

Psychiatric Misdiagnosis in The Dysautonomias

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Disclaimers

- ▶ “Off-label” uses of medications
 - ▶ No financial conflicts of interest
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An Illustrative Case

- ▶ KM is a 21-year-old woman first diagnosed with panic and anxiety at age 5.
- ▶ At that time, little things would frighten and upset her.
- ▶ She had to be home-schooled, since a school environment was overstimulating.
- ▶ Gradually, she became agoraphobic, because any time she went out her heart would quickly start to race, and then she would get nauseous and break out in a cold sweat.

The Case of KM, continued

- ▶ She was treated with a great variety of anti-anxiety medications, and many kinds of counseling and psychotherapy, with only modest improvement.
- ▶ At age 17, the rest of her family was going to a baseball game, which required taking the subway. Although they had little hope of her going to the game, they thought that if she could at least get on the train with them that would be a milestone.

The Case of KM, Continued

- ▶ One of her physicians had the idea that since propranolol, an adrenaline–blocking drug, was used successfully by many people with “stage–fright,” maybe her apparent fear of going out might similarly be helped by propranolol.
- ▶ She took a small dose of propranolol, went with her family, got on the subway, went to the baseball game, and told her parents, “This is the best I’ve felt in a very long time.”

KM, today

- ▶ Now 21 and in college, has many friends, plays sports, and in short, is enjoying something pretty close to the life of a normal 21-year-old.
- ▶ She also has done a remarkable job of stabilizing her lax joints, and with improved muscle tone and aerobic capacity her autonomic symptoms have improved, and she has been able to stop most medication.
- ▶ BUT, sadly she lost much of her childhood because the true nature of her condition was not recognized.

Diagnosing the Wrong Deficit

- ▶ *The New York Times*, Sunday 4/27/13
- ▶ Dr. Vatsal G. Thakkar, a psychiatrist, described the case of a young man referred to him for treatment of ADD.
- ▶ It turned out that the man did not have ADD, but rather a sleep disorder.
- ▶ With treatment of his sleep disorder, his “ADD” symptoms resolved.
- ▶ Dr. Thakkar cited several studies showing high rates of sleep problems in kids with ADD

Diagnosing the Wrong Deficit

- ▶ Dr Thakkar concluded by pointing out that clonidine, used for decades to treat high blood pressure, was recently approved by the FDA to treat ADD, and that clonidine tends to improve sleep.
- ▶ So close.....

My Response (*NY Times*, 4/29/13)

- ▶ Thanks for shedding light on the misdiagnoses given to patients with sleep disorders. I see many chronically tired patients similarly misdiagnosed with panic or anxiety disorders. The common thread in these conditions is essentially too much adrenaline. {not really, but....}

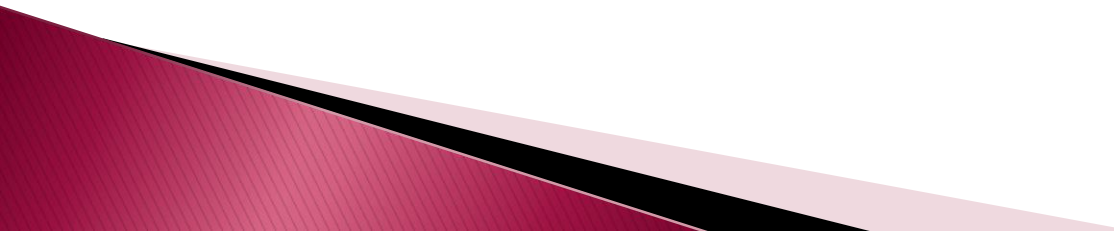
My Response, continued

- ▶ After a poor night's sleep, many people's bodies respond to fatigue by making extra adrenaline to keep them going. The extra adrenaline can then further aggravate sleep. Statements like, "Once we got my son's sleep straightened out, his A.D.D. disappeared," or "Once my daughter started sleeping better, her anxiety went away" are commonplace.

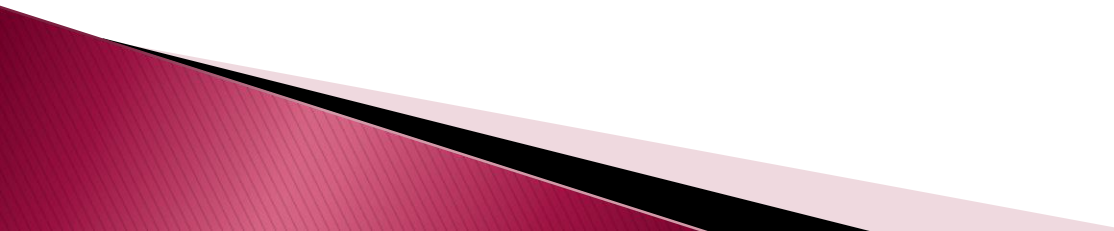
My response, continued

- ▶ “If you’re not already convinced, consider the drug clonidine,” Dr. Thakkar concluded. Why would clonidine be effective for treating high blood pressure, and A.D.H.D., and sleep problems? Because it suppresses adrenaline production.
- ▶ Thank you for encouraging your readers to see that some apparently psychiatric disorders are instead disorders of adrenaline and the autonomic nervous system.

Basics of the Autonomic Nervous System

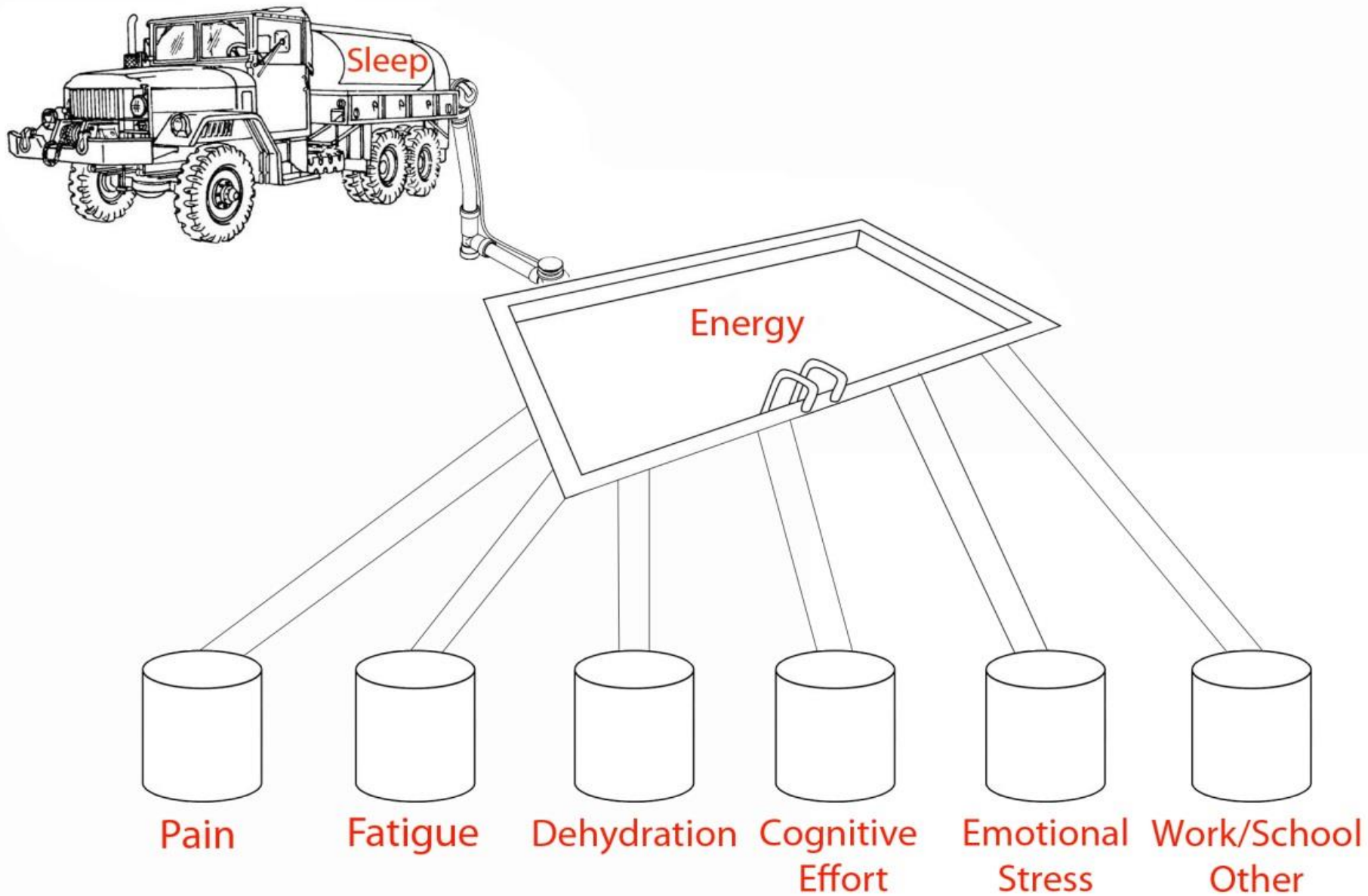
- Regulates all body processes that occur “automatically”
 - Sympathetic nervous system: “fight or flight,” the accelerator
 - Parasympathetic nervous system: “rest and digest,” the brake
- 

Autonomic Dysfunction in the Joint Hypermobility Syndromes

- ▶ Concept of an energy reserve
 - ▶ Sleep restores energy
 - ▶ Activity, pain, stresses deplete it
- 

Sustained Sympathetic Stress

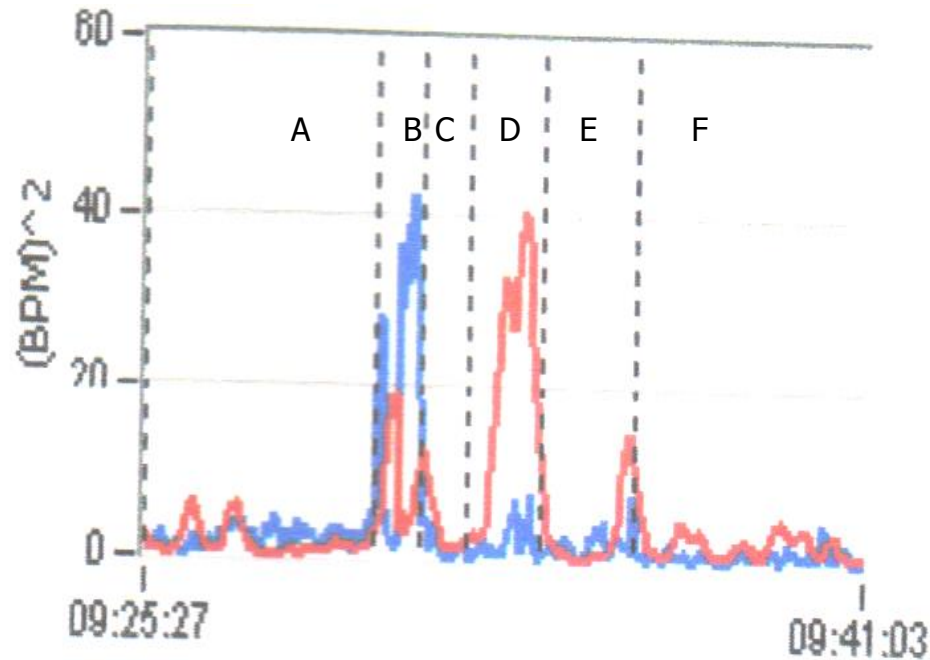
- ▶ Many ongoing stresses can cause sustained sympathetic activity:
- ▶ Pain
- ▶ Fatigue
- ▶ Dehydration
- ▶ Other, e.g. family, financial, work– or school–related, current events
- ▶ Sustained sympathetic stress eventually leads to “depletion” of reserves



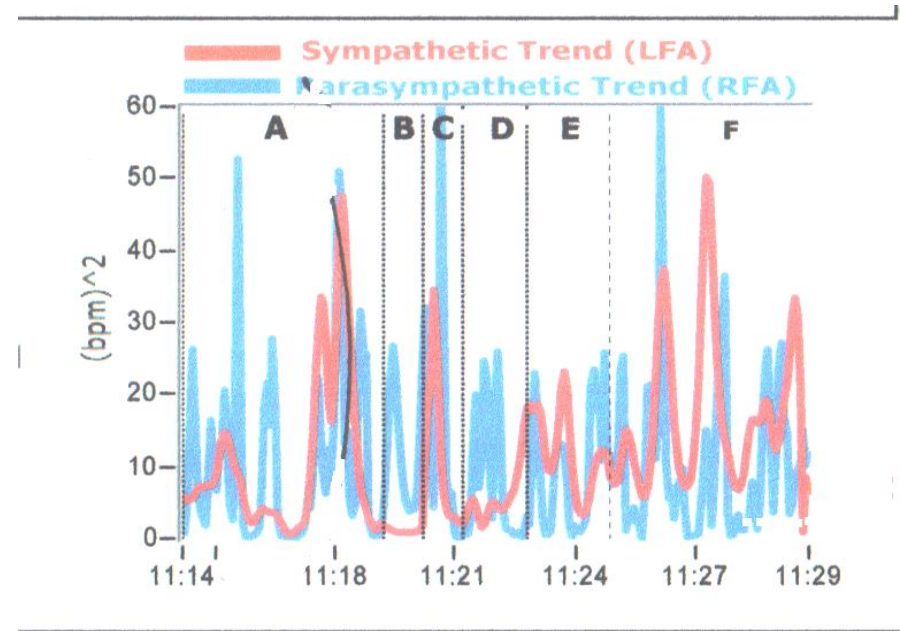
Autonomic Dysfunction in the Hypermobility Syndromes

- ▶ Central paradox: the lower the reserves, the more exaggerated the stress response, so the body “overresponds” to minor stresses
- ▶ The overresponse often triggers an overcorrection, then another...

Sympathetic and Parasympathetic Activity with Autonomic Maneuvers



Normal



EDS with Dysautonomia

A=Baseline, B=Deep Breathing, C=Rest, D=Valsalva, E=Rest, F=Stand

Why Would the Body Do This?

- ▶ An evolutionary perspective:
- ▶ If you were being chased by a wild animal, the fight or flight response would kick in
- ▶ But after a while you would tire and, exhausted, find a place to hide and rest.
- ▶ If you then saw the animal coming toward you again, you would want your last little bit of adrenaline to have a maximal effect, and you would not want to feel tired or pain

Sympathetic Surge Symptoms

- Palpitations, chest tightness
- Shortness of breath
- Muscle tension
- Jittery, restless, "fight or flight"
- Shaking, trembling, nervous
- Flushed, hot, sweaty
- Irritability
- Trouble falling and/or staying asleep
- Gut relaxes

Parasympathetic Surge Symptoms

- ▶ Nausea, abdominal pain, diarrhea
- ▶ Chills, cold sweat
- ▶ Lightheadedness (heart rate, BP fall)
- ▶ Fatigue, malaise

Sympathetic Depletion/Hyperarousal

- ▶ Trouble with concentration, easily distracted
- ▶ Trouble starting and/or finishing tasks
- ▶ Tendency to avoid tasks that require sustained concentration
- ▶ Trouble with details, make careless mistakes
- ▶ Difficulty with organizing, problem solving, decision making, multi-tasking, prioritizing
- ▶ Trouble listening when spoken to
- ▶ Losing or forgetting things
- ▶ Easily fatigued

Even More Depletion/Extreme Hyperarousal

- ▶ Sympathetic activity is sufficient to mask pain and fatigue
- ▶ Feel good, with less fatigue and pain
- ▶ Lots of energy, get a lot done
- ▶ Feel optimistic, maybe you're finally getting better
- ▶ Trouble sleeping, but despite that you have a lot of energy
- ▶ Rapid speech, you're in a hurry to "make hay while the sun shines."

Sustained Parasympathetic “Response”, “Tired but Wired”

- ▶ Nausea, loss of appetite
- ▶ Abdominal discomfort
- ▶ Lightheadedness
- ▶ Fatigue, malaise
- ▶ Instead of intermittent, these symptoms now are nearly constant
- ▶ Now you have your foot on the gas and the brake at the same time

These concepts personified:

- ▶ ML is a lovely 33 year old first diagnosed with CFS at age 17, (later with EDS). BP was 70/40, needed IV fluids. 75–80% recovered, got married, had two children, gradually tapered off almost all of her meds.
- ▶ Last year, worsening pain, fatigue, cognitive problems, and autonomic dysfunction, including persistent nausea and frequent diarrhea. Advised to resume some pain medication, get more rest, etc., but did not.

The Case of ML, continued

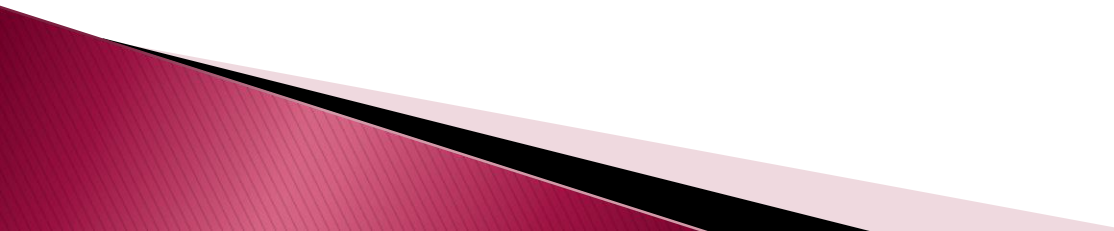
- ▶ One night, at dinner with friends, she had a wave of nausea, then diarrhea, cold sweat, and “started passing out.” Realizes now that she had been “way overdoing it” that day.
- ▶ Admitted that “pain has been pretty bad.” “One day I took a Percocet and got an immediate energy boost and felt so much happier.”

The Case of ML, continued

- ▶ The day before her appointment, she woke feeling tired, but then “felt really good all day. I went to church, did stuff with my family, and organized my whole closet in the afternoon when I usually have to rest. My pain was better and I was talking really fast. I tried to go to sleep at 10, but I was still wide awake at midnight, and then I started to get stomach pain and nausea, and feel dizzy and weak all over.”

So why do people with
dysautonomia look and feel
like they have psychiatric
conditions?

Diagnostic Criteria of Some Common Psychiatric Disorders (DSM-5)

- ▶ Anxiety
 - ▶ Panic
 - ▶ Attention Deficit Disorder
 - ▶ Bipolar Disorder
- 

Generalized Anxiety Disorder

- ▶ A. Excessive anxiety and worry occurring more days than not, for at least 6 months, about a number of events or activities (e.g. work or school performance)
- ▶ B. The person finds it difficult to control the worry
- ▶ C. The anxiety and worry are associated with three (or more) of these six symptoms (with some present more days than not for 6 months):

Generalized Anxiety Disorder (continued)

- (1) restlessness, feeling keyed up, on edge
- (2) being easily fatigued
- (3) difficulty concentrating, mind going blank
- (4) irritability
- (5) muscle tension
- (6) sleep disturbance (difficulty falling or staying asleep, or restless, unsatisfying sleep)

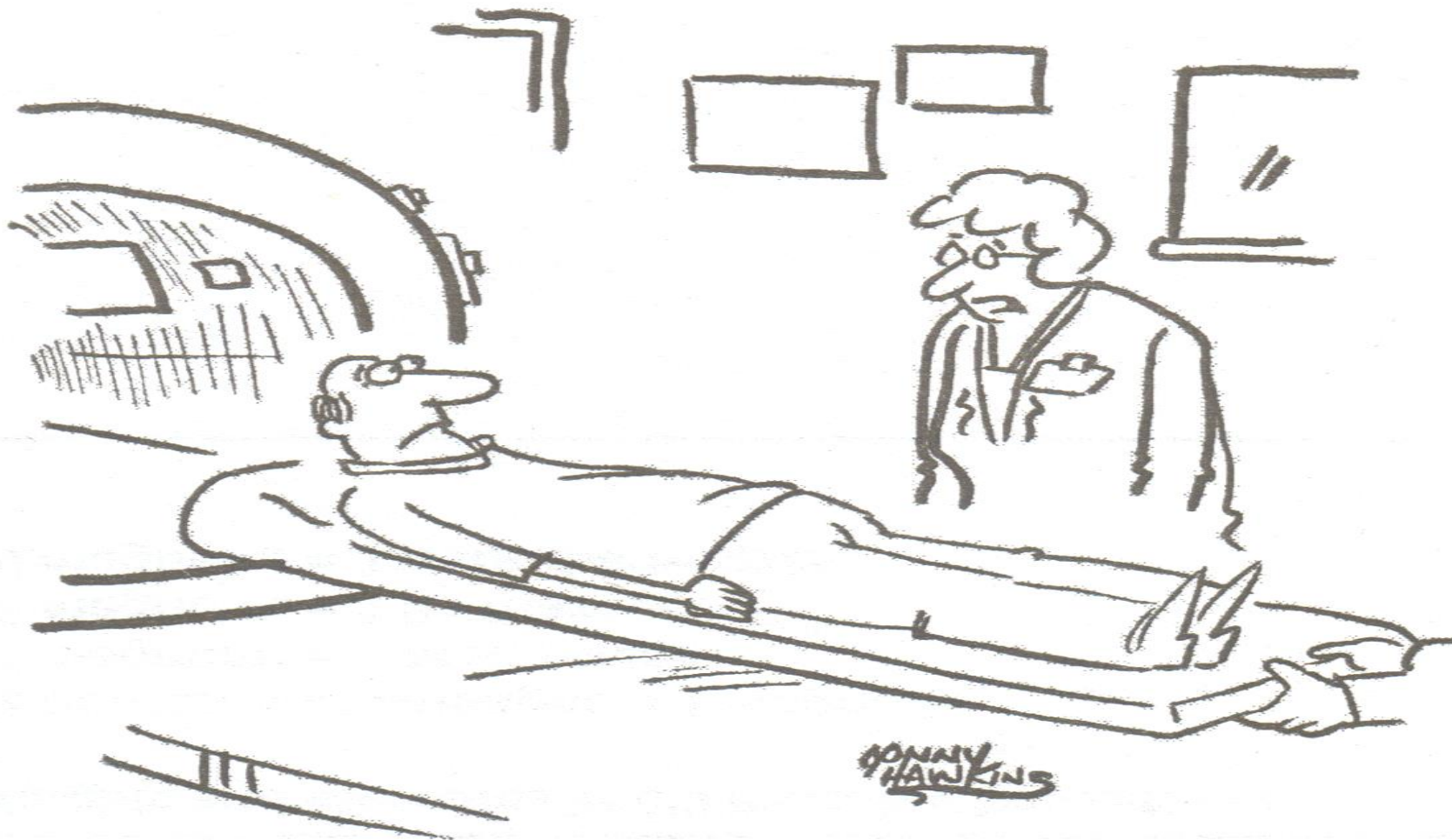
Generalized Anxiety Disorder (continued)

- ▶ D. The anxiety, worry, or physical symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- ▶ E. The disturbance is not due to a drug of abuse or medication, or general medical condition (e.g., hyperthyroidism) or mood disorder (e.g. panic, social phobia disorder)

Generalized Anxiety Disorder (continued)

- (1) restlessness, feeling keyed up, on edge
- (2) being easily fatigued
- (3) difficulty concentrating
- (4) irritability
- (5) muscle tension
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Don't these symptoms sound familiar?



"The MRI reveals that your head is riddled with conventional wisdom."

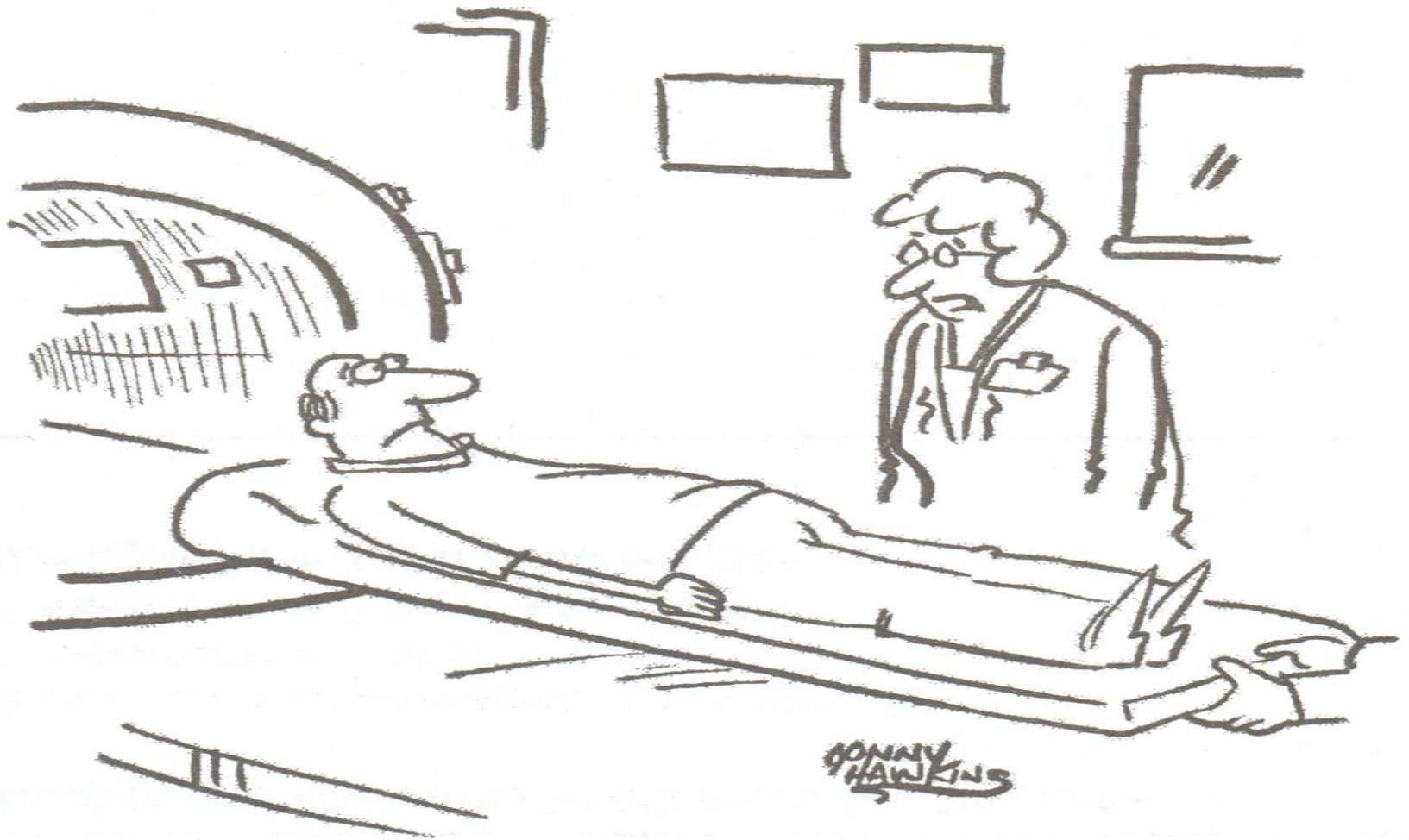
Panic Attack (DSM-5)

- ▶ An abrupt surge of intense fear or discomfort that peaks within minutes and is associated with 4 or more of the following symptoms:
- ▶ Palpitations–pounding or rapid heart rate
- ▶ sweating
- ▶ trembling or shaking
- ▶ sensation of shortness of breath, smothering
- ▶ feeling of choking
- ▶ chest pain or discomfort

Panic Attack (continued)

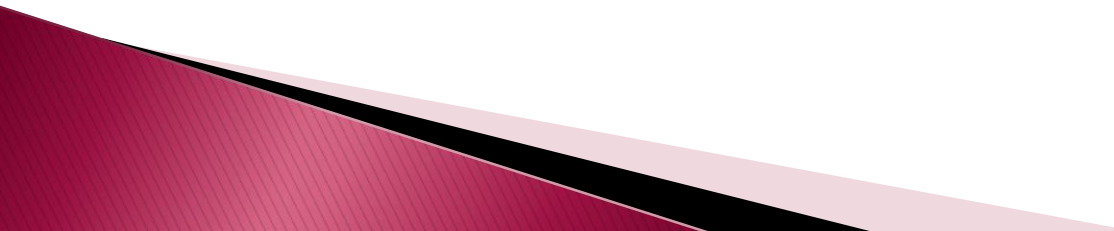
- ▶ nausea or abdominal distress
- ▶ feeling dizzy, unsteady, lightheaded, or faint
- ▶ feelings of unreality (derealization) or being detached from oneself (depersonalization)
- ▶ fear of losing control or going crazy
- ▶ fear of dying
- ▶ numbness or tingling sensations
- ▶ chills or hot flushes

The attacks are not due to drug/medication), a general medical or other psych. condition



"The MRI reveals that your head is riddled with conventional wisdom."

Panic Disorder

- ▶ Recurrent unexpected panic attacks
 - ▶ A month or more of worry about having another or more panic attacks, and/or
 - ▶ Significant maladaptive changes in behavior to avoid having panic attacks, e.g. avoiding exercise or unfamiliar situations
 - ▶ Symptoms not attributable to medication or another medical or psychiatric condition
- 

Treatments for “Panic,” “Anxiety”

- ▶ Benzodiazepines (clonazepam et al)
 - Make you feel calmer, **but**
 - Can cause fatigue, sleepiness
 - Can cause or worsen depression
 - Can impair cognitive function
- ▶ Serotonin Reuptake Inhibitors (SSRI's)
 - Make you feel calmer, worry less, **but**
 - Can cause shallower, more restless sleep
- ▶ Psychotherapy/Counseling
 - Might help you cope with being sick, react less to certain stresses...**BUT**

What if “Panic” Isn’t Really Panic?

What if “anxiety” isn’t really anxiety?

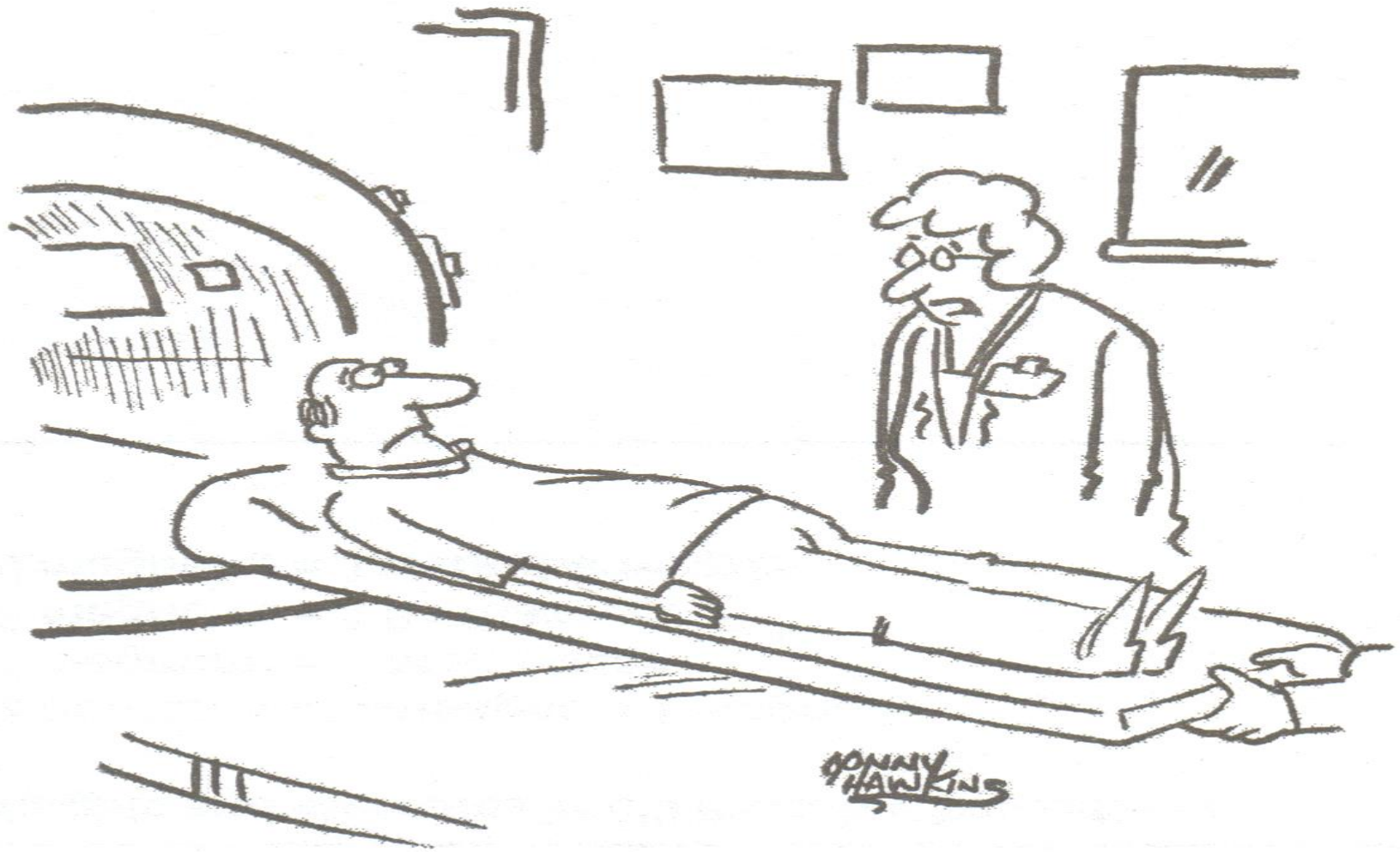
Then you’re really not treating the underlying problem, you’re only masking the symptoms, as in the case of KM

DSM-5 Criteria For Adult ADHD, Inattentive Type (ADD)

- ▶ A persistent pattern of inattention, which interferes with functioning and is characterized by 6 or more of the following symptoms for at least 6 months, to a degree that negatively impacts social and occupational/academic activities: Often:

ADD (continued)

- Doesn't pay attention to details, makes careless mistakes
- Has trouble keeping attention on tasks.
- Does not seem to listen when spoken to.
- Does not follow through on instructions and fails to finish schoolwork, chores, or job duties.
- Has trouble organizing activities.
- Avoids, dislikes, or doesn't want to do things that take a lot of mental effort for a long period of time.
- Loses things needed for tasks and activities.
- Is easily distracted.
- Is forgetful in daily activities.



"The MRI reveals that your head is riddled with conventional wisdom."

Treatments for ADD

- ▶ Counseling/Psychotherapy
 - Can help with management of daily activities
- ▶ Stimulants
 - Can help with focus, concentration, energy, **but**
 - Can worsen “hyperarousal,” “anxiety,” “panic”
 - Energy boost is temporary, fatigue becomes even worse (“the push–crash cycle”)
 - Dependence, tolerance can develop
 - Can worsen sleep problems, digestive symptoms, palpitations, etc.
 - **BUT.....**

What if you have the symptoms of ADD just because you're exhausted?

- ▶ Then you're really not treating the underlying problem. You're only masking the symptoms, as in the case of the patient in *The New York Times* article
- ▶ And in fact, particularly with the use of stimulants, there's a good chance you're making the underlying problem worse

Hypomania (associated with Bipolar Disorder)

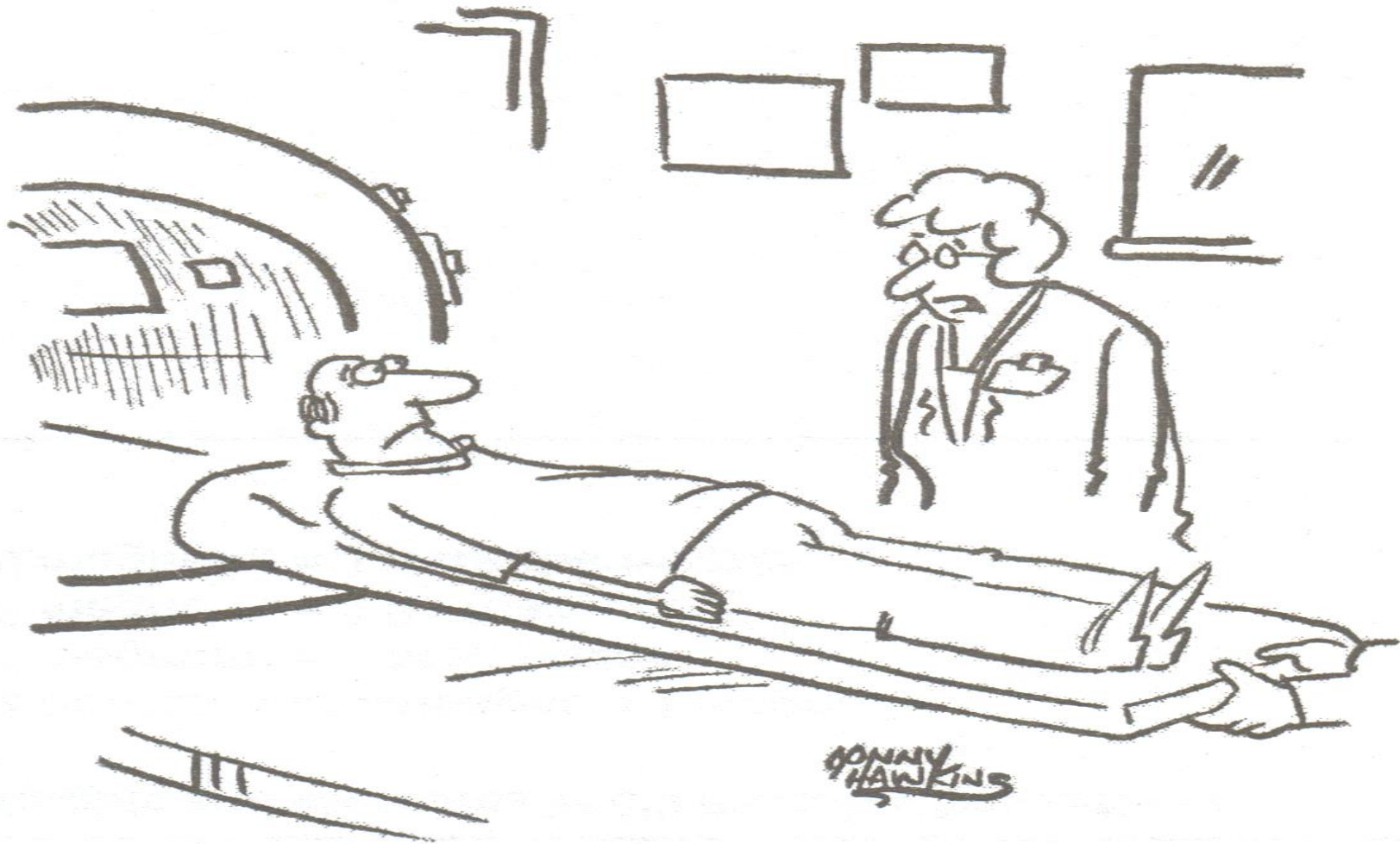
- ▶ A distinct period of abnormally and persistently elevated, expansive, or irritable mood, and abnormally or persistently increased activity or energy, lasting at least 4 consecutive days, and present most of the day nearly every day
- ▶ During this period at least 3 of the following symptoms (4 if the mood is only irritable) have persisted, represent a noticeable change from usual behavior, and have been present to a significant degree:

Hypomania (continued)

- ▶ Inflated self-esteem or grandiosity
- ▶ Decreased need for sleep (e.g feels rested after only 3 hours of sleep)
- ▶ More talkative than usual
- ▶ Flight of ideas, racing thoughts
- ▶ Easily distracted
- ▶ Increase in goal-directed activity, or psychomotor agitation
- ▶ Excessive involvement in activities that have a high potential for painful consequences

Hypomania (continued)

- ▶ The episode is associated with an unequivocal change in functioning of the individual that is uncharacteristic of the individual when not symptomatic
- ▶ The disturbance in mood and change in functioning are observable by others
- ▶ Episode not severe enough to cause marked impairment in social/occupational function
- ▶ The attacks are not due to drug/medication), a general medical or other psych. condition

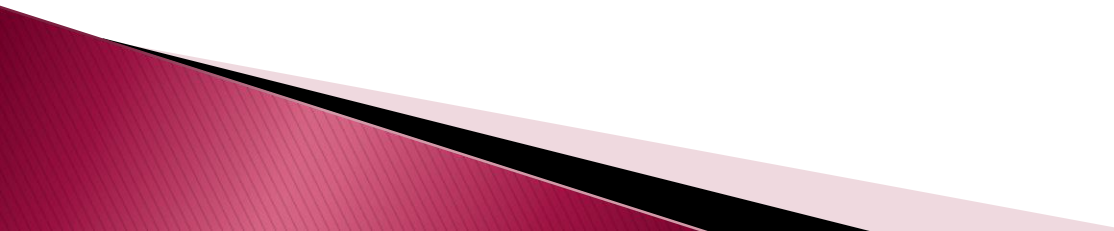


"The MRI reveals that your head is riddled with conventional wisdom."

Treatment for Hypomania/Bipolar

- ▶ “Mood stabilizers”, etc. **BUT**,
- ▶ Of course, this is again treating the symptoms and not the underlying problem

Even More Harm than Good

- ▶ These misdiagnoses don't just treat the symptoms rather than the underlying problems. They also:
 - ▶ Delay the possibility of a correct diagnosis
 - ▶ Expose patients to the risk of side effects of medications that they probably don't need
 - ▶ Raise doubt in the minds of patients, maybe their symptoms really are primarily psychological, not physical
 - ▶ Put inaccurate diagnoses in the medical record
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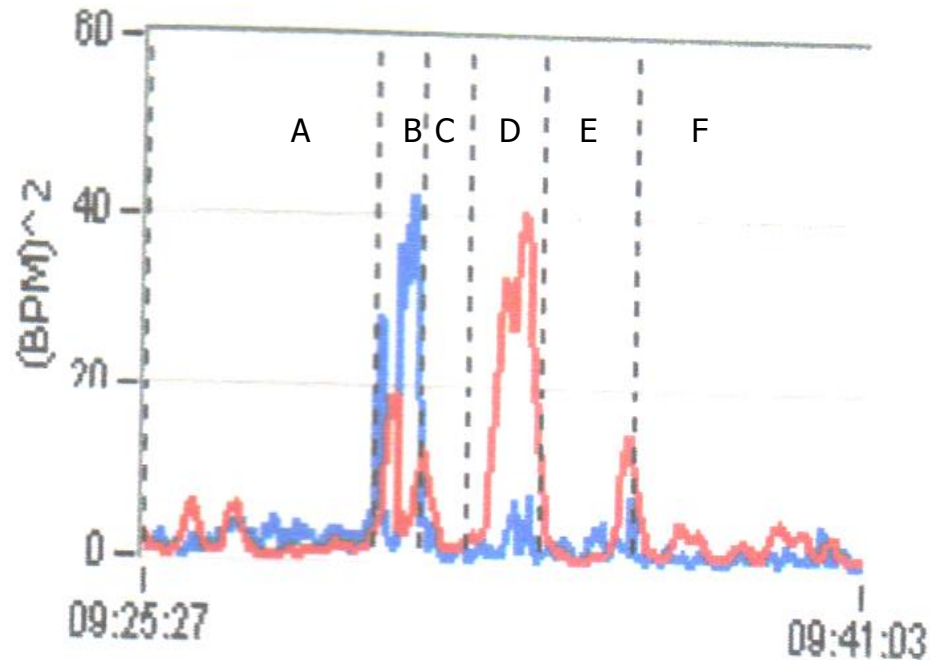
Autonomic and Psychiatric Conditions Can Coexist

- ▶ This of course makes diagnosis and treatment even more complicated

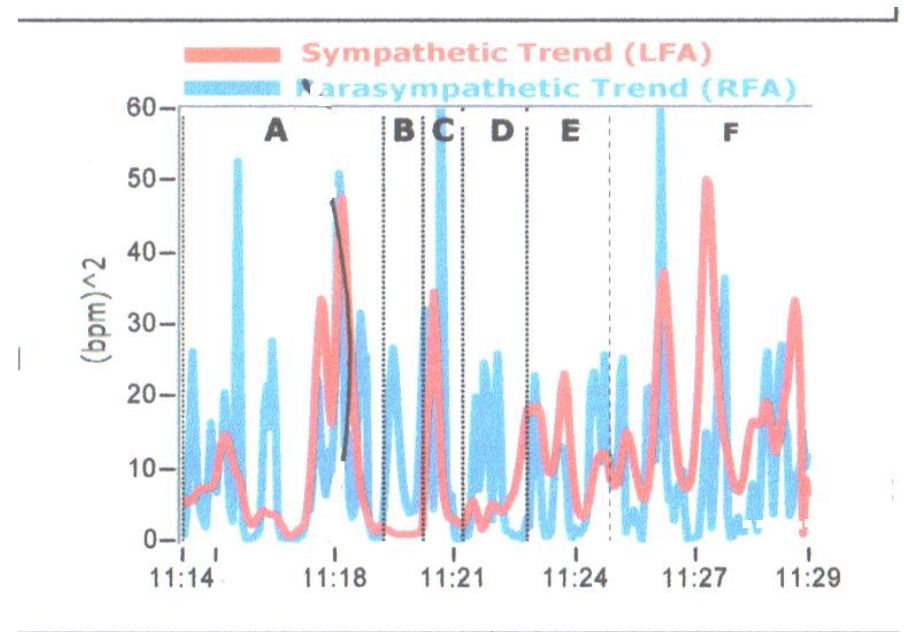


"Come back when you're feeling better."

Sympathetic and Parasympathetic Activity with Autonomic Maneuvers



Normal



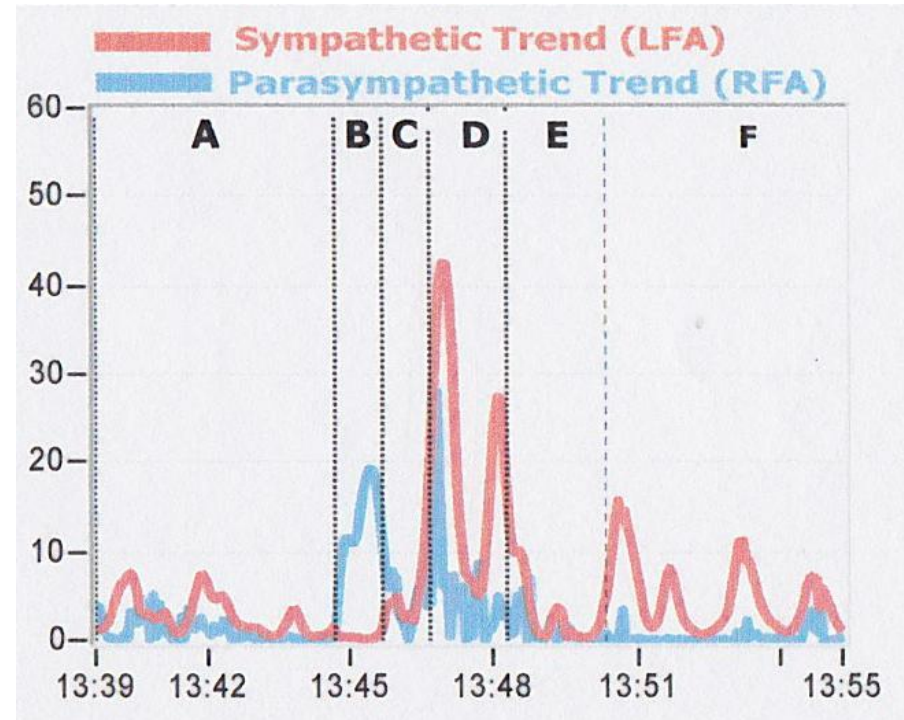
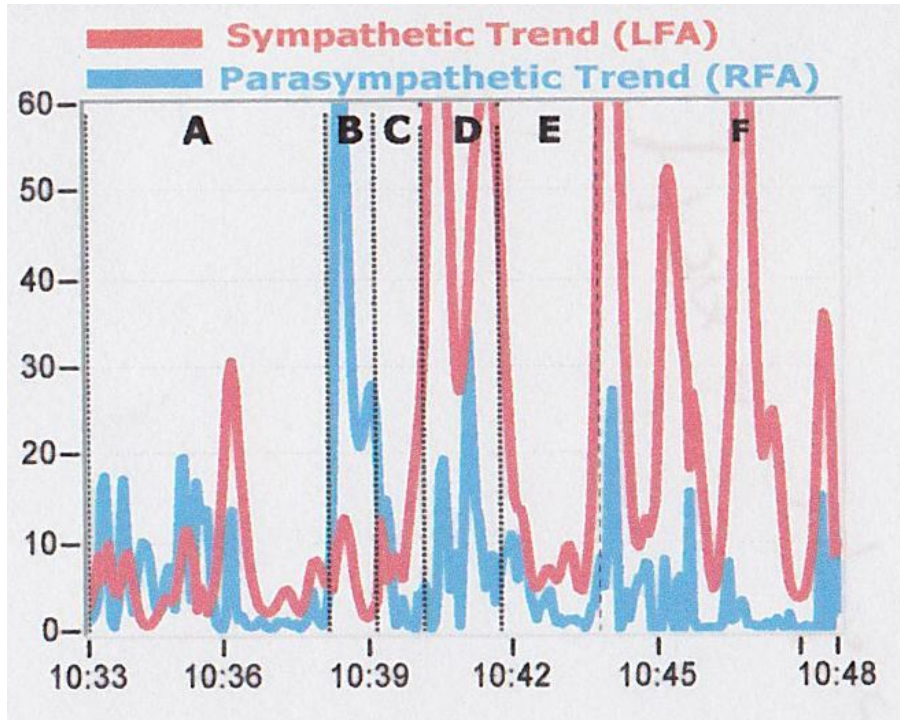
EDS with Dysautonomia

A=Baseline, B=Deep Breathing, C=Rest, D=Valsalva, E=Rest, F=Stand

Sympathetic and Parasympathetic Activity with Autonomic Maneuvers

At Diagnosis

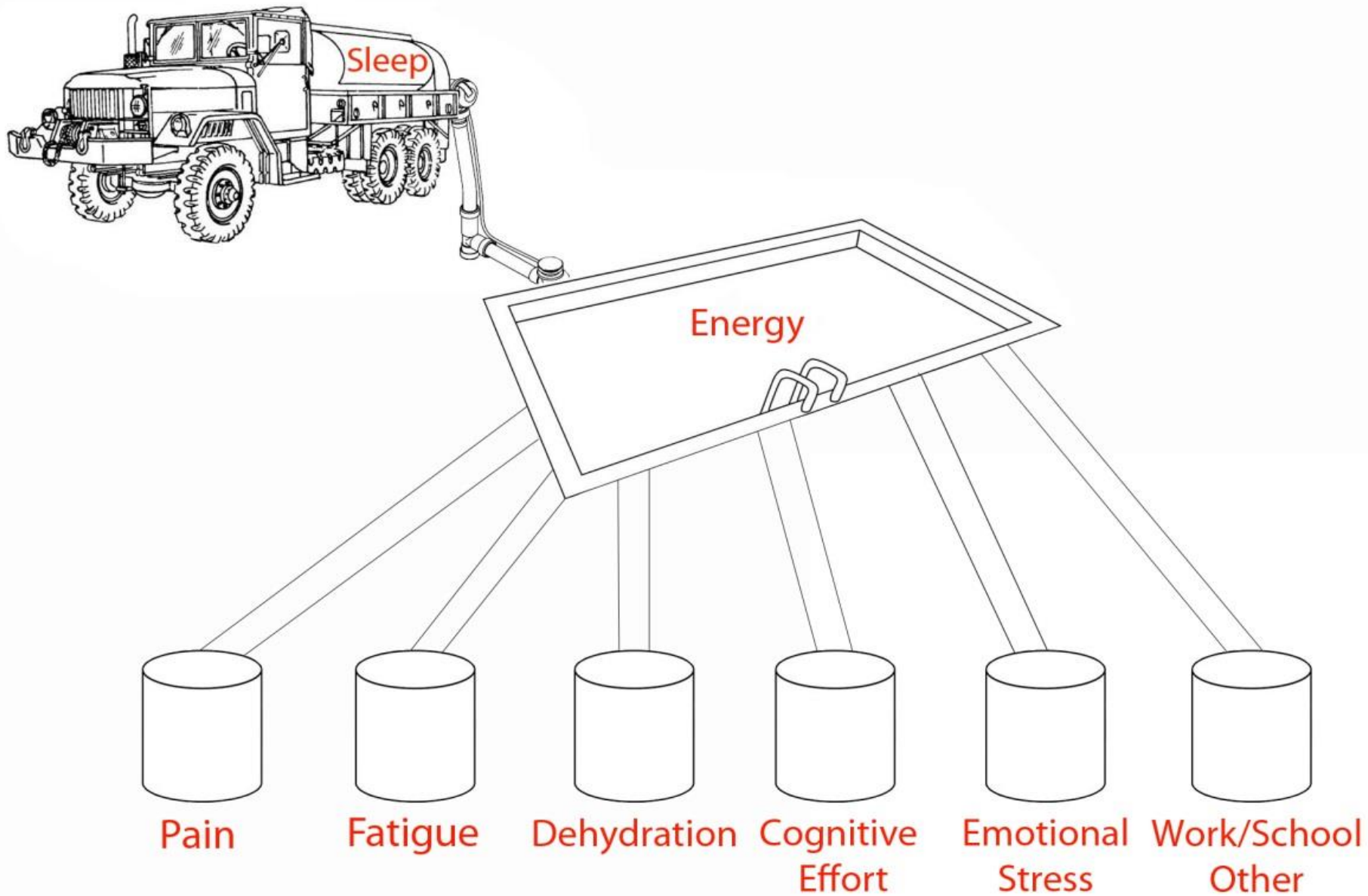
After 18 months of treatment



A=Baseline, B=Deep Breathing, C=Rest, D=Valsalva, E=Rest, F=Stand

Treatment of ANS Dysfunction: Restoring Autonomic Balance





Treatment of ANS Dysfunction: Restoring Autonomic Balance

- ▶ Address underlying problems:
 - Better sleep—quantity and quality
 - Adequate—really—pain control
 - Adequate salt and fluid
 - Avoid hypoglycemia
 - Minimize emotional stresses
 - Don't “push through” fatigue

Summary

- ▶ Autonomic dysfunction is often characterized by “over–response” and “over–correction” to stressful stimuli.
- ▶ Autonomic symptoms can be easily mistaken for symptoms of psychiatric conditions, especially anxiety, panic, and ADD, and at times even hypomania
- ▶ Treatment should be directed at correcting the underlying autonomic dysfunction, as well as reassuring patients that they **DO NOT HAVE** psychiatric conditions!

Acknowledgements

Dysautonomia International for inviting me,
and working so hard to spread awareness
and understanding

Dr. Peter Rowe for encouraging me when
others thought I was nuts

All my patients, for having the confidence
in me to let me experiment on them and
learn from them!