BEDHEAD

Why It Exists: A Patient-Led Design Rationale for Chronic Illness Self-Management

Why This Exists

People living with chronic illness are routinely expected to manage their own health with little to no support in doing so. Across conditions like ME/CFS, Long COVID, fibromyalgia, dysautonomia, autoimmune disease, and other fluctuating illnesses, patients are routinely expected to monitor symptoms, regulate activity, identify triggers, coordinate care across specialties, and avoid deterioration, all between appointments. Yet most patients are left without systems that actually help them do any of that.

Modern healthcare increasingly relies on patient self-management, and in principle that's not a bad thing. Many patients want more autonomy, more understanding of their conditions, more say in their care. The problem is that responsibility has been transferred to patients without an equivalent transfer of support. For people with long-term fluctuating conditions, most healthcare labour now happens outside clinical settings. It is a workload that is rarely acknowledged, let alone compensated.

They're told to pace themselves. Listen to their body. Reduce stress. Track symptoms. Manage energy. Advocate for themselves. None of this advice is necessarily wrong. The problem is it's delivered without practical frameworks for carrying it out while simultaneously experiencing fatigue, brain fog, pain, sensory overload, emotional exhaustion, and wildly fluctuating capacity.

The situation becomes especially brutal in illnesses involving uncertainty, delayed symptom exacerbation, or limited treatment pathways. Many healthcare systems are still structurally organised around acute episodic care, despite the increasing prevalence of chronic illness. Patients are left navigating long-term physiological instability in systems designed for short-term intervention. Welfare and financial support structures often follow the same pattern, compounding the stress at every turn.

BEDHEAD emerged from this gap. It's a low-friction behavioural and interpretive support system designed to help people navigate the practical realities of chronic illness adaptation over time. Research on chronic illness self-management consistently shows that successful adaptation depends on far more than information access: cognitive load, emotional regulation, self-efficacy, identity, and perceived control all shape outcomes (Audulv et al., 2009; Bandura, 1997; Lorig et al., 2006). The same research shows that people disengage from systems that feel demanding, clinical, shame-inducing, or disconnected from the realities of fluctuating illness (Kyngås, 2000; van Puffelen et al., 2019).

The underlying premise is simple: people living with chronic illness deserve systems designed around the realities of their lives, not systems that demand they constantly transcend them.

The Nature of Fluctuating Illness

One of the defining characteristics of many chronic illnesses is the collapse of predictable cause and effect. Symptoms fluctuate without obvious explanation. Physical, cognitive, emotional, or sensory activity can trigger delayed and disproportionate worsening, sometimes days later (NICE, 2021; National Academies, 2015). A person may feel relatively fine during an activity and crash badly afterwards, making it genuinely difficult to connect the dots.
Over time, this unpredictability alters a person's relationship with their own body. Many patients describe losing trust in their ability to read their own signals. Activities that once required no thought become loaded with risk assessment. Work, socialising, concentration, even emotional stress, all become physiologically consequential in ways that resist prediction.

Research consistently emphasises that fluctuating illness creates unique behavioural challenges precisely because the body itself becomes an unreliable feedback source (Audulv et al., 2009; Paterson, 2001). In stable systems, you act, get a result, and calibrate. In fluctuating chronic illness, outcomes are delayed, inconsistent, cumulative, and shaped by multiple overlapping variables. Sleep, stress, hormonal shifts, infection, sensory load, medication side-effects, emotional demand all interact in ways that make interpretation genuinely difficult.

This is how "boom and bust" cycles develop. Periods of relative energy encourage overexertion, followed by crashes that require prolonged recovery. It's not poor discipline. It's people trying to participate in normal life within systems that reward consistency and visibility while offering nothing for fluctuating capacity. BEDHEAD was designed around this nonlinearity. Rather than treating health as a stable baseline occasionally disrupted by symptoms, it assumes fluctuation is the default. That changes the purpose of tracking entirely, the goal is not to produce perfect daily consistency, but to support longitudinal pattern recognition across changing contexts and capacities. A single day rarely reveals much. Meaning usually emerges across weeks and months.

Why Existing Tools Fail

There's no shortage of tools designed to help people track symptoms, build habits, or manage their health. Many chronically ill people cycle through them and abandon them repeatedly. This is largely because these tools are made for sick people, not by them.

Digital health apps typically prioritise optimisation, automation, and continuous interaction. Log consistently. Respond to notifications. Maintain streaks. Interpret graphs. Navigate menus. All of this assumes stable cognition, reliable executive function, visual tolerance for screens, and sustained energy. For someone experiencing fatigue, brain fog, pain, or increased sensitivity, these assumptions break down fast. Research repeatedly shows that engagement and retention are major challenges in mobile health, particularly when apps are burdensome or poorly suited to their target population (Amagai et al., 2022; Kidman et al., 2024). Abandonment usually means the tool became another source of friction in an already overloaded life, a mere reminder of illness rather than something that eases its grip.

Symptom trackers tend to have a separate but equally serious problem: they collect data without supporting interpretation. Users accumulate disconnected information about sleep, pain, food, mood, and activity and come away no clearer on what any of it means. In conditions involving delayed exacerbation, isolated daily metrics reveal very little. A symptom only becomes meaningful when understood in context: What preceded it? Was it delayed? Did it repeat? Can it be recognized and alleviated next time? Was it connected to stress, sleep, sensory overload, food, hormonal shifts, emotional demand? Meaning emerges through longitudinal pattern recognition, and most tools offer no scaffolding for that.

Traditional medical diaries feel clinically sterile, designed for information extraction rather than emotional usability. Wellness planners present a different failure, they are built around optimisation, consistency, and upward progress, they tend to be glorified to-do lists. For someone with fluctuating illness, a planner designed around constant output can turn every crash into a visible personal failing, increasing anxiety and depression as a result.
BEDHEAD occupies the neglected space between clinical tracker, wellness culture, and productivity infrastructure. The priority is usability under reduced capacity. Analogue-first design reduces screen burden. Icon-based tracking reduces writing demand. Modular structure allows partial engagement. Humour and softer language reduce the clinical weight that makes so many tools feel exhausting or patronising. It is clearly built by someone living with illness, not merely designed for them.

Pacing as Literacy, Not Restriction

Pace yourself" might be the most common and least useful piece of advice given to people with energy-limiting conditions. Patients hear it constantly. Most have no real framework for what it means in practice, and it typically translates as "do less, if not nothing at all". Much of the language around chronic illness management has historically been shaped by ideas of compliance, adherence, and behavioural correction, reducing complex human adaptation to a simplified model of obedience. In many cases, successful pacing simply means not participating in social, work, or everyday life to any meaningful degree, with little emphasis on when to prioritise living over coping.

Audulv and colleagues describe self-management as an ongoing process of inner negotiation, not instruction-following (Audulv et al., 2009). People integrate illness into ordinary life through shifting patterns, competing priorities, and constant adaptation, juggling employment, caregiving, finances, relationships, social expectations, and emotional exhaustion simultaneously. "Non-compliance" is often not failure. It's someone attending an important event knowing there'll be a payback, or maintaining social connection because isolation is also harmful, or choosing meaning over perfect symptom minimisation. That's not irresponsible. It's human.

The instruction to pace is also particularly hard to apply in post-exertional conditions where exertion doesn't produce immediate feedback. A person may appear and feel functional during an activity while unknowingly accumulating physiological strain that only becomes visible later through crashes, worsening cognition, or prolonged recovery. When cause and effect are separated by hours or days, intuitive learning is simply not available. External scaffolding becomes necessary.

BEDHEAD treats pacing as behavioural literacy. The goal is building awareness of how the body responds to different kinds of exertion over time: physical, cognitive, emotional, sensory, and social. All of these carry costs, and most tracking systems only account for one. The journal's tracking systems, reflection prompts, graphs, and review structures support this interpretive process, helping users identify early warning signs, understand thresholds, trace delayed consequences, and recognise which activities carry disproportionate costs.

The concept of "energy loans" in the journal came directly from lived experience, acknowledging that people sometimes consciously borrow against tomorrow, and that this is a different thing from failing to pace. It's as important to do things despite limitations from time to time as it is to observe them. BEDHEAD rejects moralised pacing narratives accordingly: no punitive streak systems, no completion pressure, no framing of missed days as failures. Shame is one of the most reliable reasons people abandon self-management systems. The aim is a tool people can return to repeatedly without that weight and only when needed.

Designing for Lowest Capacity

Most health management systems are built around an implicit model of the ideal user, they're organised, cognitively clear, emotionally regulated, consistently motivated. Chronic illness disrupts all of that. A system that feels manageable on a good day may be completely inaccessible the next. For chronically ill users, low-capacity states are not edge cases to design around eventually. They are the central reality that determines whether a system survives long-term.

Icons, visual markers, stars, colour systems, and low writing-demand tracking all reduce the effort required to engage with the journal during exhaustion or cognitive impairment. Someone who cannot comfortably write paragraphs can still stamp or shade a circle, mark a symbol, or complete a visual rating. Research from art therapy and expressive therapies supports this: visual and symbolic processing often remains more accessible than extended verbal articulation during overwhelm or fatigue (Malchiodi, 2003; Hinz, 2009).
The modular structure reflects the same principle. Users are not expected to complete every section every day. Missing entries are not failure states. Partial use is still meaningful. This resists the perfectionism embedded in most productivity and wellness systems, where consistency equals success and any interruption equals failure.

Being analogue-first follows the same logic. Digital systems fragment attention through notifications, menus, pop-ups, blue-light, screen glare, and constant context-switching. Even simple interactions require sustained visual focus, fine motor control, working memory, and executive function.

For someone with brain fog or sensory sensitivity, that overhead accumulates quickly, and the apps sit alongside social media and entertainment, competing for whatever attention remains. Physically marking a page or colouring a graph is a categorically different kind of engagement. Research on handwriting and cognition suggests physical writing may support memory consolidation and reflective processing in ways screen-based interaction does not (Mueller & Oppenheimer, 2014).

There is also something meaningfully different about paper as an object. A journal exists in physical space, something you can pick up and turn through, rather than a folder buried inside a device. Leafing through weeks and months of entries creates a stronger sense of longitudinal reality, something chronic illness frequently erodes because day-to-day variability dominates attention and gradual change stays invisible. When an app helps you track your biometrics, it will always be, at best, a good app. When a journal helps you realise your triggers, come to terms with changed circumstances, and discover what actually works for you, the improvements belong to you. The individual has done the work. That sense of agency matters enormously in illnesses where patients so often feel that nothing is within their control, especially their treatment plans.

Preserving easy re-entry is part of all of this. Shame is what stops people coming back after a gap. The journal’s tone, structure, and framing all work to keep that door open.

Pattern Recognition and Feedback Loops

Symptoms in chronic illness often look fragmented and inconsistent when viewed in isolation. A single day tells you very little. Fatigue worsens without obvious explanation. Crashes seem to arrive from nowhere. Without longitudinal structure, many patients spend years trying to interpret complex physiological patterns using memory alone, often impaired memory at that.

Raw data without interpretation produces frustration rather than clarity. A symptom only becomes useful when understood in context. This is why the journal emphasises correlation over single-variable tracking. Daily tracking in BEDHEAD is intentionally lightweight, small consistent anchor points that feed into larger feedback loops across weeks and months. Those daily records become material for weekly reviews, which feed into monthly reflections, which slowly make patterns visible that were previously impossible to see.

Without that structure, symptom monitoring can collapse into hypervigilance, obsessive scanning for deterioration that generates anxiety rather than insight. Research on rumination suggests that repetitive self-monitoring without resolution worsens distress over time rather than reducing it (Nolen-Hoeksema et al., 2008). Chronic illness creates ideal conditions for exactly this as symptoms are unpredictable, uncertainty is constant, and people are often left trying to retrospectively interpret crashes and flares without clear answers. The journal attempts to externalise some of that processing through writing, tracking, grounding, and structured reflection, rather than leaving it to circulate as endless internal analysis. Observation is balanced with containment, tracking is orientation rather than control, with consistent prompts to notice the positives at least as much as the negatives.

Emotional Processing, Identity, and Dignity

Chronic illness is often framed primarily in terms of symptoms and physical limitations. People living with long-term illness frequently describe the emotional consequences as equally disruptive. Illness alters identity, relationships, future plans, self-trust, financial stability, and social participation. It frequently disrupts a person's entire sense of continuity with their previous life.

Michael Bury described chronic illness as "biographical disruption", a fundamental interruption of previously assumed narratives about the self and the future (Bury, 1982). People grieve former versions of themselves while adapting to bodies that no longer behave predictably. The grief is often subtle, expressed as reduced spontaneity, shrinking participation, fear of commitment, the slow narrowing of what feels possible. A great many chronically ill people also spend significant energy questioning whether their symptoms are "real enough," whether they are overreacting, whether they can trust their own perceptions, especially after any cases of medical gaslighting. Research across ME/CFS, fibromyalgia, and medically contested illness consistently shows that invalidation significantly worsens emotional distress, self-doubt, and isolation (Charmaz, 1991; Nettleton, 2006).

Beyond the inner experience, illness reshapes how people understand themselves socially and relationally. Employment, friendships, education, intimacy, hobbies, and financial independence all shift simultaneously. The situation is compounded by invisibility. Many chronically ill people look healthy while privately managing exhaustion, pain, dizziness, cognitive dysfunction, and post-exertional crashes, which produces constant pressure to prove the legitimacy of illness or maintain appearances of normality. When someone does muster the energy to re-engage socially, ordinary small talk forces the issue. "How are you?" "What have you been up to?" "What do you do for work?" Each question asks the individual to explain, and sometimes defend, the very illness they were hoping to get a break from. The problem of illness becoming a parasitic identity, a mask that cannot be shaken off, is a critical point that clinical and medical literature tends to overlook. Too often, patients forced to fight for a diagnosis commit thereafter to defending it rather than moving beyond it. There is little more detrimental to well-being and recovery than concluding that "I AM sick" rather than "I HAVE such and such condition." Research on chronic illness and disability shows that visibility and social legitimacy significantly shape adaptation (Charmaz, 1991; Livneh & Martz, 2012). Healthcare systems and society more broadly often reinforce psychologically damaging identities that actively work against recovery.

BEDHEAD treats emotional responses as legitimate consequences of living inside unstable physiological conditions and fragmented care systems, not as secondary problems to manage around the "real" illness. Fear, grief, shame, frustration, uncertainty, guilt, boredom, and loneliness belong in the picture. The journal's tone uses softness, humour, reflective prompts, and moments of irreverence deliberately. Humour in particular functions as emotional regulation within chronic illness communities, a way of acknowledging suffering without being fully consumed by it. Creativity, small pleasures, identity, relationships, and meaning sit alongside symptom tracking throughout. These are not extras. They are central to sustaining psychological wellbeing under reduced capacity.

The Body, the Nervous System, and Creativity

Modern healthcare often treats the body as an object: measurable, diagnosable, repairable. Chronic illness reveals the limits of that framing. Illness is not experienced abstractly; it is lived. Drawing on phenomenological philosophy, Merleau-Ponty understood the body not as an object a person has, but as the very medium through which they inhabit and engage with the world (Merleau-Ponty, 1945). Chronic illness alters this medium. Space, time, movement, effort, attention, and possibility all begin to feel different. Things that healthy bodies navigate without conscious thought become charged with calculation.

After years of fluctuating symptoms, many patients describe their bodies as unpredictable, unreliable, or alien. The body becomes unusually visible to consciousness, and that constant bodily awareness is exhausting. Over time, many people become trapped between two unhelpful extremes, either ignoring bodily signals in order to function socially, or being consumed by anxious monitoring of every sensation. BEDHEAD’s grounding prompts, pacing reflections, breathing exercises, sensory awareness tools, and body-based check-ins all try to support a middle ground of gentle observation.

Attending to nervous system regulation is part of this. Many chronically ill people develop patterns of anticipatory vigilance. Compassion-focused therapy describes how many people become trapped oscillating between threat-drive (push through, produce, keep up) and collapse (crash, withdrawal, shame) without adequate access to restorative states (Gilbert, 2010). This maps precisely onto boom-and-bust chronic illness patterns.

Rest itself is often psychologically complicated for chronically ill people, as many feel guilty or ashamed when not being productive, meaning rest may not actually be restorative if the nervous system remains in a threat state. The glorification of productivity that runs through modern culture needs to be carefully dismantled before real rest becomes possible. The BEDHEAD Beditations and grounding tools were developed from this understanding. They do not claim that nervous system work resolves serious illness. They offer practical support for reducing unnecessary additional strain, so that whatever capacity a person has is less consumed by the overhead of being unwell.

Experience is also not only processed through analytical reasoning. Emotional states, bodily awareness, stress, memory, and identity are processed symbolically, visually, spatially, and this becomes especially important during fatigue, overwhelm, or cognitive dysfunction when sustained verbal articulation is difficult. Stars for sleep quality, shading for mood, circles, stickers, colour graphs: these are not decorative. They externalise experience, reduce cognitive load, and provide lower-pressure ways of engaging with difficult realities. Research from art therapy supports this: visual and symbolic interaction can create exploratory space where people engage with difficult emotions more accessibly than through direct verbal confrontation (Winnicott, 1971; Malchiodi, 2003). Humour functions similarly. Naming difficult experiences creatively makes them easier to approach, discuss, and integrate. It does not trivialise illness. It makes it less relentlessly heavy.

The Hybrid System: Journal and Website

BEDHEAD was always designed as a hybrid system rather than a standalone journal. Single-platform health technologies tend to become cognitively dense and emotionally exhausting over time. BEDHEAD separates daily low-friction interaction from heavier informational and analytical work.

The journal handles daily tracking, reflection, orientation, symbolic interaction, and embodied engagement. The website handles health literacy, resource navigation, calculations, extended explanation, reference material, and larger-scale pattern interpretation. The division is deliberate as forcing all self-management into a single environment creates unnecessary overload for people whose cognitive capacity fluctuates day to day.

Chronic illness patients are often expected to make complex decisions using fragmented, inaccessible, or contradictory information. Medical terminology is unfamiliar. Healthcare systems are difficult to navigate. Online health information varies wildly in quality. People are trying to process all of this while fatigued, cognitively impaired, or emotionally depleted. Health literacy is not simply the ability to read medical information; it is the ability to meaningfully interpret, contextualise, remember, and apply it within daily life (Bodenheimer et al., 2002; Lorig et al., 2006).

The Groundworks sections of the journal and guides/tools on the website emerged from this. Rather than functioning as a medical authority, they offer accessible orientation frameworks and practical interpretive tools. Sleep, nutrition, hydration, pain, gut health, nervous system regulation, medication literacy, movement, and pacing are approached without rigid prescriptions, because chronic illness populations are physiologically heterogeneous and what helps one person worsens symptoms for another.

Tools like the Stats Calculator emerged from recognising that many chronically ill people struggle to identify trends across long time horizons while managing fatigue and cognitive dysfunction. Tests & Scans, Functional Assessment Finder, Medication Literacy, Vitamindex, and the healthcare navigation guides all address recurring informational barriers in the same spirit: patients leaving appointments not knowing what a test measured, why it was ordered, or how to prepare for the next consultation.

The website is designed to be entered when useful, not to demand constant interaction. No log-in, no streaks, no notifications, no behavioural nudges. The analogue journal stays lightweight and approachable while the digital tools remain optional. Together they create a feedback loop: daily experience becomes observable pattern, pattern supports interpretation, and interpretation informs adaptation.

Contextual Realities, Communication, and Patient-Led Design

One of the least visible burdens of chronic illness is communication. Many patients spend years trying to translate fluctuating, hard-to-describe experiences into forms that clinicians, family, and employers can understand, often compressed into a 15-minute appointment while fatigued, in pain, possibly after travelling, while simultaneously trying to remember everything that has happened since they were last seen. Research consistently shows that communication quality shapes patient outcomes, trust, and emotional wellbeing (European Observatory, 2016).

When that communication repeatedly breaks down, it worsens care quality and erodes self-trust alike. The journal's tracking systems and longitudinal structures are designed partly for communication as much as for private self-observation. Patterns recorded over time help users explain to clinicians what worsens symptoms, how long recoveries take, what functional limitations actually look like, and how things fluctuate contextually. The aim is to give people better raw material for conversations that often feel one-sided or rushed.

Self-management advice also frequently focuses on individual behaviour while underestimating the structural conditions surrounding it. People are encouraged to rest more, pace better, reduce stress, without enough acknowledgement that many are attempting this while in insecure employment, unstable housing, with caregiving responsibilities, without adequate transport, or without social support that accommodates fluctuating capacity. Research consistently demonstrates that health outcomes are deeply shaped by social determinants: poverty, housing insecurity, social exclusion, and unequal access to care (Marmot et al., 2020; European Observatory, 2016). The journal and website include sections on financial stress, welfare systems, workplace adaptation, shared living, and mobility supports because these factors determine whether self-management strategies are practically implementable at all. Administrative and systemic navigation is treated as cognitive labour that deserves support, not a separate burden to figure out alone.

BEDHEAD emerged from lived experience rather than from clinical or institutional frameworks applied retrospectively to chronic illness populations. This matters because patient-led design changes what problems become visible in the first place. Many healthcare technologies are designed from provider perspectives and therefore prioritise metrics like compliance, efficiency, and symptom reduction, while overlooking the forms of friction that dominate daily life for chronically ill people: cognitive overload, pacing guilt, the psychological cost of constant self-monitoring, etc. These realities stay invisible unless the designers are living them. Working from lived experience also changes assumptions about authority. BEDHEAD does not treat users as passive recipients of expert instruction. People living continuously inside illness observe patterns across months and years that institutional systems simply do not capture, and that experiential knowledge is treated here as genuine expertise. It does not replace scientific or medical knowledge; it complements and corrects it. The project is also explicitly iterative, not a finished solution or a universal framework. Chronic illness populations are heterogeneous, and adaptation varies across diagnoses, cultures, environments, and individual needs.

Chronic illness frequently disrupts the continuity between body, memory, identity, behaviour, time, and future planning. Several writers across chronic illness phenomenology describe this as a disruption of coherence itself (Bury, 1982; Charmaz, 1991; Frank, 1995). BEDHEAD attempts to intervene gently in that fragmentation: helping people notice patterns, externalise memory, reduce cognitive friction, communicate more clearly, and reconnect experiences across time. It does not promise control over illness. In many cases, control is simply not available. What it offers is reduced confusion, clearer orientation, and a framework for living inside uncertainty with more self-knowledge and less unnecessary suffering. It is not fundamentally about journaling. It is about creating a gentler interface between people and the realities they are already living inside.

References

- Amagai, S., Pila, S., Kaat, A. J., Nowinski, C. J., & Gershon, R. C. (2022). Challenges in participant engagement and retention using mobile health apps. Journal of Medical Internet Research, 24(4), e35120.
- Audulv, Å., Norbergh, K. G., Asplund, K., & Hörnsten, Å. (2009). An ongoing process of inner negotiation. Journal of Nursing and Healthcare of Chronic Illness, 1(4), 283–293.
- Bandura, A. (1997). Self-efficacy: The exercise of control. W. H. Freeman.
- Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient self-management of chronic disease in primary care. JAMA, 288(19), 2469–2475.
- Bury, M. (1982). Chronic illness as biographical disruption. Sociology of Health & Illness, 4(2), 167–182.
- Charmaz, K. (1991). Good days, bad days: The self in chronic illness and time. Rutgers University Press.
- European Observatory on Health Systems and Policies. (2016). Assessing chronic disease management in European health systems.
- Frank, A. W. (1995). The wounded storyteller. University of Chicago Press.
- Gilbert, P. (2010). Compassion focused therapy. Routledge.
- Hinz, L. D. (2009). Expressive Therapies Continuum. Routledge.
- Kidman, P. G., Curtis, R. G., Watson, A., & Maher, C. A. (2024). When and why adults abandon lifestyle behavior and mental health mobile apps. Journal of Medical Internet Research, 26, e56897.
- Kyngås, H. (2000). Compliance of adolescents with chronic disease. Journal of Clinical Nursing, 9(4), 549–556.
- Livneh, H., & Martz, E. (Eds.). (2012). Coping with chronic illness and disability. Springer.
- Lorig, K., Holman, H., Sobel, D., Laurent, D., González, V., & Minor, M. (2006). Living a healthy life with chronic conditions (3rd ed.). Bull Publishing.
- Malchiodi, C. A. (Ed.). (2003). Handbook of art therapy. Guilford Press.
- Marmot, M., Allen, J., Boyce, T., Goldblatt, P., & Morrison, J. (2020). Health equity in England: The Marmot Review 10 years on. Institute of Health Equity.
- Merleau-Ponty, M. (2012). Phenomenology of Perception (D. A. Landes, Trans.). Routledge. (Original work published 1945)
- Mueller, P. A., & Oppenheimer, D. M. (2014). The pen is mightier than the keyboard. Psychological Science.
- National Academies of Sciences, Engineering, and Medicine. (2015). Beyond myalgic encephalomyelitis/chronic fatigue syndrome. National Academies Press.
- National Institute for Health and Care Excellence. (2021). ME/CFS: Diagnosis and management (NICE guideline NG206).
- Nettleton, S. (2006). I just want permission to be ill. Social Science & Medicine, 62(5), 1167–1178.
- Nolen-Hoeksema, S., Wisco, B. E., & Lyubomirsky, S. (2008). Rethinking rumination. Perspectives on Psychological Science, 3(5), 400–424.
- Paterson, B. L. (2001). The shifting perspectives model of chronic illness. Journal of Nursing Scholarship, 33(1), 21–26.
- van Puffelen, A. L., et al. (2019). Effectiveness of a self-management support program for type 2 diabetes. PLOS ONE, 14(6), e0218242.
- Winnicott, D. W. (1971). Playing and reality. Tavistock.