

finally announced the formation of a task force to address AFM.⁴

Being a neurologist trained in clinical research has required me to navigate a tight balance between “staying in my lane” as a parent member of a closed group and exploring the potential for the wealth of information available on the AFM parent site to enhance scientific discovery, treatment advances, and hypothesis generation. Ironically, through social media networks that connect me to other medical professionals, I have read comments about the savviness of parents accessing and leveraging information from our parent group. Here, group moderators have played a critical role. They not only facilitate member entry, social cohesion, and dissemination of information about external resources (e.g., clinical trials or CDC case reporting), but also seek pathways through which knowledge can flow back to medical professionals. For example, a partnership with AFM specialists has de-

veloped, initially by means of a new public, parallel Facebook group, and eventually by inclusion of parents’ voices in working groups led by clinicians. Furthermore, moderators have supported several initiatives to create “working knowledge” through data repositories, using data from consenting members only, that will expand AFM case ascertainment and data generation.

When my son developed AFM, despite the privileges of being vaccinated, insured, and immediately connected to a sophisticated health system, the path to recovery was highly uncertain. His paralysis would shape his development in all spheres: physical, emotional, social, and academic. At each step, we relied mainly on the determination of my son and his therapists and on connections — the shared experiences of parents who allied with professionals to pave a path of rehabilitation when no systems were in place.

After 4 long years, my son recently began to swing his right

arm. I excitedly shared “then and now” videos of him on the AFM parent site. I did so picturing parents lying awake next to their newly paralyzed child. I hoped the images would renew their optimism and determination to engage their child — and their insurer — for a new round of morning rehabilitation exercises.

Disclosure forms provided by the author are available at NEJM.org.

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Perchance to Think

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The note said, “r/o AI, r/o RA.” A doctor at another institution had done an unnecessarily expansive panel of blood tests for my patient that revealed a slightly low cortisol level and a slightly high CRP level. We primary care docs are used to being sent miscellany to sort out — it’s part of the deal. But still. Adrenal insufficiency and rheumatoid arthritis? First thing on a Monday morning?

As my patient began updating me on his six other chronic conditions, I surreptitiously pulled up a Web page on adrenal insufficiency. Not that I don’t remember every detail of adrenal vagaries, mind you. And sure, I’d rememorized it all for my board recertification, but let’s just say that adrenal insufficiency resides in the wobbliest, farthest-flung cortical gyrus I possess.

While my patient described

his radicular pain, his diabetes, and his GI symptoms, I dug through the fine print to remind myself which way the diurnal variation in cortisol runs. I tried to answer my patient’s questions while simultaneously working my way through the merits of the standard high-dose ACTH stim test versus the low-dose ACTH stim test, at the same time strategizing about how to convince our phlebotomists to do 0-, 30-, and

60-minute blood draws. As my patient lined up his 15 medications on my desk — all of which needed refills and all of which could interfere with adrenal function, cortisol testing, or both, I

and forms and papers spilling out of my mailbox. There would never be any “later.” But if I made any clinical decisions now, they would be haphazard, rife with potential for error. I finally threw in the

mulate a clinical question more cogent than “please eval.” I want to figure out which tests I can undertake in primary care so that everyone’s time is well spent.

But I’d struck out on all counts: I gave substandard care to my patient, dumped on my colleagues, and still didn’t fully grasp adrenal insufficiency. I’d managed to come out of this single case feeling ignorant, inept, and disgusted all at once.

In the pressurized world of contemporary outpatient medicine, there is simply no time to think. With every patient, we race to cover the bare minimum, sprinting in subsistence-level intellectual mode because that’s all that’s sustainable. We harbor a fear of anything “atypical” popping up. I dread symptoms that don’t add up, test results that are contradictory, patients who bring in a bagful of herbal supplements with instructions to “ask your doctor.” If I can’t spring to a conclusion in a minute flat, I’ll never keep up. God help me if the medical history includes Sturge–Weber syndrome or anything with ANCA.

If it requires thinking, I’m sunk.

This is an embarrassing admission for a field that prides itself on intellectual rigor. But with the frenetic pace of medicine today, there’s no time or space (or reimbursement) for cogitation. We end up over-ordering tests because it feels more workable in the moment. We over-refer to specialists because we don’t have the mental bandwidth to integrate confounding data. Beyond the financial waste, modern medical practice is a petri dish for medical error, patient harm, and physician burnout. There’s no surer way of grinding down committed clini-

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realized I simply could not sort this all out in the moment.

What I needed was time to think.

I found myself pining for those medical school Saturdays in the library — endless hours to read and think. Nothing but me, knowledge, and silence, facing off in a battle of concentration. How I hated those study sessions then, and how I would have given my left adrenal for a few minutes of one now.

But a gazillion EMR fields were demanding attention. Three more charts were waiting in my box. The patient still had two MRI reports and an EGD for me to review, plus a question about PSA testing. His adrenal insufficiency was swamped by my cerebral insufficiency.

I could tell him I’d review his case later and get back to him. But what “later” were we talking about? My patient session would run overtime by hours. There were last week’s labs to review, student notes to correct, patient calls to return, meds to renew,

towel and scribbled a referral to endocrinology, hustled the patient out the door, and hurried the next person in.

Every time patients enter our office, it’s like they open the closet door. Sometimes there are only a handful of items inside, neatly laid out, and we can address everything effectively in a few minutes. Other times, it’s bedlam in there. I never feel right ending a visit until I have a basic sense of order. Even if I don’t have all the answers, I need to have a handle on the issues and a workable plan. Only then can I close the closet door.

But this visit was a sorry mess, and I’d punted, dumping the whole muddle into someone else’s hands. Referring possible adrenal insufficiency to endocrinology isn’t wrong, but the way I’d arrived at that decision felt like a cop-out.

We internists do have a semblance of pride. I want to have a reasonable grasp of the situation before I refer, so I know that the referral is justified. I want to for-

cians than forcing them to practice the cookbook medicine we've always derided.

A few days after that visit, I happened on *Core IM*, an internal medicine podcast created by some of my New York University colleagues. One of the hosts mentioned an episode on adrenal insufficiency. "It's one of those topics," he observed, "that's never nailed down fully."

Ah, so I wasn't the only idiot who couldn't iron out adrenal insufficiency on the spot. I listened to the episode and then reread the chapter. With an actual case in hand, the physiology clicked more easily. The next day, I went to work early, opened the patient's chart, and resifted through his data.

I still wanted him to see an endocrinologist, but at least now I didn't feel like I was handing off a mess. I appended my initial note with a more intelligible

analysis and called the patient to explain our plan. When I closed out the chart, I felt satisfied with the case for the first time. I felt the kind of relief that comes after you've finished spring-cleaning your closet. Now you know where the sweaters are!

Of course, sorting out this one issue for this one patient took a full hour outside his visit. I couldn't have pulled it off in the moment, and I can't carve out an extra hour during that nonexistent "later" for every patient with a complex problem. But that's what so many of our patients' conditions require — time to think, consider, revisit, reanalyze.

From the billing-and-coding perspective, that process is supremely inefficient. There's no CPT code for contemplation. But extra time dedicated to thinking — with either longer patient visits or protected time for "panel management" — could actually be

remarkably efficient. We would save money by reducing unnecessary tests and cop-out referrals. We'd make fewer diagnostic errors and avert harms from over-testing. And allowing doctors to practice medicine at the upper end of our professional standard would make a substantial dent in the demoralization of physicians today.

But I'm not optimistic. Time to think seems quaint in our metrics-driven, pay-for-performance, throughput-obsessed health care system. Regrettably, cerebral insufficiency will probably remain the working diagnosis for years to come. No amount of ACTH stimulation can cure that.

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