-known TICORA study reported: "Present treatment strategies for rheumatoid arthritis include use of disease-modifying antirheumatic drugs, but a minority of patients achieve a good response."⁷ Data from clinical trials show response rates to RA treatments vary greatly between PRD, and most have limited response.⁸

4. Suggesting behavior changes such as diet and exercise will improve or prevent RA.

There is no evidence that a diagnosis of Rheumatoid Arthritis can be prevented by behavior modifications. Smoking is the only behavior that may be associated with an increased risk; however, many people develop RD without ever smoking. Most people living with Rheumatoid Disease (PRD) do not affirm that symptoms or damage are dependent upon diet. Although a minority of PRD do feel improvement with dietary changes, this should illicit increased research and caution should be taken against assuming PRD are culpable for being sick and

hence blaming the victim. Most PRD were otherwise healthy and active when struck by the disease.

5. Leaving out the biggest part of the story: what the disease is really like.

Failing to consult men and women who live with Rheumatoid Disease before publishing a story leads to neglecting crucial aspects of an RA story.

6. Using inappropriate images

Most frequently, images include photographs of elderly people or of aged hands. Other unsuitable images have included stock photos beautiful models⁹ or scenarios that are out of place and not applicable to most people living with the disease. I have never seen a real photo of RD used in an RD story except in a rare feature story of an actual patient.

7. Minimizing the disease, its treatments, or its sufferers.

Dismissiveness toward Rheumatoid Disease or PRD is obvious when a new drug makes the news as the Food and Drug Administration or the European Medicines Agency approves or rejects a new treatment.¹⁰⁻¹¹ Frequently, the disease and its treatments are minimized, and PRD are presumed to be weak or malingering. Repeatedly RD has been called “a chronic inflammatory disorder that usually affects small joints in the hands and feet” while disease treatments have been referred to as “pain relievers” [see also [HALL OF SHAME: awful articles on Rheumatoid Disease](#)].

Alternatively, reporters may identify a rare patient in remission or who can run a marathon and present her story as example for average people living with Rheumatoid Disease, making disparaging insinuations about those with more common experiences such as “this patient is extraordinary because she does not let the disease limit her” or “does not let the disease define what she can do.” Yet, thousands of PRD I’ve communicated with fight the disease with tenacity to accomplish as much as possible.¹²⁻¹³

Personal note: I’ve been approached numerous times by reporters asking me to help them identify such unique patients. When they are responsive, I encourage reporters by explaining why that might not be the most accurate angle to covering the disease. However, reporters, patients, and patient advocates in at least four countries have told me that editors demand such an approach, which they regard as more “upbeat.”

FOOTNOTES

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² Young, K. Preclinical rheumatoid disease: there are no joints in the lungs. Rheumatoid Arthritis Warrior. 2012 Mar 18 [cited 2013 May 28]. Available from: <http://rawarrior.com/preclinical-rheumatoid-disease-there-are-no-joints-in-the-lungs/>

- ³ Young, K. Where the Rubber Meets the Road or What If Only the Cancer in Dave's Kidneys Was Treated? Rheumatoid Arthritis Warrior. 2013 Mar 11 [cited 2013 May 28]. Available from: <http://rawarrior.com/where-the-rubber-meets-the-road-or-what-if-only-the-cancer-in-daves-kidneys-was-treated/>
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- ⁵ McInnes IB, Schett G. The pathogenesis of rheumatoid arthritis. New Engl J Med [Internet]. 2011 Dec 8 [cited 2013 Jan 24]; 365:2205-2219. Available from: <http://www.nejm.org/doi/pdf/10.1056/NEJMra1004965> doi: 10.1056/NEJMra1004965
- ⁶ Pincus T. Are patient questionnaire scores as "scientific" as laboratory tests for rheumatology clinical care? Bulletin of the NYU Hospital for Joint Diseases [Internet]. 2010[cited 2012 May 31];68(2):130-9. Available from: <http://mdhaq.org/Content/Forms/Literature/21-TP-ScientificBasis-HJDBull-2010.pdf>
- ⁷ Grigor C, Capell H, Stirling A, McMahon AD, Lock P, Vallance R, Kincaid W, Porter D. Effect of a treatment strategy of tight control for rheumatoid arthritis (the TICORA study): a single-blind randomised controlled trial. Lancet. 2004 Jul 17-23 [cited 2013 25];364(9430):263-9. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/15262104>
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- ⁹ Young K. Kim Kardashian, magazines, & a trendy practice that bugs me. Rheumatoid Arthritis Warrior. 2012 Aug 8 [cited Jun 6]. Available from: <http://rawarrior.com/kim-kardashian-magazines-a-trendy-practice-that-bugs-me/>
- ¹⁰ Young K. Aftermath of the FDA vote on Pfizer's RA JAK inhibitor, tofacitinib. Rheumatoid Arthritis Warrior. 2012 May 15 [cited 2013 Jun 6]. Available from: <http://rawarrior.com/aftermath-of-the-fda-vote-on-pfizers-ra-jak-inhibitor-tofacitinib/>
- ¹¹ Young K. Mind-boggling! – Aftermath of tofacitinib FDA hearing part 2. Rheumatoid Arthritis Warrior. 2012 May 25 [cited 2013 Jun 6]. Available from: <http://rawarrior.com/mind-boggling-aftermath-of-tofacitinib-fda-hearing-part-2/>
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