

## Four Years On Stabilisation, Residual Deficits, and Reframed Prognosis After Multifactorial Secondary Dysautonomia

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Submitted: 2026, Mar 27; Accepted: 2026, Apr 20; Published: 2026, Apr 30

**Citation:** Knox, B. H. (2026). Four Years On Stabilisation, Residual Deficits, and Reframed Prognosis After Multifactorial Secondary Dysautonomia. *Adv Neur Sci*, 9(2), 01-03.

### Abstract

#### Executive Summary

Four years after the final autonomic insult, recovery is best characterised as **functional stabilisation with persistent reserve limitation**, rather than restoration of premorbid physiology. Cardiovascular and gastrointestinal autonomic systems have re-established coherence sufficient to support daily life. However, **energy availability, autonomic reserve, and precision-dependent functions (notably bladder coordination)** remain compromised.

Importantly, what was once interpreted as progressive autonomic failure is now understood—mechanistically and longitudinally—as **multifactorial secondary dysautonomia arising from cumulative injury**, with a prognosis defined by stabilisation and adaptation rather than neurodegeneration.

The following link goes to the musical performance of my lyrics, which capture the story and what it has felt like.  
<https://heyzine.com/flip-book/ffbee87bbb.html>

### 1. What Has Gone Right: Meaningful Gains at Four Years

#### Cardiovascular Stability

- Severe orthostatic hypotension has markedly reduced
- Syncope and collapse are now rare
- Blood pressure corrections occur reliably, though more slowly than normal
- Heart rate regulation has regained flexibility and sinus rhythm stability

#### Interpretation:

This reflects **partial baroreflex reintegration**, not perfection — but enough to remove “cliff-edge” physiology and restore upright life.

### 1.2. Gastrointestinal Autonomic Function

- Motility is predictable and manageable with treatment
- Flares occur but are contained
- Gut instability no longer triggers whole-system crashes

#### Interpretation:

Visceral stability now supports autonomic balance rather than undermining it.

### 1.3. Cognitive and Psychological Recovery

- Autonomic anxiety loops have quietened
- Cognitive clarity returns when physiology is supported
- Hypervigilance has been replaced by **attentiveness and confidence**

This represents not resignation, but **mastery through understanding**.

### 2. What Is Still Not Up to Scratch — and Why That Matters

#### A. Persistent Loss of Systemic Reserve

The defining long-term deficit is reduced autonomic and metabolic reserve.

- Stability exists at baseline
- Capacity for stress remains limited
- Heat, illness, poor sleep, overexertion, or cortisol demand spikes still expose vulnerability

#### Key Principle:

Stability allows life to continue.

Reserve determines how fully it can be lived.

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## B. Progressive Fatigue Despite Stabilisation

Fatigue has become **more prominent**, not less, as recovery has progressed.

This is not relapse. It reflects:

- Increased metabolic cost of upright and cognitive function
- Blunted neuroendocrine (HPA-axis) responsiveness
- Inability to rapidly restore homeostasis after exertion

Energy is **usable but not freely spendable**. Overreach produces delayed, multi-day payback rather than immediate collapse.

## C. Late-Emerging Bladder Dysfunction

Lower urinary tract symptoms have worsened during systemic stabilisation:

- Voiding hesitancy
- Incomplete emptying
- Post-void dribbling

### Mechanism:

Persistent autonomic–somatic dyssynergia with incomplete recovery of sacral parasympathetic coordination.

### Crucially:

This reflects **precision failure**, not deterioration. Bladder control is a high-order autonomic task and often recovers last — or incompletely — in low-reserve systems.

## 3. Why These Problems Appear After Things Improve

During early illness:

- Activity is constrained
- Demand is low
- Deficits are masked

During recovery:

- Upright time increases
- Cognitive and social engagement return
- Environmental exposure expands

This **unmasks the true energetic ceiling** of the system. Fatigue and bladder dysfunction become dominant *because other systems are now stable enough to allow demand*.

## 4. The Critical Reframing: From “Progression” to “Accumulation”

Earlier interpretation assumed pure autonomic failure — a progressive neurodegenerative model.

What is now clear is a **three-hit cumulative injury model**:

- Viral autonomic and cardiac injury
- Cardiac tamponade
- Open heart surgery

The catastrophic instability of 2022–2023 represented **delayed autonomic collapse following cumulative trauma**, not ongoing degeneration.

This distinction changes everything:

- Prognosis
- Expectations
- Management priorities
- Psychological burden

Secondary dysautonomia stabilises and adapts. It does not

inexorably decline once insults cease.

## 5. Integrated Prognosis Going Forward

What Is Likely

- Continued stability rather than deterioration
- Gradual, modest improvements in buffering and predictability
- Independence maintained with pacing and respect for limits

What Is Unlikely

- Neurodegenerative conversion
- Escalating autonomic failure
- Loss of independence driven by dysautonomia alone

Recovery is **maintained, not completed**.

## 6. What This Means in Real Life

Four years on:

- Life is livable, plan-able, and meaningful
- Medical crises are rare
- Function is reliable within known limits

But:

- Margins remain thin
- Energy must be stewarded
- Precision systems (fatigue regulation, bladder control) lag behind stability

This is not failure.

It is the honest footprint of survival after cumulative autonomic injury.

## 7. Closing Synthesis

This report documents a nervous system that has reorganised rather than collapsed.

Stability has replaced chaos.

Function has replaced fragility.

Understanding has replaced fear.

What remains imperfect is real — and deserves acknowledgement.

What has improved is substantial — and deserves recognition.

Four years on, this is not cure.

But it is recovery.

**Four Year Outcomes [The big picture that tells the story and the impact upon my body over a four year journey]**

<https://heyzine.com/flip-book/ffbee87bbb.html>

Four years on...

Four years on.

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There were three hits—

Not one sudden fall,

But three hard moments

That asked too much

Of one body.

Heart.

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Gut.  
Pressure.  
Strength.  
And when they had passed,  
The body had no shield left.

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Standing was danger.  
Stillness was waiting.  
Every step  
Was a question.  
Waiting... waiting...  
Fear stood where confidence once lived.

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The heart forgot its rhythm.  
It rushed.  
It paused.  
It searched.  
It searched...  
Then slowly—  
It remembered how to listen.

---

This is not the body I had,  
But it is the body I live in now.  
Not broken. Not lost.  
Learning balance.  
Learning truth.

---

The balance that once failed  
Did not disappear forever.  
Slowly... slowly...  
Corrections came late—  
But they came.  
And falling became steadier ground.

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Recovery was never  
Becoming who I was before.  
Never before.  
It was becoming steady.  
It was becoming grounded.  
It was learning to stand aga  
in.  
My strength is not endless now.  
Life costs more than it once did.  
Life costs more.  
Life costs more.  
So I choose how I spend it.

---

'Oku 'ikai ko e sino na'aku ma'u,  
(This is not the body I once had)  
Ka ko e sino 'oku ou mo'ui ai he 'aho ni.  
(But it is the body I live in today)  
'Oku 'ikai ke motu pe mole,  
(Not broken. Not lost.)  
'Oku ou ako 'ae palanisi,  
(I am learning balance)  
'Oku ou ako 'ae mo'oni.  
(I am learning truth)  
The body once pulled itself apart.  
Now it listens.  
Now it cooperates.  
Together.  
Together.  
Energy is no longer free,  
But it is faithful when respected.  
Faithful.  
Faithful.  
When I listen,  
I can live fully.

---

Fear once ruled this body.  
Now understanding does.  
Understanding does.  
This is not weakness—  
It is wisdom.

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E lē o le tino sa iai muamua,  
(This is not the body I once had)  
Ae o le tino ou te ola ai nei.  
(But it is the body I live in now)  
E lē gau, e lē leiloa,  
(Not broken. Not lost.)  
Ua ou a'oa' o le paleni,  
(I am learning balance)  
Ua ou a'oa' o le upu moni.  
(I am learning truth)  
Four years on,  
I am not healed completely.  
But I am standing.  
I am steady.  
I am living well.  
Not without limits—  
But without fear

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