Why I became a rheumatoid arthritis warrior

The patient activist Kelly Young, says that doctors’ understanding does not align with patients’ experiences

When I was diagnosed as having rheumatoid arthritis in 2006, I knew nothing of its symptoms or treatments. I had no concept of typical disease presentation or what the medical profession thought about it. I had not heard of DMARDS (disease modifying antirheumatic drugs), cytokine, or DIP (distal interphalangeal) joints.

Weekly injections of adalimumab and 25 mg of methotrexate effectively reduced fatigue and symptoms of vasculitis, but daily fevers and constant joint inflammation continued, leaving me unable to accomplish most of my usual tasks. After two and a half years, my sympathetic rheumatologist confessed to not knowing what else to prescribe. Then I read everything I could.

Passing time brought more functional loss. While I mourned my old life I was determined not to surrender to a perpetual downward slide. I would fight this disease in whatever way I could find. I devoted academic articles, news stories, and patients’ reports, recording what I learnt in a blog called RA Warrior (http://rawarrior.com).

Usual explanations of rheumatoid arthritis had led me to think that I had atypical presentation of the disease and response to treatment. So I concentrated on the experiences of others. Months later I became convinced that, although I might be in a minority, I was not unique, and eventually I dared to write about my experiences. For example, hands were neither the first involved joints, nor the worst involved joints; disease activity was stable, without flaring; swelling did not correlate with other symptoms; neck joints were involved; and symptoms were not alleviated by treatment.

People responded in large numbers, and I was often surprised to discover how many deviated from what was said to be the norm. Comments on websites and social media are not scientific sampling, but the number was large enough that I began to question conventional assumptions. By mid-2012, 21 500 had become fans of our Facebook page, exceeding 1% of all patients with rheumatoid disease in the United States. In 2013, it will reach 2%.

In 2011 and 2012 we conducted surveys that confirmed what patients had been saying in the past few years. We found that stiffness was limited to mornings in only a quarter of patients; most people undergo protracted diagnosis; swelling is not usually correlated with damage; few people experience sustained remission; and the vast majority experience fevers, correlated with fatigue.

Regarding disease activity and responses to treatment, our population mirrored large samples such as those described by Wolfe, Strand, and others. I often noted academic sources that confirmed our findings. Examples of inconsistencies between patients’ experiences and clinicians’ perceptions included clinicians thinking that DIP joints are not affected; that swelling distinguishes disease activity; that spinal joints are often not involved; that small joints are affected first, and that most patients have an exceptional response to treatment.

Over the years my audience grew and I was grateful to participate in many events representing people with rheumatoid disease. People often asked when the RA Foundation would improve the lot of patients with the disease. But there was no such organisation in the United States. Early in 2011 we remedied that by creating the non-profit making Rheumatoid Patient Foundation.

Reviewing history and current investigations with great interest, the foundation has begun to consider patients’ concerns. We have identified the fundamentals of care and initiated a return to the term “rheumatoid disease” because it is impractical to label a systemic disease by one of its symptoms: arthritis.

In 2013 we established rheumatoid awareness day, on 2 February. Thankful for partnership with supportive professionals, we work on education, research, and advocacy. Being patients ourselves makes the work challenging but also adds resolve and clarity to our mission.

I often receive inquiries from patients whose doctors assert that they are mistaken about symptoms. When doctors question involvement of the jaw joint, I recall a poster session on researching a topical steroid for jaw inflammation. When doctors dismiss spinal joints, I recall many friends who needed spinal surgery or a woman who died because she did not have surgery. Many such examples compel me to ensure that doctors understand the reports of their patients with rheumatoid disease.

Comprehending the patient experience is essential to improving care, and this experience often differs from what textbooks lead clinicians to believe. Several clinicians with rheumatoid disease have submitted comments to my blog, such as, “I am a physician with RA. I have been so let down by my profession . . . Feeling like I have to prove how awful I feel fills me with self doubt. You can’t measure pain. That’s not the worst part; daily fevers and 25 pound weight loss have left me barely functional. But I’m seronegative and apparently doing just great! I used to run 10k. I walked around for 2 years with two ruptured discs in my spine before finally having surgery. I am no stranger to pain. I have kept trucking through it all. The only thing I want is my life back. Not pity. Not attention. Not pain meds. You are leading a trail of awareness letting patients know that it’s ok to stand up for their needs and rights and hopefully our rheumatologists will be re-educated as well.”

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References are in the version on bmj.com.
Introduce standard cigarette packets now

Has the UK government kowtowed to tobacco industry lobbying? The argument for plain tobacco packaging is clear—it would save lives—and the arguments used against it are false, argues Robert West

Public health experts were disappointed and surprised not to see legislation to introduce standard packaging for cigarettes included in the Queen’s speech. The idea behind standard packaging is simply to prevent tobacco companies from using the cigarette packets to market products that are toxic and addictive. Cigarettes would be sold in standard packs that would carry health warnings and the name of the brand.1

Tobacco companies would not be permitted to construct packs to look like lipstick holders or perfume boxes, or to use stylish designs and colours to tap into or build an identity or create positive feelings about their contents. Australia has already put this legislation into place.

Cigarettes would never be allowed to be sold if they were introduced today (we have regulations preventing sale of ingestible products containing high levels of carcinogens), and the principle of preventing tobacco companies from marketing cigarettes is already established. Most of the adult population of England supports the legislation.2 There is clear evidence that the move would reduce the attractiveness of cigarettes to young people.3 Much of the groundwork for the legislation, including an extensive public consultation, has already been done. The public health minister, Anna Soubry, only recently stated that she thinks the measure would be beneficial for public health.4 Legal opinion has made it clear that the tobacco industry is likely to fail in any legal action claiming restriction of trade or usurping of trade marks.5 The leader of the opposition (as well as many Conservative and Liberal Democrat MPs) has publicly stated that his party would support the legislation and ensure a speedy path through parliament.

Given all this, it is easy to understand the disappointment and surprise at the government’s failure to act. We can only speculate about the reasons and hope that it is not because the government has been influenced by those with vested interests in the tobacco industry or taken in by the many false arguments used by those who wish to obfuscate the issue.

Here are some:

**False argument 1**—We all have the right to make choices, even unhealthy choices, and governments should not interfere in that right.

*Response*—This legislation restricts the activities of tobacco companies, which damage the health of other people.

**False argument 2**—This is the thin end of the wedge. The next target will be burgers and fish and chips.

*Response*—All policies are judged on their own merits. Cigarettes are unique as the only consumable product that has no safe level of use.

**False argument 3**—It is nonsense to imagine that young people are taken in by attractive packaging when deciding whether to smoke. We should not patronise them by assuming they are so stupid.

*Response*—No one suggests that marketing is the sole driver of smoking uptake in the young. But it is falsely naive to pretend to think that the attractive imagery and packaging, on which cigarette companies spend many millions of pounds, has no influence on uptake of smoking.

**False argument 4**—Standard packaging would make it easier to counterfeit cigarettes and increase illicit trade.

*Response*—Cigarette packet designs are already easy to counterfeit, and standard packaging would not make this any easier. What makes cigarette packets hard to counterfeit are the covert tags incorporated, which would remain.

**False argument 5**—Cigarette manufacturers use packaging to set premium brands apart, and without this smokers would gravitate to cheaper brands, reducing the cost of smoking and undermining this important source of deterrence.

*Response*—This could easily be countered by raising duty to compensate, so money would in effect flow from tobacco companies to the public purse.

**False argument 6**—Standard packaging is based on “junk science.” There is no hard evidence that this policy would reduce smoking rates.

*Response*—“Junk science” is the label used by tobacco industry supporters to try to discredit many studies with findings that conflict with their interests. The tobacco industry claimed for decades that there was no “hard evidence” that smoking caused lung cancer; no “hard evidence” that secondhand smoke exposure posed a health risk; and no “hard evidence” that cigarettes were addictive. The evidence for the introduction of standard packaging is clear: package designs make cigarettes more attractive and appealing to young people than plain packaging.6 For the tobacco industry to argue that such appeal has no influence on behaviour while spending millions on it lacks credibility.

Even were the standard packaging legislation to prevent only one young person in 20 from taking up smoking,7 and have no effect at all on people who are already smoking, I estimate that it would still save some 2000 lives each year in the United Kingdom—more than all the people killed by all illicit drugs put together (see box).8

Will continued failure to act on this make the decision makers in the present government culpable for those deaths? In my opinion, yes. Robert West is Cancer Research UK director of tobacco studies, Health Behaviour Research Centre, University College, London WC1E 6BT robert.west@ucl.ac.uk

Competing interests: My salary and much of my research is funded by Cancer Research UK. I am a trustee of the stop-smoking charity, QUIT, and co-director of the National Centre for Smoking Cessation and Training. I have undertaken research and consultancy for companies that manufacture smoking cessation medications.

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FROM THE FRONTLINE Des Spence

War of the words

What we perceive as intelligence is 10% intellect and 90% presentation. A serious expression, the right accent, a knowledge of literature and classical music, and a propensity for attending the theatre are the trappings of the intelligent elite. At medical school you could know who the intelligent were: they were in the library with their intellectual status symbols, piles of thick textbooks and research papers, slowly digesting facts to be vomited up in exams.

For facts are the currency of the bright—safe, certain, yet often dangerously wrong. I was a crammer. My only books were lecture notes, illustrated guides, and short books of lists and bullet points—medicine for dummies. I was, and still am, a facts junkie.

Now consider the presentation of our intellect through the written word: what we write in exams. The thesaurus is the weapon of choice of the obtrusive, and jargon in official writing is the bloody crusade against acronyms, theses, and jargon in official writing. And there are messages that were the trappings of the intelligent elite.

Along with succinctness, readers value clarity in writing. The Plain English Campaign is fighting a long and bloody crusade against acronyms, obtuseness, and jargon in official writing. And there are messages that medicine could give up if they were sufficiently motivated. I wrote to him again, explaining what I meant by “physically addictive,” but he did not expand on his initial response.

Soon afterwards, Martin Broughton, chief executive of British American Tobacco (BAT), told a House of Commons committee: “Let us accept, for the sake of taking the argument forward, the common understanding that smoking is addictive.” I wrote to ask Broughton whether this meant that he accepted that nicotine was physically addictive.

A BAT employee eventually replied to say that the company agreed that DSM-IV diagnostic criteria for nicotine withdrawal does occur in some smokers when they quit and so, the employee wrote, nicotine could be defined as an addictive drug. The employee went on to say that although nicotine replacement therapy may help some smokers, the key to quitting is self-belief and motivation.

Forget cannabis or cocaine. Nicotine is the gateway drug for most drug addicts. Millions start smoking around puberty, soon become nicotine addicts, and die prematurely in consequence. Big tobacco actively encourages large-scale childhood recruitment to a lethal enslavement while claiming that smoking is simply a personal choice.

This is serious wickedness. Big tobacco is clearly fearful of plain packaging.

The government has apparently capitulated to big tobacco’s recent advertising campaign about “hard evidence” for enforcing plain cigarette packaging. By downplaying addiction both big tobacco and the government effectively tell vulnerable adolescents that becoming addicted to a drug doesn’t really matter. Only about a fifth of regular smokers smoke 10 a day or fewer. In contrast, hardly 10% of regular drinkers ever become physically addicted to alcohol.

A decade ago, after US tobacco barons reluctantly accepted that nicotine was physically addictive, I wrote to John Carlisle, the Tobacco Manufacturers’ Association’s director of public affairs, to ask whether the British tobacco industry agreed. His reply was that the word “addictive” had been applied to many things, including shopping, the internet, chocolate, and coffee—as well as hard drugs. Carlisle wrote that smokers could give up if they were sufficiently motivated. I wrote to him again, explaining what I meant by “physically addictive,” but he did not expand on his initial response.

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This is serious wickedness. Plain packaging is a promising and transparent approach to reducing smoking initiation. That big tobacco is so worried strongly suggests that they fear it really would reduce their profits of slavery.