

SIDE EFFECTS: The complexity of “knowing”

We see, especially from new folks, a constant stream of questions around the issue of side effects of meds with the most extreme posture being rejection to using any med because of the belief that everything bad will happen. Others, being new to our “old friend” are seeking guidance on the various forms of treatment.

Two major issues arise in asking us for our views on this question:

1. For all of our personal experiences which we can offer, personal experience is only one kind of limited knowing and, regardless of conviction, our knowing may not be valid (which means, “conviction” is not proof.)

2. Related to this idea is that we don’t know who among us has the scientific training & experience to evaluate what we read and/or believe.

3. Our sharing in chat groups, in the daily discourse of life, radio/t.v. talk programs, etc. are unchecked territories for the spread of confusion, mistakes, and outright distortions. Most of this is unintentional but, whatever the medium and motivation, assuming what we hear is “true” is not wise. (I jokingly tell my neighbors in the 55+ community where I live, that I never accept a rumor until it has been confirmed at least six times!)

People involved in group dynamics, training, and counseling commonly use an exercise in which the members watch this change, distortion, and confusion as it actually occurs. Many of us have sat in a circle of 15-20. The leader tells participant #1 a story with 4-6 simple but clear facts and #1 is to tell #2 what he has been told. Each person tells the story in turn to the next person while the group watches, working hard to not cringe or laugh as each telling becomes more altered, changed, or distorted. I’ve seen the story so altered that the meaning has been reversed or the basic facts beyond recognition!

The point is: this is how our minds work. We really are quite limited in our capacity to hold onto material with accuracy. Police know that six witnesses see six different accidents; psychologists know that our memories about our personal lives can be counted on to alter our experiences. We change our memories of events, the sequences of events or the people who were in the

events in the memory. This is not intentional lying. But it is a quality of memory which we need to be aware of, especially when we make “truth claims” in the absence of evidence.

A couple of comments about how this affects our messages:

1. When sumatriptan started to be used by CH folks, the question about rebound attacks was not clear. Subsequently, medical literature, which I’ve seen, either says, “perhaps”, or avoids the question (suggesting nothing to report). A few sources say no rebound.

In recent months, however, messages here have regularly made categorical statements, “Imitrex creates rebound attacks.” This shift from “no” to “yes” has been subtle and has taken several years to develop.

The consequence of this shift has been messages from new folks which caught my eye which say, in substance, “I haven’t used Imitrex and I won’t because it causes rebound attacks.” Which is to say, these folks who have little or no experience have accepted a “fact” which has not been established in scientific literature.

2. Verapamil has also been described, recently, as “extending my cycles”. However, medical literature that I’ve seen doesn’t touch this issue.

Here, I can only speculate on the sources of these shifts. There is a difference between “rebound” and “recurrence” of an attack. These are different events and easily confused, arising from different sources and leading to prolonged pain of CH. But, if we don’t understand these distinctions our personal suffering can continue and the new comer who is seeking our guidance will be given incorrect information.

A second source of confusion: CH cycles are not, as too often presented, fixed in time of year and duration. Many people have erratic cycle in terms of calendar time and duration. That implies that, for such individuals, we can’t say that Verapamil has extended the cycle. Only large pooled data can offer some decent, reliable knowledge.

So, how can we operate so that we don't confuse or mislead ourselves and people who are seeking our guidance?

1. Clearly label the source of our information/facts: "My experience is...; my doc's recommendation has been...; Dr. Goadsby said at the last convention...; this medical journal suggested..." This style fairly gives the reader some idea of how much weight can be applied to our "truth".
2. Remind ourselves that our memory, especially of very specific scientific material, is going to be elusive. Make some notes of material which is of real value to you so that we can share it accurately.
3. Keep in mind that the goal of our messages is not to win an argument but, rather, to share information which will benefit the reader. A wee bit of hard fact is more useful than a shotgun blast of generalizations!
4. Try and write to the level of English which the writer is using. We are now dealing with a worldwide membership and so using American brand names, idioms, slang, etc. when dealing with someone, e.g. in the Baltic countries, won't reach them effectively.