

# Living with Dysautonomia: A Narrative-Clinical Case Study of Autonomic Dysfunction and Lived Experience

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## Key Messages

- Dysautonomia is a complex, multisystem condition with major consequences for function and quality of life.
- Narrative medicine adds clinically meaningful insight that is often missed by conventional symptom reporting alone.
- Poetic reflection can serve both as qualitative data and as a therapeutic mode of meaning-making.
- Integrating patient voice into assessment and care planning may improve empathy, diagnostic awareness, and person-centred care.

## Abstract

**Background:** Dysautonomia represents a heterogeneous group of disorders affecting the autonomic nervous system (ANS), resulting in widespread, multisystem dysfunction. Despite increasing clinical recognition, patients frequently encounter diagnostic delays, fragmented care, and limited acknowledgment of their lived experience.

**Aim:** This paper explores the lived experience of dysautonomia through an integrated narrative-clinical lens, using poetic reflection as qualitative data to illuminate symptom burden, disease progression, and adaptive coping.

**Design:** A qualitative case study methodology was employed, incorporating a longitudinal series of 30 rhyming couplets authored by the patient. These poetic reflections were thematically analysed and aligned with established clinical literature across neurological, autonomic, neuromuscular, and psychological domains. This narrative medicine approach bridges subjective experience with biomedical understanding.

**Results:** The poetic corpus revealed pervasive symptomatology, including cognitive dysfunction, chronic fatigue, orthostatic intolerance, gastrointestinal and urological dysregulation, sensory hypersensitivity, and emotional instability. These findings align closely with clinical features of postural orthostatic tachycardia syndrome (POTS), pure autonomic failure (PAF), and related dysautonomic conditions. Psychological comorbidities - including anxiety, depression, and insomnia - emerged as significant amplifiers of disease burden. Despite these challenges, the patient demonstrated resilience through creative expression, spiritual grounding, and adaptive coping strategies.

**Conclusion:** This case study highlights the complexity and multidimensional burden of dysautonomia. Narrative and poetic expression provide a valuable adjunct to clinical discourse, enhancing empathy, diagnostic awareness, and person-centred care. Integrating patient voice into clinical frameworks is essential for advancing both understanding and treatment of chronic autonomic disorders.

**Keywords:** IDysautonomia, Autonomic Dysfunction, Narrative Medicine, POTS, Chronic Illness, Patient Experience

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## 1. Introduction

Dysautonomia encompasses a spectrum of disorders characterised by dysfunction of the autonomic nervous system, which regulates involuntary physiological processes including cardiovascular control, digestion, thermoregulation, and bladder function. Although increasingly recognised within clinical practice, dysautonomia remains underdiagnosed and frequently misunderstood, often leading to prolonged patient distress and fragmented healthcare journeys [1,2]. This paper presents a narrative-clinical case study, utilising poetic self-expression as a form of qualitative data. Through rhyming couplets, the patient articulates the lived experience of dysautonomia over time. These reflections are analysed alongside established medical literature, offering a dual lens: one scientific, the other deeply human. This integration reflects the principles of narrative medicine, where storytelling becomes a vehicle for clinical insight and compassionate care.

## 2. Neurological and Sensory Dimensions

Cognitive impairment - often described as "brain fog" - is a hallmark of dysautonomia and is prominently reflected in the patient narrative: Cognitive fog, it is hard to think clear, Mood swings and memory problems that bring fear. Such symptoms are frequently associated with cerebral hypoperfusion and autonomic instability, impairing executive function, attention, and memory [3]. Visual disturbances and sensory hypersensitivity further compound functional impairment: *My vision blurs, and lights are too bright, Sensitivity that's causing quite a fight.*

Emerging research suggests that neuroinflammatory processes and dysregulation of vagal-sympathetic balance may contribute to these sensory phenomena, reinforcing the need for interdisciplinary investigation and management.

The patient describes persistent musculoskeletal pain, weakness, and involuntary contractions:

*Spasms strike, and I feel so tight,*

*Muscle contractions that just will not take flight.*

*My muscles weaken, it is hard to stand,*

*Loss of strength that's taking over my hand.* These features are consistent with autonomic neuropathy, where impaired vascular regulation leads to reduced perfusion of skeletal muscle, contributing to fatigue, pain, and decreased endurance. Such symptoms significantly limit mobility and independence, underscoring the systemic nature of dysautonomia.

## 3. Autonomic Dysfunction Across Systems

A defining characteristic of dysautonomia is its multisystem impact, evident throughout the patient's account.

### 3.1. Cardiovascular Instability

*Supine hypertension...*

*Orthostatic hypotension...*

*These contrasting states reflect impaired autonomic regulation of vascular tone and heart rate, central to conditions such as POTS and PAF.*

## 3.2. Gastrointestinal and Urological Dysfunction

*Bowel dysfunction...*

*Diarrhea's urgency...*

*Bladder dysfunction...*

*Urgency that's hard to bear...*

These symptoms are attributable to disrupted parasympathetic and sympathetic signalling, affecting motility, continence, and visceral regulation.

### 3.3. Respiratory and Systemic Symptoms

Shallow breathing, sinus congestion, and fluctuating appetite further illustrate the pervasive reach of autonomic imbalance.

### 3.4. Psychological and Emotional Burden

The psychological impact of dysautonomia is profound and often under-recognised:

*Anxiety's grip...*

*A constant worry that's always haunting me.*

*Depression creeps in...*

*Loss of interest...*

Autonomic dysfunction directly influences emotional regulation through its interaction with limbic and cortical systems. Additionally, the unpredictability of symptoms contributes to chronic stress, reinforcing cycles of anxiety and fatigue.

Sleep disturbance is another critical factor:

*Sleepless nights...*

*Insomnia is my constant friend.*

Disrupted sleep further exacerbates cognitive and emotional instability, creating a reinforcing cycle of decline.

## 4. Disease Progression and Adaptation

The patient describes dysautonomia as a dynamic and fluctuating condition:

*Symptoms ebb and flow, like the ocean's tide...*

This unpredictability is characteristic of many autonomic disorders and presents challenges for both diagnosis and management. Despite this, the narrative also reflects adaptation and resilience: Resilience grows as I face each new test, Learning to navigate, doing my best. Management strategies - supported by current literature - include hydration, salt supplementation, compression therapy, graded exercise, and pharmacological interventions. Increasingly, holistic approaches incorporating psychological support, nervous system retraining, and spiritual coping mechanisms are recognised as essential components of care.

## 5. Discussion

This case study demonstrates that dysautonomia is not merely a physiological disorder but a deeply lived, multidimensional experience affecting body, mind, and identity.

The integration of poetic narrative provides:

- Enhanced clinical insight into symptom complexity
- Emotional depth often absent in standard reporting
- A patient-centred framework for understanding chronic illness

Narrative medicine, as demonstrated here, offers a valuable tool for bridging the gap between clinical objectivity and human experience. For clinicians, it reinforces the importance of listening - not only to symptoms, but to stories [4-7].

## 6. Conclusion

Living with dysautonomia is characterised by uncertainty, systemic disruption, and profound personal challenge. Yet, within this experience lies resilience, adaptation, and meaning-making.

This paper affirms that:

- Dysautonomia requires multidisciplinary, person-centred care
- Patient narratives are essential to clinical understanding
- Creative expression can serve as both data and therapy

By honouring the patient voice, medicine moves closer to its deepest purpose: not only to treat disease, but to understand the person who lives with it.

## Declarations

Ethics Approval and Consent to Participate: Not applicable.

Consent for Publication: The author consents to publication.

Competing Interests: The author declares no competing interests.

Funding: No external funding was received.

Author Contributions: Sole author.

## Patient Contribution Statement

The author is the patient and sole contributor to this study, providing both the lived experience and the narrative data through original poetic reflections. This dual role enables an integrated perspective that combines subjective experience with clinical interpretation.

### • Implications for Practice

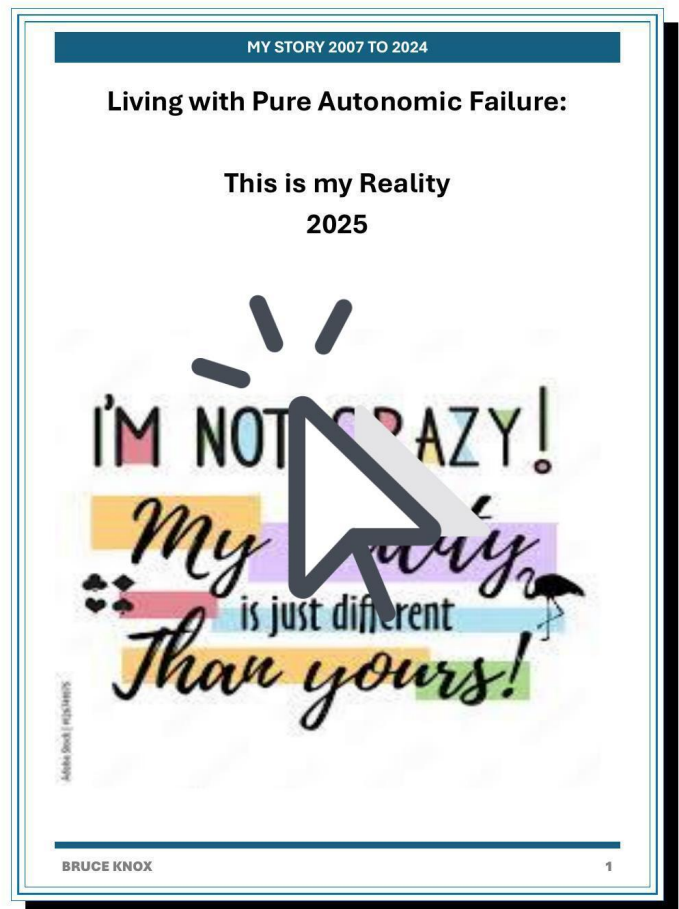
Clinicians should recognise dysautonomia as a multidimensional condition requiring integrated, multidisciplinary care approaches that address both physiological and psychosocial domains. Incorporating patient narratives into clinical assessment can enhance diagnostic accuracy, therapeutic alliance, and personalised care planning. Creative and reflective modalities may also serve as valuable adjuncts in supporting patient coping, resilience, and long-term disease management.

### • Segue Bridge: Introducing the Songs as Lived Science

The following collection of songs and lyrical reflections emerges not as artistic embellishment, but as an extension of lived clinical experience. In the context of pure autonomic failure (PAF) and its potential progression toward broader neurodegenerative conditions, these pieces function as narrative data - capturing symptom evolution, physiological disruption, and psychosocial impact in a form that complements traditional biomedical discourse. Music and poetry offer a unique interpretive lens through which the complexity of autonomic dysfunction can be communicated. Each song reflects a specific dimension of dysautonomia: cardiovascular instability, gastrointestinal dysmotility, thermoregulatory failure, neurogenic pain, cognitive impairment, and emotional burden. Together, they provide a phenomenological account that aligns

closely with established clinical descriptions while rendering visible the often-invisible burden of disease. What follows, therefore, is not simply a creative appendix, but a patient-centred narrative framework - where art and science converge to deepen understanding, foster empathy, and illuminate the realities of living with autonomic failure.

In these songs, the science of dysautonomia is not diminished - it is humanised, not simplified - it is embodied, and not concluded - it continues to unfold in the lived experience of the patient. To listen to this musical collection, please navigate to the final page where you will find the cover page for the selection housed in Hazen. Simply click on the arrow or the link at the bottom of the page to open the music. To turn the page, click on the right-hand corner, the music will begin to play. Then, turn the next page for the following song. Enjoy!



### • Brief Medical and Scientific Commentary on Each Song Welcome to Collection of Personal Song and Rhyme

This opening piece frames autonomic neuropathy as a disorder of disrupted neural signalling within the autonomic nervous system, affecting cardiovascular, gastrointestinal, and thermoregulatory control. It reflects the educational intent of the collection, aligning with the need for improved patient and clinician awareness of rare dysautonomias.

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- **Introducing Rare Disorders**

Rare disorders such as PAF often suffer from delayed diagnosis and limited healthcare pathways, despite affecting significant populations collectively. The song highlights the public health challenge of under-recognition and the need for coordinated systems of care and advocacy.

- **Each Night**

This piece reflects gastroesophageal and laryngopharyngeal dysfunction, common in autonomic failure due to impaired vagal control. Symptoms such as reflux, dysphagia, and nocturnal airway discomfort arise from dysmotility and reduced sphincter coordination.

- **My Hip**

Musculoskeletal pain in dysautonomia may arise from altered posture, deconditioning, or neuropathic mechanisms. This narrative also reflects the importance of biomechanical factors (e.g., limb length discrepancy) that may coexist with or exacerbate neurological conditions.

- **The Ballad of Progression Steps**

This song chronicles a longitudinal clinical trajectory, illustrating how autonomic dysfunction can evolve over time following triggers such as viral illness or surgical interventions. It captures hallmark features including orthostatic hypotension, urogenital dysfunction, and cardiovascular instability, consistent with progressive autonomic neuropathy.

- **Autonomic Progression 2007-2024**

Here, the focus is on the gradual loss of autonomic regulation, particularly baroreflex failure, leading to fluctuating blood pressure, tachycardia, and impaired homeostasis. The description aligns with known pathophysiology of neurogenic orthostatic hypotension and dysregulated cardiovascular control.

- **Progression Symptoms**

This piece provides a systems-based overview of dysautonomia, including cognitive impairment (brain fog), gastrointestinal dysmotility, bladder dysfunction, and thermoregulatory instability. It reflects the multisystem burden characteristic of advanced autonomic failure.

- **Progression Impact on Emotions**

Neuropsychiatric symptoms such as anxiety, depression, and emotional lability are common in chronic autonomic disorders. These may arise both from central nervous system involvement and the psychological burden of living with a progressive,

unpredictable condition.

- **My Stage 3 Lament**

This lament reflects advanced autonomic failure, where widespread dysregulation affects multiple organ systems. Clinically, this stage is associated with significant functional impairment, reduced quality of life, and increasing dependence on supportive care.

- **Progression PAF to MSA**

Pure autonomic failure may, in some cases, precede multiple system atrophy (MSA), a neurodegenerative synucleinopathy. The song captures this uncertainty and the clinical reality that early autonomic symptoms can evolve into more complex neurological syndromes.

- **My Stage 3 Celebration**

Despite disease progression, this piece reflects resilience and adaptive coping. From a clinical perspective, it underscores the importance of rehabilitation, exercise, and psychosocial support in maintaining function and wellbeing in chronic autonomic disorders.

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