A rationale is presented for the elimination of the word dementia as a diagnostic term. It is viewed as a generalization that is pejorative and harmful based on historical and current patient, caregiver, and physician perspectives. Suggestions for more meaningful and nonstigmatizing terminology are offered. Primary among these is to change the meaning of the abbreviation FTD from frontotemporal dementia to frontotemporal disease. This article combines the personal aspects of the caregiver experience (Dr Trachtenberg) with the professional input of the scientist and physician intimately involved in the field (Dr Trojanowski). This collaboration led to the unified conclusions that are expressed.

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The word dementia has become a convenient tool by which many physicians describe a broad group of symptoms common to many brain disorders. Unfortunately, the clinical diagnosis often carries with it unintended cruel connotations in the lay language and a concomitant destructive potential.

The Merriam-Webster Online Dictionary of 2004 defines dementia first as “mental deterioration of organic or functional origin.” Although a generalization, it seems innocuous and close to what is intended by physicians. However, on further reading almost every dictionary refers to its derivation from Latin, meaning madness or out of one’s mind. The Merriam-Webster Online Dictionary supplies the following 3 synonyms from Roget’s Thesaurus: insanity, lunacy, and madness. Non–English languages have some even more devastating translations and alternative meanings, ranging from idiocy, imbecility, mental deficiency, and moronism in German, to mental derangement in French, to insanity and lunacy in Italian. These definitions, not the medical diagnosis, are most commonly known to the public. Accordingly, persons diagnosed as having dementia could be seen by the lay community as being out of their mind or crazy.

When sufficiently provoked in our childhood, calling someone demented was one of our worst epithets short of vulgarity. Things have not changed much, as witnessed by an advertisement on the Comedy Channel that described a future program as “extreme, idiotic, and demented.” A similar example is the horror film by Francis Ford Coppola entitled Dementia 13. Even the venerable Garrison Keillor in a November 6, 2004, radio skit called dementia “a proven method of weight loss” and implied its victims are “crazy.”

With this lay use woven into everyday language, imagine being told by a physician that you have dementia. This non–specific generality can easily rob patients of their humanity in the eyes of others and, most important, in their own eyes. The term can stigmatize and isolate, making others reluctant if not outright fearful of dealing with the person. At its unkindest, it is a word without hope, which is a crucial tool when faced with a devastating illness.

A personal awareness of the problem started in 1998, when the vivacious wife of the author was told she had dementia. She thought she was being told she would be put away in an institution. The word dementia has become a convenient tool by which many physicians describe a broad group of symptoms common to many brain disorders. Unfortunately, the clinical diagnosis often carries with it unintended cruel connotations in the lay language and a concomitant destructive potential.

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of one of us (D.I.T.), then married 40 years, developed a visual problem attributed to brain dysfunction. At the time, she was an adjunct university English professor, a freelance writer, the mother of 2 daughters, and the grandmother of a new baby girl. She had a keen intellect and a marvelous sense of humor. Her life centered about her family and the world of words. She was attempting to get her first book published. Things were good and gave every indication of only getting better, so we thought.

The cause of her ailment was initially uncertain. Her first symptom was simultagnosia, or visual agnosia (from Greek, meaning “not to know”). Her eyes were fine, but her brain (specifically the visual cortex) frequently and randomly did not properly resynthesize the visual messages it received. A simple example is that there were times when she was not sure which end of the cat was the head and which was the tail.

Positron emission tomography of her brain showed areas of decreased metabolism in both occipital lobes and, to a lesser extent, in her left temporal lobe, corresponding to her clinical deficits. We were told that it was the result of a prior severe closed head injury or, more likely, the start of a focal degenerative disease. The imaging report specifically stated, “The findings are not characteristic of Alzheimer disease.” In our early simplistic thinking, this statement took dementia off the table, because we mistakenly thought the term synonymous only with Alzheimer disease. We were happily ignorant of the rest of the family of cognitive and memory disorders that fell broadly under its rubric.

However, several months later a rehabilitation neurologist in a conversation in the patient’s absence used the word dementia in reference to her diagnosis. An immediate epiphany occurred, and suddenly the potential danger and threatening sentence of the word became manifest. It was frightening that somebody might say it to her while she was still able to fully grasp and sense its toxic effect and that it would hasten and seal her fate in the manner of a self-fulfilling prophecy.

We are not arguing for denying information to patients. Her physicians certainly informed her about her eventual diagnosis (corticobasal disease), albeit without using the word dementia. However disastrous the message, using words specific to each neurologic disease should be an act devoid of cruel connotations. It is kinder and far better informs the patient. Just as our society long ago stopped using the words mongoloid, imbecile of the mongoloid type, Mongolian idiot, moron, idiot savant, cripple, and midget were also in common medical usage, and their families (written communication, January 2004). Their use is a concern of morality and of common humanity. It is not too long ago that other terms such as mongoloid, imbecile of the mongoloid type, Mongolian idiot, moron, idiot savant, cripple, and midget were also in common medical and lay use. These words disappeared not through scientific revelation (no studies exist to that effect, to our knowledge) but rather primarily because of consciousness raising, educating, and lobbying by various advocacy groups. They made it abundantly evident that these types of pejorative and degrading terms were no longer acceptable. So it is now with dementia. Persons with cog- nitive disorders often cannot be their own advocates, so it falls on those of us who are not similarly afflicted to act on their behalf to assure that they are afforded the respect that they deserve. We have used personal history to help illuminate the type of revelatory experiences that the medical world needs to deal with to be more sensitized to the necessity for change.

Regardless of the words used to describe her ailment, things have changed greatly for the patient in the past 5 years. Her visual perception is much worse. She can no longer read, write, cook, or perform the simplest of household chores. Although she seems to know what she wants to say, she often cannot find the words and is forced to abort her conversation. She still maintains her fierce sense of independence but tragically has lost the ability to act on it. Therefore, she is imprisoned within herself and is forced to be totally reliant on others, much to her painful dismay, bouts of great anger, and periods of weeping depression.

Despite the enormity of these losses, she remains a loving and palpable woman. Her persona has not changed. She is still frequently aware and has not lost her sense of humor. She is warm and compassionate. As always, there is enormous love between husband and wife. Her smile and embrace still support her spouse. She is decidedly neither out of her mind nor a lunatic.

To help others comprehend and deal with such a disorder, we have spoken of visual, cognitive, and memory problems, which are accurate representations of the patient’s disease and how her physicians have talked about the issue with her. It has been paramount to be honest but also not to use words to cause her to be perceived as more compromised than she was. This approach ultimately allowed us to comfortably explain and then read this essay to her. She liked it and considered it important for others to read.

Unfortunately, there as yet exists no treatment for her disease. More disaster is certain to follow for her and for the multitude of similar patients and their families. Still, it remains vital to view the affected persons as the total human beings that they are and not focus on the possible outcome that may yet face them. However, it is imperative that this is not done under the shadow of a demonizing label. Vital goals are to help preserve dignity and to maintain a sense of self-worth as long as awareness remains. Should awareness depart, it is still uncivilized to dehumanize any human being.

In this vein, Andrew Kertesz, MD, FRCPC, a professor of neurology and director of cognitive neurology at the University of Western Ontario, London, Canada, has said that for some time he has requested that his staff avoid the use of the word dementia when dealing with patients and their families (written communication, January 2004). He finds it derogatory. Instead, he simply refers to each neurodegenerative entity as a specific disease (eg, corticobasal disease or frontotemporal disease), an effective and logical resolution to the problem, which we suggest other professionals could readily adopt and follow. If a generalized or broad umbrella category is needed, then cognitive impairment and neurocognitive impairment are among the several possibilities that are clear, truthful, and nonpejorative. New research continues to reveal more
about the unique features of each of the various disorders. It should lead to specific treatments based on these individualized characteristics. Dementia is a dead-end diagnosis, a word with only negatives for the patient’s future. But hope now exists, and patients dare not be deprived of it.

What we are advocating is another important addition to the changing attitudes toward persons with disabilities. It has great support among caregivers and increasing support among physicians. It is not scientific theory or law but rather science and medicine catching up with advancing human sensitivity and values.

The objections of some neuroscientists to the transitional inconveniences of such change do not justify retention of the term dementia. In the end as in the beginning, the premise is simple. The word should be removed from the lexicography of neurologic and psychiatric disease. Hence, we recommend a convenient and compassionate substitution of the word disease in the meaning of the overarching abbreviation FTD from frontotemporal dementia to frontotemporal disease. In this way, we can speak about frontotemporal disease to our patients and their families without stigmatizing this disorder or those facing the daunting challenge of living with it.

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