

Medically Lost:

Inside Medicine's Systemic Dysfunction

Robert Spearman. June 23, 2025. [CC BY-ND 4.0](#)

Why I Wrote This

Preface

This document began as a personal attempt to document why the medical system repeatedly failed to provide a coherent picture of what was happening to me, and why no one seemed able to connect the pieces. I've lived this problem for decades, and it's not just my experience but those of countless others navigating long, undiagnosed, or misunderstood illness. While those of us who are *medically lost* experience system failure at seemingly every turn, these same problems can touch anyone.

These are not simply the failures of individual doctors or nurses. Some are excellent, some are harmful, and most are constrained by systems that discourage listening, reflection, or innovation. What we may experience as personal failures are often just symptoms of deeper systemic flaws.

I've written this in the hope that it will help others—patients, clinicians, caregivers, and system builders—see more clearly what so often remains unseen as a whole. The first stage in solving any problem, no matter how complex, is to define it.

This is not a research paper or a policy brief. I'm not a clinician or healthcare professional. My background is in economics, systems architecture, and entrepreneurship. In its most useful form, economics is the science of how individuals and societies make decisions when resources or information are limited—and how those decisions can be structured to improve outcomes. It's both descriptive and prescriptive: a lens for understanding behavior, and a tool for designing systems that better serve people.

This document reflects a systems perspective shaped by experience, observation, and a firsthand understanding of how institutions repeatedly fail to see the whole. It uses economic and systems reasoning as practical tools for understanding how institutional design, incentives, and professional norms shape patient experiences and broader outcomes—grounding analysis in results rather than ideology.

Systemic Dysfunction

Introduction

Modern medicine has made extraordinary advances, yet there remains a significant—and often invisible—population that falls through its cracks. These individuals suffer from persistent, often debilitating symptoms that evade clear diagnosis or explanation. While the NIH estimates that 25 to 30 million Americans live with a rare or undiagnosed disease, the number of people who remain *medically lost*—undiagnosed, misdiagnosed, or poorly supported—is almost certainly much larger. Many of these conditions are not rare at all; they are simply misunderstood, overlooked, or dismissed.

These failures are not confined to the margins. The same systemic limitations—time constraints, fragmented care, diagnostic blind spots, suboptimal incentives, and cultural rigidity—affect nearly everyone navigating the healthcare system. For the medically lost, these breakdowns converge into a kind of *medical exile*. For others, they show up as delays, misfires, and dismissals that erode trust and postpone care. The consequences include not only unrelieved suffering and wasted potential, but avoidable harm—even death.

This document outlines the biggest issues and traces some of the root causes of these failures—not to assign blame, but to illuminate the larger picture. It is written for those who have felt invisible inside the system, and for those who are trying to build something better.

Disintegrating Specialists

Fragmented Knowledge Without Synthesis

Modern healthcare is divided into specialties that rarely communicate effectively. But a deeper issue is the lack of a shared framework for synthesis—no one is trained or empowered to assemble scattered symptoms into a coherent whole. General practitioners, while often the first point of contact, are trained to manage common, well-defined conditions and refer out. They rarely have the time, training, or mandate to interpret multisystem dysfunction. As a result, patients with complex symptoms may see multiple specialists without ever receiving an integrated diagnosis or treatment plan.

Another deep fracture lies in the institutional separation of mind and body. Rather than treating mental and physical health as interconnected, the system enforces their division through insurance codes, billing pathways, education, and licensing boundaries. Clinicians often focus narrowly on either physical or mental dimensions, missing how they interact. This isn't just a logistical failure—it's a conceptual one. Connections are lost, treatment fragments, and root causes remain hidden when the system can't see the patient as a whole.

A teenage girl with undiagnosed neurological Lyme might be told her symptoms are psychosomatic and referred to a psychologist—while the infection insidiously progresses. Meanwhile, an unrecognized neurodivergent adult in sensory overload might describe intense

fatigue, heaviness, or shutdown—prompting tests for metabolic or neurological illness while the root cause goes unseen. In both directions, physical and mental suffering are too often mislabeled, misrouted, or dismissed—leaving the patient lost in a system that treats the body and mind, and even each part of the body, as if they don’t belong to the same person.

Too Little Time to be Understood

Time Constraints

Standard appointment slots (15–20 minutes) are too short to explore complex histories or nuanced symptoms. Even longer visits often leave patients with chronic or unclear issues feeling unheard. Without ongoing guidance, those walking a delicate line between setbacks and progress can drift into greater dysfunction. Most clinicians just don’t have the time—or reimbursement—for deeper engagement between visits.

Patients may spend a lot of effort filling out detailed intake forms, only to discover the clinician hasn’t reviewed them. Sometimes it’s time pressure; sometimes the data is simply ignored. Either way, it’s a missed opportunity to build understanding and trust.

One of the most quietly disheartening changes in modern medicine is how rarely physical exams are performed anymore—or how superficial they’ve become. Many patients arrive with symptoms that affect their whole body, yet rarely does anyone check their reflexes, muscle tone, gait, or skin texture. Instead, there’s often a quick glance, maybe a stethoscope tap, followed by labs and imaging orders. These tools are valuable, but they don’t replace the insights a trained eye and hand can gather in real time. For those with complex, systemic illness, it can feel like no one is really looking.

When needs fall outside standard models, patients are often labeled “difficult.” But this reflects system constraints more than patient behavior. These individuals may require more time, nuance, or cross-disciplinary input than a typical visit allows. What gets labeled as noncompliance or anxiety is often uncertainty, trauma, or complexity. The system isn’t built for patients like this—so it can treat their difficulty as personal rather than structural.

Some clinicians still try—reviewing what others overlook, integrating patient insight, or taking risks to explore unresolved patterns. But doing so often comes at a cost, both personal and professional. The structure penalizes complexity, even when that complexity holds the key to better outcomes.

I Already Know What's Wrong With You

Cognitive Bias in Diagnosis

Clinicians often default to familiar diagnoses, especially under time pressure. Medical training emphasizes Occam's Razor—the simplest explanation is usually correct—but this can cause multi-factorial or atypical conditions to be dismissed. Symptoms that are hard to quantify or don't match textbook patterns are often overlooked.

Patients themselves may not report longstanding symptoms if they've come to see them as normal. Subtle, slow-developing issues—especially cognitive or autonomic—can go unrecognized by both patient and provider, further delaying care.

There's also a mismatch in goals: patients want to improve function or prevent decline, while the system is oriented around rule-based decision trees and liability avoidance. Symptoms that don't trigger urgent action are often deprioritized.

Paradoxical reactions—when a treatment causes the opposite or an unexpected effect—often confuse both doctor and patient. But rather than prompting deeper investigation, they're often brushed aside, blamed on the patient, or deemed irrelevant—shutting down what could have been a useful area of exploration.

At the cultural level, many patients and clinicians are reluctant to question medical authority. Trust in the system delays second opinions and reinforces diagnostic inertia. Diagnostic overshadowing—when one label (especially psychiatric or neurodivergent) causes clinicians to interpret every new symptom through that lens—is a well-documented problem for those with autism or mental health diagnoses.

Neurodivergent patients—especially those on the autism spectrum—may be misread due to flat affect, factual communication, or difficulty verbalizing under stress. Their clear reports of physical symptoms are often dismissed as anxiety or noncompliance. Similarly, women and those visibly struggling to advocate for themselves frequently have their concerns minimized, with physical complaints framed as emotional—an issue supported by studies on gender bias and medical gaslighting.

Standard health questionnaires also assume recent change from a baseline of health, which doesn't fit patients with lifelong or gradual-onset conditions. Key symptoms may go unreported—not because they're unimportant, but because the form never asked the right question.

Because of this, many patients are forced to become their own diagnosticians—not out of choice, but necessity. Generalists hesitate to order non-routine tests. Specialists may dismiss cases outside their focus. To be taken seriously, patients often learn medical language, identify promising specialists, and advocate for their own workups.

Diagnostic framing matters. The same symptoms can lead to very different conclusions depending on who's looking. A patient with shin pain might be told by a surgeon that it's

compartment syndrome and requires surgery, while a massage therapist sees it as treatable with manual work. For medically complex patients, learning to question not just the diagnosis, but the urgency and assumptions behind it, becomes a survival skill.

Hickam's Dictum—the idea that “patients can have as many diseases as they damn well please”—is a necessary counterweight to diagnostic oversimplification. It reminds us that complexity is not diagnostic failure—it's biological reality.

You're Perfectly Normal

Laboratory Limitations and Diagnostic Blind Spots

Lab testing is a cornerstone of modern medicine, yet it often fails those with chronic or complex illness. Routine panels are designed to detect common diseases—not subtle dysfunction. Many patients receive "normal" results despite persistent, debilitating symptoms.

Reference ranges—used to determine what's "normal"—are based on population averages labeled as "healthy," yet those averages often include individuals with undiagnosed or early-stage conditions. As a result, being "within range" doesn't necessarily indicate good health—only that a value aligns with a statistical slice of the population. This can mask subtle or early dysfunction, especially in complex or chronic cases.

A major issue is the misuse of testing—either by ordering the wrong tests or by misinterpreting the results, both of which are surprisingly common. For example, many clinicians still rely on total B12 and total testosterone, unaware that these often fail to reflect actual availability in the body. These labs persist more from habit than accuracy—they're easy to order, widely available, and seem authoritative. But total B12 includes both active and inactive forms, so levels may appear normal even when cells are starved. Similarly, total testosterone doesn't account for how much is bound to carrier proteins like SHBG, meaning patients can have textbook symptoms despite "normal" results. Without checking active form (or using related markers like MMA or SHBG) doctors may dismiss clear dysfunction, leaving patients unsupported and confused.

Basic screenings for insulin-related problems also fall short. Fasting glucose and A1C can appear normal even when serious metabolic dysfunction is present. Post-meal spikes in glucose or insulin, or episodes of reactive hypoglycemia, may go undetected without tests like fasting insulin, C-peptide, or glucose tolerance curves. In rare cases like type B insulin resistance—an autoimmune condition with sky-high but ineffective insulin levels—standard screening metrics become outright misleading. Even in more common scenarios, many patients report dramatic improvement on low-carb diets despite "normal" lab results, revealing dysfunction that conventional thresholds fail to detect.

Context matters—and is often ignored. A patient already following a low-carb or ketogenic diet may have normal glucose and insulin levels simply because the diet suppresses the very

dysfunctions being tested. Without considering the patient's current dietary state, clinicians may overlook insulin resistance, reactive hypoglycemia, or atypical metabolic patterns. Lab results may suggest everything is fine—yet the symptoms persist.

More specialized testing brings new risks: unreliable lab practices, misinterpretation, or methodological inconsistency. Some physicians report Lyme disease antibody markers only appearing after successful treatment, probably due to immune suppression during active infection. Sensitive tests handled improperly can yield false negatives—shutting down further investigation prematurely.

Most clinicians are neither trained nor given time to critically assess these subtleties and limitations. If the labs look "normal," the system often defaults to reassurance or dismissal, ignoring signs of under-recognized dysfunction. The result is a patient with normal results, unresolved symptoms, and no path forward—told they're perfectly fine when they are anything but.

Illness by Degrees

The Nonbinary Nature of Systemic Illness

Many systemic conditions don't present as clear-cut diseases but fall along spectra of dysfunction. Immune dysregulation, mitochondrial distress, or autonomic imbalance often occur in gradients—some patients meet strict criteria, but many others fall into gray zones without formal labels or treatment protocols. Medicine tends to recognize only those at the extreme end of this distribution. The rest—who still suffer to varying degrees—go unacknowledged.

Cystic fibrosis commands clinical attention because it represents a severe, unmistakable expression of CFTR gene dysfunction. But that focus obscures a broader reality: CFTR-related disorders are far more common but much harder to recognize. They can cause chronic sinus infections, pancreatic insufficiency, male infertility, or thick mucus without lung involvement. These milder forms often appear in adulthood and don't match the classic disease profile. Yet CFTR mutations are relatively common—especially among people of European ancestry—suggesting a wide distribution of partial dysfunction that medicine rarely investigates. These patients remain invisible because their illness is common, not extreme, and easy to overlook.

As with other spectrum-based disorders, narrow diagnostic framing prevents intervention—even when treatment could meaningfully improve quality of life. For many patients, the problem isn't that their illness is too rare—it's that it's too complex or subtle to fit the system's binary view of disease.

Illness Likes Company

Cascading Illness and Immune Vulnerability

Chronic illness can begin with an infection—sometimes obvious, sometimes overlooked. In some cases, the immune system never fully resets, leading to long-term inflammation, autoimmunity, or systemic dysfunction. But whatever the initial cause, once dysfunction sets in, vulnerability to new infections or viral reactivations increases. Mold exposure, Lyme disease, parasites, and chronic viruses are frequently missed, in part because testing is too narrow or insensitive. This mutual reinforcement—where infections trigger dysfunction, and dysfunction increases susceptibility to further infection—is rarely acknowledged in mainstream care. The end result is a vicious cycle of escalating illness.

Systemic dysfunctions rarely stay isolated. Once core processes like immune regulation, detoxification, or energy metabolism destabilize, other systems begin to fail. These downstream effects can lead to secondary diagnoses, compounding symptoms, and growing treatment complexity. Early recognition is critical. But when each problem is treated in isolation, clinicians may miss the larger pattern—and patients are left to manage a cascade on their own.

One Day at a Time

Cognitive and Energy Impairments

Many chronic conditions affect both mind and body—causing brain fog, word-finding issues, processing delays, and profound fatigue. These are often accompanied by pain, insomnia, dizziness, temperature dysregulation, malabsorption, and chemical sensitivities. While disruptive, these symptoms often lack formal diagnostic categories or clear medical labels.

This combination of low energy and low mental clarity makes it harder to advocate, follow treatment plans, or complete daily tasks. Navigating the healthcare system itself can become overwhelming.

When basic functioning is compromised, patients may miss or fail to schedule follow-up appointments, struggle to articulate their needs, or be perceived as disengaged. This increases isolation and reduces access to support—worsening outcomes, even when help is technically available.

It's All in Your Head

Psychological Consequences of Dismissal and Chronic Suffering

When no diagnosis is found, patients are often told their symptoms are psychosomatic, imagined, or the result of stress. Depression and anxiety—common reactions to chronic illness

—are frequently mistaken for causes rather than consequences. This reversal blocks further investigation and erodes trust.

The emotional toll of being unwell and dismissed is profound. Medical invalidation, physical pain, and social isolation reinforce each other—leading to anxiety, depression, and even trauma, including that caused by medical encounters. These effects aren't secondary—they're central to the lived experience of many who are medically lost.

Cultural belief in medical infallibility can delay second opinions or alternative exploration. When doctors find nothing wrong, patients are often left in limbo—without a diagnosis, they receive no validation that their suffering is real. This uncertainty breeds stigma. Friends, family, and employers may express doubt, especially if the person appears healthy. Over time, that doubt can be internalized. Patients may begin to question their own experience, feeling ashamed or at fault for not getting better. This dynamic is especially common among women, people of color, and others who are more likely to have their symptoms minimized or dismissed.

Chronic illness also strains personal relationships. Patients may hide symptoms to preserve employment or social belonging. Conditions like IBS-D demand constant vigilance, forcing some into isolation—not only due to illness, but also misunderstanding.

For some, the weight becomes life-threatening. Studies show significantly higher suicide risk among patients with misunderstood or undertreated conditions like fibromyalgia, chronic fatigue, or persistent pain. The burden isn't just physical—it's existential. When suffering is invalidated and no path forward is offered, despair takes root. These are not rare tragedies—they are predictable outcomes of a system that fails to see—and cannot support—those who fall outside its narrow frame.

Choose a Number

Coding-Driven Medicine and Diagnosable Conditions

Modern medicine prioritizes what can be measured, named, and billed. If a symptom doesn't map cleanly to a reimbursable code, it may be ignored or dismissed. Even consistent, distressing problems can be scattered across unrelated diagnoses—leaving a fragmented record and no cohesive care plan.

Many patients never receive a diagnosis at all. If there's no checkbox for what's wrong, it often goes untested. There is no billing code for sulfur-processing dysfunction, for example—so it's rarely investigated.

Others are misdiagnosed. Vague or systemic symptoms might be labeled anxiety or depression. Fatigue might be blamed on lifestyle. Inflammatory signs might be written off as normal labs or noncompliance.

This isn't just a billing failure—it's a conceptual one. Patients are sorted into diagnostic bins that don't always reflect the reality of their condition. Medicine too often mistakes

categorization for understanding. For many, a diagnosis is just a name for the place they've been stuck.

You Say You Want a Diagnosis

Diagnosis Is Not a Root Cause

A diagnosis is often mistaken for an explanation. In reality, it's a label—a shorthand for a recognizable pattern. It may unlock access to treatment or legitimacy, but it rarely answers deeper questions: *Why did this happen? What's sustaining it?*

In complex cases, a diagnosis is more of a starting point than an endpoint. Yet once a label is applied, investigation often stops. Treatment becomes standardized, and uncertainty is pushed aside.

Worse, one diagnosis can eclipse others. A patient may have multiple overlapping conditions—immune dysfunction, metabolic stress, neurological imbalance—but receive only the first one that fits. Additional layers are missed or dismissed, especially if they challenge the system's standard logic.

Many diagnoses describe effects, not mechanisms. Conditions that appear similar on the surface may arise from very different—or even unknown—root causes. Naming a condition doesn't mean understanding it. This gap—between classification and comprehension—is one of medicine's most persistent blind spots.

Band-Aid or Cure?

Symptom Relief vs. Root Causes

Modern medicine thrives on managing symptoms, especially in acute care. But in complex or chronic conditions, that same strength becomes a liability—masking deeper dysfunction and delaying real answers. Symptom suppression often replaces true investigation, and protocols prioritize measurable improvement over meaningful resolution.

Once a diagnosis is assigned, clinicians typically default to a standardized treatment protocol—one that suppresses symptoms, stabilizes metrics, or blocks biological pathways. These interventions may ease discomfort or reduce short-term risk, but they rarely ask *why* the problem exists in the first place. For example, a patient experiencing sneezing, congestion, or irritated eyes might be prescribed antihistamines to relieve symptoms—while an underlying issue like insulin resistance or mast cell activation goes undetected and unaddressed. The root cause remains untreated—sometimes even unexamined.

When initial treatments fail, patients are frequently escalated through more aggressive symptom-management protocols—often without revisiting whether the original diagnosis was

correct or whether the treatment approach was ever appropriate. Protocols compound, complexity increases, but the core dysfunction may still be ignored.

Root cause care requires a shift in mindset—from suppressing symptoms to understanding systems. It demands time, nuance, and iterative processes. It is complicated and individualized. This usually doesn't fit cleanly into billing codes or clinical guidelines, but it is often the only path to true recovery for medically complex individuals.

There's a Pill for That

Pharmaceutical Dominance and Neglected Alternatives

Both patients and clinicians are shaped by the belief that every problem can be easily resolved by a drug. But medications often carry high risks: they're systemically active, not well individualized, frequently burden the liver, and are typically studied only for short-term use—not in the long term or multi-drug combinations real patients often take.

Lower-risk options—like nutritional changes, supplements, or environmental interventions—are rarely considered first, even though they are usually much safer and sometimes more effective. What patients lack isn't just access to medication—it's access to an approach that starts with root causes instead of symptoms.

When the Drug Becomes the Problem

When drugs fail or cause harm, the reflex is usually to prescribe again. Side effects are minimized, vaguely explained, or not mentioned at all. Yet when they do occur, they are often dismissed as unrelated, blamed on the patient, or left untreated. Some are temporary, but others cause permanent damage, compounding both complexity and suffering.

In complex conditions—especially those involving immune dysregulation or metabolic fragility—medications can backfire in unexpected ways. A drug prescribed to manage one symptom may cause a functional system to fail entirely. Yet when patients report these reactions, they are often met with skepticism or dismissal—especially if the response falls outside known side effects or contradicts expectations.

Protocols intended for acute illness are sometimes applied without modification to long-term conditions. In chronic Lyme, for example, short-term antibiotic guidelines are often used despite little chance of resolution—leaving both clinicians and patients frustrated. And when no drug is available, patients are frequently told that no treatment exists at all.

The Alternatives We Ignore

Yet safer, often more effective approaches exist—if we're willing to look beyond the prescription pad. Consider Type 2 diabetes: while insulin is widely prescribed, a medically supervised ketogenic diet could reverse the condition in potentially millions of cases—

removing the need for insulin entirely. But that path is rarely discussed. The system defaults to pharmaceutical dependency, despite long-term cost, risk, and the physical pain of daily injections.

The structure of pharmaceutical innovation helps explain why. Patented drugs are incentivized; non-patentable approaches—like nutrition, lifestyle, or microbial support—are not. Medical training emphasizes trial-backed care, which can lead to the dismissal of promising therapies simply because large-scale studies are unavailable or impractical.

Meanwhile, medications are aggressively marketed to physicians, shaping prescribing habits and reinforcing the belief that drug-based solutions are primary, proven, and superior. Even well-known botanicals like holy basil, used medicinally for thousands of years, remain understudied not because they lack promise, but because they lack profit.

Even when medication is needed, sensitivity to fillers or additives can cause avoidable harm. Compounding pharmacies can tailor formulations, but clinicians are rarely trained to recognize ingredient reactivity. A 2019 study in *Science Translational Medicine* found that over 90% of oral medications contain at least one inactive ingredient that could cause an adverse reaction—an overlooked trigger for many with sensitivities, inflammation, or mast cell issues. Common culprits include dyes, gluten (from wheat-derived starches), and even lactose (a dairy-derived sugar). Frustratingly, pharmacies do not reliably screen for sensitivities in inactive compounds.

Public discussion often centers on drug pricing. But the real opportunity is deeper: to reduce reliance on medications in the first place by restoring function with lower-risk, patient-centered strategies.

Who Are You Gonna Believe?

Logic Gaps in Evidence-Based Medicine

Grounding medical care on logic and the scientific method is essential—but what qualifies as “evidence” is often defined too narrowly, ignoring feasibility and context. The bar for proof is set so high that other inputs—even common sense or patient experience—can be sidelined. Meanwhile, unexamined errors in reasoning further delay progress and erode trust.

Randomized controlled trials (RCTs) are the gold standard for population-level conclusions. But when “evidence-based care” is interpreted as “only RCT-backed care,” it shrinks what’s possible. RCTs are costly and limited in scope—leaving many promising options unexplored or unsupported.

Medical education reinforces this rigidity, emphasizing guidelines over curiosity. Doctors are trained to follow algorithms, often under pressure from liability and billing systems, even when patient outcomes diverge. This fosters a culture that prizes certainty and punishes deviation. Yet many standard-of-care guidelines aren't held to the same rigorous standards used to discredit alternative approaches—a hypocritical gap rarely acknowledged.

Even more problematic is how RCT data gets applied. Using population averages to guide individual care ignores outliers and masks variability—a bias known as the ecological fallacy. This one-size-fits-all approach fails many, especially those with rare or complex conditions.

One of the most damaging logical errors in medicine is equating a lack of studies with ineffectiveness—a pernicious fallacy with real-world consequences. Many low-cost or non-patentable therapies lack large trials not because they don't work, but because studies are difficult to fund or design. Dismissing them outright conflates *absence of proof* with *proof of absence*. When a doctor tells you that your favorite supplement “can't possibly be helping” because there are no studies—despite your clear improvement—trust begins to evaporate.

Experiential knowledge—clinical intuition, patient insight, or even N-of-1 experimentation—is usually minimized in this “evidence-based” mindset. These sources may lack statistical rigor, but are often of more practical value. A well-functioning system would fully integrate both data from trials and wisdom from practice: evidence-informed care.

By overvaluing certainty and undervaluing what's actually practical to determine, medicine often overlooks what actually helps patients. Integrating multiple forms of evidence—quantitative and qualitative, formal and experiential, population-level and individual—is practical, adaptive care which reclaims its full meaning from irrationally rigid gatekeeping.

Learned Helplessness

Lack of Training in Emerging and Foundational Fields

Most physicians receive little training in emerging fields like mitochondrial medicine, environmental illness, gene–environment interactions, or the compounding effects of multiple genetic variants within a single biochemical pathway. Even foundational subjects like nutrition are often neglected—despite their direct relevance to metabolism, immunity, and chronic disease.

As a result, many contributors to illness—malabsorption, mitochondrial dysfunction, or nutrient depletion—go unrecognized. Patients may be told their symptoms are idiopathic (no known cause) or psychological when the root issue is metabolic or nutritional.

Genetic testing is another missed opportunity. While access has improved, few clinicians are trained to interpret results beyond classic Mendelian diseases. Multi-gene patterns affecting detoxification, methylation, or immune function are often dismissed or misunderstood.

These gaps leave patients without guidance—even when data is available. Potential insights from labs or genomics go unused, not because they lack relevance, but because the system lacks tools to apply them.

In complex or chronic cases, this failure to engage emerging knowledge is not benign—it reinforces stagnation. When doctors aren't taught to recognize upstream drivers of illness, downstream symptoms multiply.

Reading for a Cure

The Overlooked Power of Belief

In some cases, the most powerful intervention isn't chemical—it's conceptual. The placebo effect—frequently dismissed as mere statistical noise—reveals the body's real and measurable response to belief, context, and expectation. If healing depends on the body's capacity to repair itself, shouldn't we actively study how mindset supports that process, rather than treat it as irrelevant?

For conditions like pain, depression, or fatigue, pharmaceutical benefits often barely exceed those of placebo. In some trials of conditions like pain or depression, for example, placebos can account for up to 75% of a drug's observed effect. Yet medicine rarely seeks to harness this influence intentionally.

This is especially relevant in psychiatric care, where medications are often prescribed without a clear underlying diagnosis. Side effects like anhedonia, emotional blunting, weight gain, or withdrawal symptoms can add new layers of suffering—and are particularly tragic when the underlying issue wasn't psychological to begin with.

Diagnostic certainty itself can act as a therapeutic tool. When clinicians express confidence, patients often improve—sometimes independent of intervention. But this performance of certainty can backfire—discouraging transparency, exploration, and honest dialogue.

The nocebo effect—the physiological harm caused by negative expectations—is equally powerful. Patients warned of side effects often experience them more intensely. Those given grim prognoses may internalize them, reinforcing a health trajectory that might otherwise have been changeable.

One striking example comes from Dr. John Sarno, who argued that much chronic back pain stems from emotional tension rather than structural injury. His reframing has helped countless people recover without physical intervention—simply by reading one of his books and changing their beliefs about pain. Studies have shown that structural abnormalities like herniated discs are common in people without pain, suggesting that many imaging “findings” in back pain cases may be irrelevant—and may even reinforce suffering by validating a purely physical narrative.

Sarno's work underscores a deeper truth: belief can heal—or harm. Yet the mind-body connection remains undervalued in mainstream care, not because it lacks evidence, but because it resists the system's preferred tools of measurement and control.

Who's Paying Today?

The Third-Party Payer Problem

In most of U.S. healthcare, patients don't directly pay for care—third-party payers like insurance companies or government programs do. This disconnect severs the natural feedback loops that drive responsiveness and quality in other industries.

Clinicians are incentivized to document what's reimbursable, not necessarily what helps. Patients, meanwhile, are kept in the dark about costs until they face denial, debt, or financial crisis. The result is a system that manages to simultaneously deliver both overtreatment and neglect, while innovation and preventive care struggle to gain traction.

In most industries, the customer's needs are paramount. But in healthcare, the patient—the one with the most at stake—has the least control. "The patient is always right" sounds more like a punchline than a guiding principle. Patients don't decide what gets delivered or reimbursed. If a symptom doesn't match a code, the system often refuses to act—regardless of how real or debilitating the problem is.

This isn't how insurance works in most sectors—and for good reason. Unlike other forms of insurance, health insurance routinely covers expected expenses like checkups or minor treatments. This inversion inflates costs, bloats administrative layers, depersonalizes interactions, and fractures care delivery. The Affordable Care Act entrenched this model further by effectively banning most high-deductible, catastrophic-only plans and reinforcing employer-based coverage through mandates and incentives.

Returning economic agency to patients, as in any other market, would better align care with actual needs and expectations. Insurance should be a safety net, not the elephant in the room, weighing down every decision and relationship.

There's Gotta be a Law Against That

Regulatory and Privacy Barriers to Innovation

Despite growing access to tools and knowledge, patients, clinicians, and entrepreneurs navigate rules that suppress experimentation, adaptation, and innovation. Laws restrict what can be recommended, tested, or claimed—especially for supplements, repurposed drugs, or off-label uses. Even well-informed practitioners risk disciplinary action for suggesting unapproved but evidence-informed strategies.

Privacy laws, while important, also introduce friction. Real-world data is siloed, stripped of useful context, or locked away entirely—limiting pattern recognition and adaptive learning. When systems can't share insights safely or efficiently, even proven approaches remain isolated.

Many healthcare regulations are shaped more by economic interests than by patient safety. In some states, new clinics or hospitals must obtain permission from existing providers before opening—a process known as Certificate of Need (CON). Scope-of-practice laws limit what nurse practitioners, physician assistants, or alternative providers can do—often based on lobbying pressure rather than patient outcomes. These barriers are framed as safeguards, but in practice, they often protect incumbents and restrict access—especially in underserved or rural areas.

Compounding pharmacies illustrate these tensions vividly. They customize medications for patients with niche needs or ingredient sensitivities—offering alternatives when standard drugs aren’t appropriate. Yet they face ongoing scrutiny and regulatory pressure, often accused of operating too far outside standardized regulatory and production pathways. Pharmaceutical lobbying has pushed the FDA to restrict bulk ingredients and limit competition, even when patients benefit.

One of the most surprising legal barriers is the limits on free speech in medicine. Although the First Amendment protects free speech in most settings, those protections are significantly narrowed in healthcare. Medical speech—what clinicians say to patients—is treated as “professional speech” and is subject to licensing rules, liability risk, and regulatory oversight. Doctors can face consequences for diverging from guidelines, even when their recommendations are evidence-informed and carefully reasoned.

For example, some doctors have had their medical licenses revoked for prescribing long-term antibiotics in chronic Lyme—despite ongoing debate. Meanwhile, non-clinicians who share their experiences may be accused of “practicing medicine without a license.” Patients are told to advocate for themselves, yet both professionals and laypeople can face real or perceived constraints when trying to share what works. The result is a system that stifles innovation, enforces conformity, and paradoxically limits speech in the very place it’s most needed—where lives are at stake.

These rules discourage exploration in favor of rigidity. They may look defensible on paper—but in practice, they block adaptation, raise costs, and stifle personalized care. In complex cases, the result isn’t safety—it’s stagnation.

Rube Goldberg Would Be Proud

Public Policy and Structural Design

Our healthcare system is so complex and indirect, it often takes a dozen steps to accomplish what should be simple—yet still fails to deliver meaningful outcomes for many patients. Meanwhile, public discourse on healthcare policy has drifted toward rhetoric rather than evidence-based reform. Terms like “market failure” or “government failure” are often invoked without clarity or accountability—even by professionals.

Economic and systems thinking reveal how institutional design, incentives, and entrenched norms shape patient outcomes—often in ways that go unexamined or unchallenged. Empathy matters, but even the best intentions cannot succeed with poorly designed systems. Achieving outcomes that matter for patients requires clear economic analysis: aligning incentives with goals, minimizing unintended harm, and maximizing social welfare.

One major warning sign is widespread dissatisfaction. In a 2024 Gallup poll, only 44% of Americans rated the U.S. healthcare system as good or excellent—the lowest in two decades. This isn't just frustration; when trust erodes at this scale, it signals a structural failure to serve the public.

The Affordable Care Act accelerated consolidation. Small practices, squeezed by billing complexity and rate disparities, were absorbed by large hospital systems. Care grew more centralized, less personal, and often more expensive—while distancing decision-making from patients.

Single-payer advocates often ignore the stark structural problems already embedded in government-run programs. The U.S. government already accounts for half of all healthcare spending. Medicare is widely used and politically popular, yet financially precarious and often frustrates or disappoints those who rely on it most.

On the other hand, cost-cutting efforts that ignore outcomes aren't solutions—a system that's less expensive but still ineffective isn't efficient. It's just failing more cheaply.

Over time, attempts to fix the system have relied more on patchwork repairs than true redesign. Policy changes often react to prior failures, piling on new rules, mandates, or payment schemes that add complexity rather than resolve it. Each new patch attempts to address the latest harm or workaround—yet compounds the very dysfunction it aims to fix.

Radical simplification is both possible and necessary—through market reforms and simple, clear rules of the game. Markets are uniquely suited to match complex, individualized needs—something centralized systems consistently fail at. Emotional appeals like “grannie’s gonna die” often confuse efficiency with equity. Who bears what cost is a separate decision layer that deserves its own debate.

To fix a system this complex, we can't rely on slogans or top-down, one-size-fits-all reforms. Real change requires more than adjusting how much we spend—it demands asking how decisions are made: who holds power, who bears the burden, and what incentives shape decisions. Until policy is grounded in economic thinking and designed to align structural goals with real-world individual and societal outcomes, we'll keep adding parts to a machine that still runs—but not well.

What's the Point?

The Purpose of Healthcare

This leads to a deeper question: What is the purpose of healthcare? Is it to treat disease—or to optimize health? These goals sound similar, but lead in very different directions. The current system focuses on managing illness, not cultivating well-being. If you aren't sick you're "healthy" and mostly ignored.

Optimizing health would require different metrics, incentives, and questions. Instead of asking “What’s wrong?” the system would ask “What would help this person function better?”

Some argue this shift is too expensive. But that assumes the current system is cost-effective. In truth, it often delivers poor value—high costs with limited benefit. Prevention is almost always more cost effective than treatment, especially for chronic conditions. Supporting well-being could dramatically reduce long-term burdens and suffering. But this isn't the system we have now.

The Disease Popularity Contest

Limited Research Funding for Chronic, Multisystem Illnesses

Research funding often favors acute conditions with clear biomarkers or strong political advocacy. Chronic, complex illnesses like ME/CFS, MCAS, POTS, or fibromyalgia remain underfunded—not necessarily because they’re rare, but because they’re hard to define and advocate for.

In 2025, the NIH projected \$3.294 billion for HIV research, serving an estimated 1.2 million Americans—about \$2,745 per person. By contrast, Lyme disease affects an estimated 476,000 people annually in the U.S., yet combined federal research funding across NIH, CDC, and HHS LymeX totals about \$157 million—roughly \$330 per case. Given the likelihood of underdiagnosis, the true funding gap is likely even wider.

Because many chronic conditions are poorly coded or misdiagnosed, their actual prevalence remains unknown. Being underdiagnosed is not the same as being rare. Invisible conditions attract less funding, fewer trials, and delayed recognition—reinforcing a vicious cycle of neglect.

Public awareness and political attention drive funding priorities. Diseases with clear narratives and strong lobbies get studied; others stay in the shadows. The result is a silent epidemic of misunderstood illness—underfunded not because of lack of impact, but because of lack of visibility.

If All Else Fails

Patients Filling the Research Void

Patients are often the first to spot patterns across symptoms, triggers, and treatments—especially in online communities where information circulates faster than formal research. Yet mainstream medicine rarely integrates these lived insights, often dismissing them as anecdotal—even when they reveal consistent patterns. When patients discover something that works but lacks RCT-level evidence, they’re often ignored—even when standard treatments have failed. Ironically, many official guidelines are themselves based on limited data or expert opinion.

At the same time, physicians struggle to keep pace with emerging findings. Medical training emphasizes established consensus, but few systems help clinicians apply early signals or adapt care to real-world complexity. The gap between what patients discover and what doctors are prepared to recognize is growing.

This forces patients into unsupported experimentation—using supplements, alternative treatments, or restrictive diets. When guidelines lag behind lived experience, people are forced to self-navigate. Some are dismissed as noncompliant, when in fact they’re doing what the system hasn’t figured out how to support.

Promising hypotheses can also be sidelined for structural reasons. The “mycobacteria hypothesis” for rheumatoid arthritis, for instance, suggested that a persistent infection (MAP) could trigger autoimmunity. Despite some early evidence, the idea was largely abandoned—due to funding gaps, methodological challenges, and lack of commercial interest, especially when treatment might involve low-cost antibiotics instead of expensive biologics.

These are not isolated cases. Similar dynamics have stalled progress in ME/CFS, chronic Lyme, and inflammation-based models of psychiatric illness. Many potentially promising ideas don’t fade because they’re disproven—they fade because they’re inconvenient, hard to monetize, or fall outside disciplinary boundaries.

Meanwhile, access to the full body of medical literature remains limited. While some NIH-funded research is public, many studies are paywalled or scattered—hindering efforts by both patients and providers to follow evolving science.

The result is a system that rewards safety over adaptability, precedent over discovery. And in complex illness, that conservatism doesn’t just delay progress—it compounds suffering. These aren’t random failures. They’re structural patterns—emerging from a system that grew piecemeal over time and doesn’t handle complex patients well.

A Complex System Not Built for Complexity

Conclusion

This document is not an argument against healthcare professionals or the system's individual contributors. Every day, clinicians, researchers, and patients push against its limits with creativity and resilience. There are glimmers of progress—but these remain at the margins. The purpose here is not to spotlight the exceptions, but to define the terrain in which they operate: a landscape shaped by structural failures, blind spots, and misaligned incentives. These patterns must be understood before they can be addressed.

The irony is that these problems are symptoms of the medical system's own chronic dysfunction—despite its sophistication it is fundamentally ill-suited to handle complexity, uncertainty, and chronicity. The impact is enormous—not only for those who are medically lost, but for anyone whose needs don't fit the system's simple pathways. These failures manifest as delayed or missed diagnoses, ineffective or harmful treatments, and dismissive clinical encounters—realities that affect millions—often at their most vulnerable moments.

Some researchers have challenged the estimate, but a 2016 study published in the *British Medical Journal* estimated that medical errors are the third leading cause of death in the US, causing over 250,000 deaths each year. While these figures often highlight acute events—like surgical mistakes or incorrect medications—they also encompass broader systemic failures. Included (and likely undercounted) are diagnostic errors, fragmented care, and unrecognized complexity—situations where missed patterns and dismissed symptoms lead to delayed or ineffective treatment. The cost of these blind spots is not theoretical—it is paid for in lives.

With many interlocking root causes and reinforcing incentives and constraints, the medical system will not be easy to change. Yet there are signs of quiet progress: patient-led data sharing initiatives, affordable whole genome sequencing, the increasing use of AI-assisted pattern recognition, functional/integrative practices, complex illness clinics, and the growing popularity of care models that operate outside the insurance system—such as direct-pay or membership-based approaches. But realizing a more humane system will require structural reform and cultural humility. It must be willing to embrace complexity, learn from and evolve with it—and shift its focus from merely treating illness to actively optimizing health.

For all its sophistication, our medical system often fails those who do not fit predefined pathways. For those who are medically lost, the path becomes one of self-education, experimentation, and perseverance. They are not just patients—they are researchers, historians, and trailblazers of their own recovery. But they shouldn't have to navigate their journey *unseen, unheard, and alone*.

If this helped you feel seen or helped you understand the system more clearly, please share it with someone else who's still trying to make sense of their experience.