A Statement of Suffering

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Note on timeframe:
This document reflects the cumulative difficulties I experienced during the year 2025, many of which remain ongoing.

Chapter 1 — Introduction: Why This Document Exists

This document exists because the conditions of my life have reached a level of complexity and severity that cannot be accurately understood through brief explanations, assessments, or isolated descriptions. The pressures I am living under are interconnected, cumulative, and ongoing. When viewed separately, they are often misunderstood or minimised. When viewed together, they reveal a reality that is far more difficult to live with than any single factor suggests.

I have been required repeatedly to explain my situation in fragments. In short appointments. On forms with limited space. In conversations where context is lost and nuance is discouraged. Each time, I am expected to summarise my life under pressure, often while already exhausted, distressed, or unwell. This process itself consumes energy and increases harm. It also creates opportunities for misinterpretation, disbelief, or dismissal.

This document is an attempt to remove ambiguity. It provides a clear, stable account of my circumstances as they currently stand. It is intended to be read as a whole. The purpose is not to persuade through emotion, but to describe reality accurately and without distortion. What follows is not an abstract account of hardship, but a detailed reflection of lived experience during the most difficult period of my life.

Many of the difficulties described in this document are not immediately visible. I often appear calm, articulate, and capable. This outward presentation is the result of long term adaptation, masking, and the necessity of functioning within systems that do not accommodate people like me. It should not be mistaken for ease, resilience without cost, or an absence of suffering. The internal reality is very different.

This document also exists because there is a persistent gap between how my situation is perceived and how it is lived. Systems designed to provide support often rely on narrow definitions of disability, productivity, and need. These definitions fail to capture the full impact of chronic stress, neurodivergence, health decline, environmental hostility, and ongoing insecurity. As a result, much of my struggle remains unseen or is treated as incidental.

What follows is a structured account of the pressures affecting my life. Each chapter addresses a specific area, while also acknowledging how these areas interact. Together, they form a complete picture of my current state of existence. This document is not an appeal for sympathy. It is a statement of truth, written with care, clarity, and open eyes.

Chapter 2 — The Hardest Year of My Life: A High Level Overview

This year has been the most difficult period of my life, not because of a single crisis, but because multiple long term pressures have converged, intensified, and begun to overwhelm my capacity to cope. Issues that were previously difficult but manageable have escalated. New problems have emerged alongside them. Together, they have created a level of strain that affects every aspect of my daily existence.

My health has declined across several domains at once. Physical difficulties, sensory changes, chronic fatigue, and mental health pressures have all worsened during this period. None of these developments exist in isolation. Each one compounds the others, reducing my resilience and increasing the effort required to complete even basic tasks. As a result, recovery time has shortened while demands have increased.

At the same time, the external conditions of my life have become significantly more unstable. My housing situation has moved from long term insecurity into an active threat of displacement. Financial precarity remains constant. Support systems that I rely on are conditional, bureaucratic, and subject to sudden change. This ongoing uncertainty creates a persistent background stress that does not switch off.

Environmental factors have also contributed to this period being uniquely difficult. The place where I live is not conducive to rest, recovery, or regulation. Noise, disruption, and conflict are part of the daily backdrop. These conditions affect my sleep, my nervous system, and my ability to recover from stress. Over time, this erodes both physical and emotional reserves.

Throughout this year, I have continued to engage with responsibilities, treatment attempts, and voluntary work where possible. However, the effort required to do so has increased substantially. Tasks that once required planning now require endurance. Activities that once offered fulfilment now require careful management or avoidance. The margin for error has narrowed.

The defining feature of this year is the accumulation of pressure without relief. There has been no sustained period of stability in which to recover. Instead, each new difficulty has arrived before the previous one has been resolved. This prolonged state of strain exceeds my available resources and defines the reality of my current situation.

Chapter 3 — Living On Benefits: Survival Under Suspicion

Living on benefits is not a stable or neutral condition. It is a state of ongoing uncertainty in which financial survival is conditional, closely monitored, and subject to sudden change. The support I receive is essential, yet it exists within a system that treats dependency as suspicion rather than necessity. This shapes my daily life in ways that are often invisible to those outside it.

The level of income provided through benefits is extremely limited. It does not allow for financial flexibility, long term planning, or resilience against unexpected costs. Any increase in expenses, whether medical, practical, or environmental, must be absorbed by reducing something else. This constant trade off creates a background stress that never fully recedes. Even small purchases require careful consideration, and essential needs often compete with one another.

Beyond financial limitation, there is the ongoing threat of reassessment, reduction, or removal of support. The possibility that benefits could be taken away is always present. This threat is not abstract. It influences decisions, discourages risk, and creates fear around any action that could be misinterpreted. Living under this condition means never feeling secure, even when eligibility is clear.

Engaging with the benefits system requires repeated proof of suffering. My difficulties must be explained, documented, and justified over and over again. This process is exhausting, particularly given the cognitive and emotional demands it places on someone who is already struggling. The burden of articulation falls on the individual least equipped to carry it.

The system does not account for fluctuation. There is little room for days when symptoms are worse, energy is lower, or functioning is reduced. Capacity is treated as static. Any appearance of competence can be misread as evidence of full ability. This creates pressure to remain visibly unwell in order to remain supported, which is both dehumanising and harmful.

Financial insecurity also limits access to things that would meaningfully improve my quality of life. Supportive equipment, specialist care, environmental adjustments, and therapeutic resources are often unavailable or unaffordable. The system provides just enough to survive, but not enough to stabilise, recover, or move forward.

Living on benefits is therefore not simply about money. It is about existing in a state of conditional legitimacy. My right to support is never fully secure. My needs are constantly questioned. This creates a persistent sense of vulnerability that affects mental health, confidence, and the ability to plan for the future.

This condition of survival under suspicion is not an incidental difficulty. It is a defining feature of my current reality and one of the primary pressures shaping my life.

Chapter 4 — Neurodivergence And Mental Health: A System Not Built For Me

I am autistic and live with long term mental health difficulties. These are not separate issues. They interact continuously, shaping how I process the world, respond to stress, and cope with demands. Many systems treat these aspects of my life as individual problems to be addressed in isolation. In practice, they form a single, complex reality that affects every area of functioning.

Autism affects how I experience sensory input, social interaction, communication, and change. Tasks that appear simple to others can require significant planning and energy. Unpredictability, noise, and social pressure are particularly difficult to manage. These challenges are not the result of unwillingness or poor attitude. They arise from neurological differences that cannot be trained away.

Mental health difficulties compound these challenges. Periods of low mood, anxiety, and emotional overload reduce my capacity to cope with demands that are already difficult. Stress accumulates quickly and takes a long time to dissipate. When pressure is sustained, functioning deteriorates rather than stabilises. Recovery requires time and environmental support that I often do not have access to.

A significant part of my ability to function involves masking. Over many years, I have learned to present as calm, articulate, and capable in order to avoid misunderstanding, judgement, or exclusion. This outward presentation is not a reflection of ease or comfort. It is the result of continuous internal effort. Masking consumes energy and increases fatigue, particularly during periods of stress.

Because I can communicate clearly and appear composed, my difficulties are often underestimated. Professionals may assume that I am coping better than I am, or that support is unnecessary. This creates a gap between how I am perceived and how I actually experience daily life. That gap places additional strain on my mental health and increases the risk of burnout.

Systems designed to support mental health and disability are often inflexible and poorly suited to neurodivergent people. Appointments are short. Processes are rigid. Communication is formal and impersonal. There is little recognition of fluctuating capacity or the cumulative impact of multiple stressors. When support fails to account for these realities, it becomes another source of pressure rather than relief.

Living with autism and long term mental health difficulties means constantly adapting to environments that are not designed with people like me in mind. The effort required to do this is substantial and ongoing. It affects my energy levels, my emotional wellbeing, and my ability to engage with other areas of life. This context is essential for understanding the impact of the difficulties described in the chapters that follow.

Chapter 5 — Medication Trials And The Cost Of Treatment

Throughout my life, and continuing into the present, I have engaged extensively with prescribed medication in an effort to reduce the difficulties I experience. This has included long term participation in treatment plans, repeated trials of different medications, and ongoing monitoring of effects. The absence of meaningful improvement is not the result of refusal or lack of effort. It is the outcome of sustained engagement with treatments that have not worked for me.

I have tried the main classes of antidepressants commonly prescribed within the NHS. These include citalopram, fluoxetine, sertraline, paroxetine, amitriptyline, mirtazapine, duloxetine, and venlafaxine. In my experience, none of these medications produced noticeable positive effects. At best, they had no impact. At worst, they caused severe and distressing side effects that further reduced my ability to function. More recently, I was prescribed vortioxetine, which similarly failed to provide benefit and added strain during the adjustment period.

Medication has also been repeatedly offered in response to my difficulties with reflux and swallowing. I have been prescribed and advised to try multiple antacid and reflux medications, including over the counter treatments and drugs such as omeprazole, lansoprazole, and esomeprazole. These medications did not relieve my reflux and had no effect on my dysphagia. Being repeatedly offered treatments that do not address the underlying condition has felt dismissive and has contributed to a sense of not being properly heard or understood.

In relation to attention and executive function difficulties, I have trialled several ADHD medications. Methylphenidate had a negative effect on my mental health. Dexamfetamine was more effective than any other medication I have been prescribed and helped in several important ways, but it also introduced problematic effects that required careful management. More recently, I have been prescribed atomoxetine, which after several months has left me feeling spaced out, impaired, and less functional overall.

Each medication trial carries a cost beyond side effects alone. Adjusting to new medication disrupts routine, sleep, appetite, mood, and energy. When adverse effects occur, they can destabilise my life for extended periods. During these periods, my ability to maintain structure, engage in self care, or work toward improvement is significantly reduced. Recovery from unsuccessful trials takes time and energy that are rarely acknowledged.

Trialling medication is often framed as a straightforward step toward improvement. In practice, it requires resilience, stability, and spare capacity. For someone already living with limited resources, each unsuccessful attempt represents further depletion rather than progress.

Chapter 6 — Therapy, Engagement, And The Limits Of Care

Throughout my life, I have engaged with a wide range of therapeutic interventions in an effort to address the difficulties I face. This engagement has been sustained, varied, and genuine. The challenges I continue to experience are not the result of avoidance or resistance to support, but of the limits and failures of the care that has been available to me.

Most of the therapy I have received through the NHS has been cognitive behavioural therapy. I have completed numerous CBT courses over many years. These interventions were often brief, standardised, and narrowly focused. In many cases, they failed to address the underlying complexity of my situation. Some courses were neutral and ineffective. Others were actively harmful, reinforcing feelings of personal failure and inadequacy when techniques did not work for me.

In addition to CBT, I have participated in other forms of NHS therapy, including counselling, psychodynamic therapy, group therapy, and EMDR. While these approaches were sometimes better suited to my needs, they were consistently limited by short time frames and strict session caps. The number of sessions offered was rarely sufficient to create meaningful or lasting change. Support often ended just as trust and momentum were beginning to form.

A recurring issue within NHS therapy has been the lack of continuity. Therapists change. Services discharge patients quickly. Long gaps occur between referrals. Each restart requires retelling difficult personal history and rebuilding trust from the beginning. This process is emotionally demanding and contributes to fatigue rather than recovery.

In early 2025, I began attending paid online therapy sessions through the platform BetterHelp. For the first time, I am working with a therapist whose approach aligns well with how my brain works. This therapy has been more helpful than anything I previously received through the NHS. The ongoing nature of the sessions allows for depth, consistency, and gradual progress rather than crisis management alone.

However, this form of support is only available for as long as I can afford it. Paying for private therapy while living on benefits creates additional financial pressure and anxiety. There is no security in knowing whether I will be able to continue accessing the care that is actually helping me. I also hold ethical and accessibility concerns about the platform itself, which adds further ambivalence to an arrangement that already feels precarious.

Therapy has helped me understand myself better and develop coping strategies where possible. It has not removed my neurodivergence, resolved my physical health issues, or eliminated the external pressures I live under. Therapy cannot compensate for unstable housing, financial insecurity, environmental stress, or systemic barriers. Its benefits exist within those constraints.

My history with therapy demonstrates sustained effort and willingness to engage in treatment. It also highlights the gap between what is offered and what is needed. Care that is brief, conditional, or mismatched to neurodivergent needs cannot resolve long term, structural difficulties. The limits of care are not a reflection of my commitment, but of the systems providing it.

Chapter 7 — Chronic Exhaustion: Living Without Reserves

I live with persistent exhaustion that affects me every day. This is not ordinary tiredness and it is not resolved by rest. Most days, I wake up already depleted, with a heavy sense of having to push myself through the day from the very beginning. There is rarely a feeling of being refreshed or restored.

This exhaustion does not have a single, clearly defined cause. It may be influenced by a combination of mental health difficulties, poor nutrition, prolonged stress, neurodivergent burnout, sensory overload, and ongoing instability. Despite raising this issue repeatedly with healthcare professionals, it has often been minimised or treated as a secondary symptom of other conditions. As a result, it remains undiagnosed and largely unaddressed.

The impact of this exhaustion is profound. Tasks that might seem minor to others require significant effort and planning. Basic daily activities such as personal care, household upkeep, and communication can feel overwhelming. Before any meaningful work or engagement can take place, a large portion of my limited energy is already consumed.

This lack of reserves affects every area of my life. It slows my thinking, reduces my tolerance for stress, and limits my ability to recover from setbacks. When demands increase, my capacity does not rise to meet them. Instead, functioning deteriorates. There is little margin for error or unexpected events.

The exhaustion also creates emotional strain. Falling behind on responsibilities leads to guilt and a sense of letting others down. Creative projects, which are a source of meaning and expression for me, often remain unfinished or untouched due to lack of energy. Social interaction becomes difficult to sustain, and relationships are harder to maintain.

Because this exhaustion is constant and largely invisible, it is easy for it to be misunderstood or dismissed. There are no clear markers that signal how depleted I am. From the outside, I may appear capable. Internally, I am operating with a severely limited capacity that shapes every decision I make.

Living without reserves means that survival tasks take priority over growth, recovery, or enjoyment. Energy is spent maintaining a baseline rather than building toward improvement. This ongoing state of depletion is one of the central realities of my life and a key factor in understanding the cumulative impact of the difficulties described in this document.

Chapter 8 — Dysphagia, Nutrition, And The Loss Of Pleasure

I live with dysphagia, which significantly affects my ability to eat safely and comfortably. Swallowing solid food can feel unpredictable and dangerous. At its worst, this has involved near daily choking episodes that made eating feel unsafe. As a result, I have often relied on liquid foods such as meal replacement drinks and soups in order to meet basic nutritional needs.

My swallowing difficulties are not attributable to a single cause. Over time, diagnostic investigations have identified esophageal dysmotility, chronic acid reflux, and a hiatus hernia, all of which contribute to impaired swallowing function. In addition to these findings, I experience episodes where swallowed food moves in the wrong direction and enters the nasal cavity, a symptom that has been difficult to communicate and has often been minimised. I also experience ongoing post-meal regurgitation, lasting for approximately thirty minutes after eating or drinking, which contributes to the sense that swallowing and digestion are unsafe and unpredictable.

The physical risk associated with swallowing has changed my relationship with food. Eating is no longer a simple or pleasurable activity. It requires constant attention, caution, and self monitoring. The fear of choking makes it difficult to relax while eating, even when alone. This persistent vigilance is exhausting and contributes to ongoing stress around meals.

Living with dysphagia also affects nutrition. Liquid based diets are limited in variety and do not always provide adequate balance. Maintaining good nutrition under these constraints is difficult and requires effort that I often do not have the energy or resources to sustain. Poor nutrition in turn affects energy levels, mood, and overall health, creating a reinforcing cycle.

Social eating has become largely inaccessible. Eating in front of others increases anxiety and risk, and managing swallowing difficulties in public is both stressful and embarrassing. As a result, shared meals are often avoided. This contributes to isolation and the loss of an important social and cultural aspect of daily life.

After a significant delay, I was eventually seen by the Speech and Language Therapy team. By the time this support was provided, I had already been living with unsafe swallowing for many months. The delay meant that I spent a prolonged period managing a serious health risk without professional guidance or reassurance.

Through SALT, I was provided with an IQoro device and given exercises to support swallowing function. Since beginning to use this device, I have noticed a degree of improvement. I cannot say with certainty how much of this improvement is due to the device itself or how durable the effect will be, but the timing strongly suggests a connection. The change has been meaningful enough that I do not consider the intervention ineffective.

While this improvement is welcome, it is limited and does not represent a resolution of the problem. The change has meant that I am sometimes able to eat certain solid foods again, but eating remains slow, cautious, and effortful. I have to take very small bites, eat deliberately, and use water with each mouthful to help food pass safely. Even with these precautions, I still experience uncomfortable sensations of food feeling stuck or going the wrong way. Swallowing is safer than it was, but it is not easy, automatic, or relaxed.

Dysphagia has taken away more than physical ease. It has removed pleasure, spontaneity, and safety from a basic human activity. The effort required to eat, combined with fear and limitation, has turned nourishment into a source of stress rather than comfort. This loss continues to affect my physical health, emotional wellbeing, and daily quality of life.

Chapter 9 — Dental Loss, Dentures, And Bodily Decline

I have lost two of my upper front teeth. One is the incisor on my right side, and the other is the adjacent tooth beside it. This loss has created a range of practical, physical, and psychological difficulties that affect daily life in ways that are not immediately obvious.

Eating has become more difficult as a result of this loss. I cannot eat while wearing my denture. The plastic plate that sits on the roof of my mouth reduces sensory feedback and makes swallowing feel less safe, particularly given my existing dysphagia. The denture is not designed to bite or chew with and serves a cosmetic purpose only. As a result, I have to remove it before eating and rely on my side teeth to bite food, which is awkward and imprecise.

The need to remove the denture adds another layer of effort and disruption to eating. Doing so in front of others is uncomfortable and socially awkward. It also draws attention to the loss of my teeth and breaks the appearance of normality that the denture is intended to provide. This has further reduced my ability to eat socially and has reinforced avoidance around shared meals. Even when alone, the repeated process of taking the denture in and out depending on activity consumes time and energy.

The denture is also physically uncomfortable to wear. Over time, I can become accustomed to this discomfort, but this does not mean it stops being a problem. It simply becomes another daily burden that I have learned to tolerate. Adapting to discomfort does not remove its impact. It requires ongoing effort and contributes to fatigue.

Tooth loss has also affected my ability to play and learn the saxophone. The embouchure required to play is altered by the absence of front teeth. Wearing the denture helps in this regard, but it is not designed for use with a musical instrument. Repeatedly inserting and removing it is awkward, and it has already broken once during use, requiring repair. Playing now carries an additional layer of anxiety around damage, discomfort, and limitation.

I am unable to access dental implants. They are not provided by the NHS in my circumstances and are far beyond what I can afford privately. This leaves me with a fragile and suboptimal solution that I must rely on indefinitely.

In addition to the teeth already lost, the two corresponding front teeth on the opposite side are unstable and slightly loose. There is an ongoing awareness that they could be damaged or lost through biting, chewing, or playing music. This has made me overly cautious and tense during activities that should be automatic. The sense of bodily fragility is constant.

Maintaining oral hygiene is essential to slowing further deterioration, but it is not straightforward. The routines recommended by dental professionals involve multiple specialist products, repeated steps, and daily consistency. These products are expensive and must be paid for out of an already limited budget. The cognitive and physical effort required to maintain these routines is significant, particularly given my neurodivergence and fatigue. Failure to meet these standards carries the risk of further tooth loss, creating a persistent sense of pressure.

Beyond the practical consequences, losing teeth has heightened my awareness of ageing, bodily decline, and mortality. This is not a superficial concern. It is a confrontation with irreversible change and loss of function that has emotional weight. The deterioration feels ongoing rather than complete, which makes the anxiety more acute.

Dental loss has affected how I eat, how I express myself musically, how I present socially, and how I relate to my own body. It represents another area in which adaptation has been required not because of choice, but because adequate treatment and support are inaccessible. The cumulative impact of these changes continues to shape my daily life and wellbeing.

Chapter 10 — Sensory Loss And Overload

Over recent years, I have experienced a decline in multiple sensory domains. These changes affect how I perceive the world, how I regulate my nervous system, and how I engage with activities that are central to my identity and wellbeing. Sensory loss does not occur in isolation. It interacts with stress, fatigue, and neurodivergence, amplifying their effects.

I live with tinnitus, which initially developed in my left ear. This has been present for several years. During the past year, I have noticed the onset of tinnitus in my right ear as well. At the same time, the tinnitus in my left ear has become more pronounced and piercing at times. This change has increased its intrusiveness and reduced my ability to habituate to it.

Alongside tinnitus, I have experienced hearing loss in the higher frequency range in my left ear, above approximately six kilohertz. This loss sits above the tinnitus frequency and creates an imbalance in stereo perception. As someone who works with sound and values accurate listening, this has been devastating. It affects not only my enjoyment of music, but also my ability to analyse, mix, and design sound with confidence and precision.

Sound that was once rich and immersive now feels incomplete or distorted. The imbalance between my ears creates constant uncertainty about what I am hearing. Tasks that rely on subtle detail require more effort and concentration. Listening has become cognitively demanding rather than restorative.

I have also experienced changes in my vision. I have been short sighted for many years and previously managed this with distance glasses without significant difficulty. More recently, my eyesight has worsened and I have been diagnosed as both short and long sighted. While varifocal lenses were initially recommended, I was later informed that the NHS will only cover single focus lenses. As a result, I do not have adequate correction for close range vision.

This has practical consequences. Reading, using my phone, and focusing on nearby objects now require holding them at an uncomfortable distance. These adjustments may appear minor, but they add friction to daily tasks and contribute to fatigue.

In addition to changes in visual acuity, I have developed increased sensitivity to bright light. Indoors, I often need to keep screens at their lowest brightness setting. Even then, light can feel straining and uncomfortable. This sensitivity reduces tolerance for screen use and further limits access to information, communication, and creative work.

The cumulative effect of sensory loss and sensory sensitivity is significant. Where senses once provided enjoyment, clarity, and grounding, they now introduce uncertainty and strain. This creates a sense of loss that is both practical and emotional.

Living with ongoing sensory changes requires constant adaptation. It demands attention, effort, and compensation strategies that consume energy. These losses are not dramatic or immediately visible, but they affect how I move through the world and how much I am able to engage with the things that give my life meaning.

Chapter 11 — Housing Instability And Environmental Hostility

I have lived in my current flat for seventeen years. During that time, it has become the centre of my routines, coping strategies, and sense of stability. That stability is now under direct threat. My landlord is selling the property. A buyer has already been found, and the buyer has made it clear that they want the flat vacant before completing the purchase. This means that I will be required to leave my home.

This is not a hypothetical risk or a distant possibility. It is an active and ongoing process. The certainty of displacement has introduced a level of fear and instability that affects my mental health, my sense of safety, and my ability to plan for the future. Losing a home after such a long period of residence is not a simple relocation. It represents the loss of familiarity, security, and the fragile equilibrium I have built to survive under difficult conditions.

The housing options available to me are effectively nonexistent. Due to financial limitations, disability related needs, and the wider housing crisis, there are no viable alternatives that would offer comparable safety or stability. The prospect of being forced into unsuitable accommodation or homelessness is a constant and distressing concern.

In addition to the threat of eviction, the environment in which I currently live is hostile to my wellbeing. The flat is located on a busy main road and directly above a café and restaurant. I have a strained relationship with the owners following a serious disturbance on the night they opened. Their presence is unavoidable. I must pass them whenever I leave my home, which creates ongoing anxiety and discomfort.

Next door to the café is a shisha bar that attracts loud and rowdy crowds, particularly at weekends. Music and noise from this venue are intrusive and unpredictable. I also live near a bus station. Late at night, bus drivers often park outside the flat and communicate by shouting, sometimes around one in the morning. In addition, there is a hospital nearby, resulting in frequent sirens at all hours of the day and night.

This constant noise affects my sleep, my nervous system, and my ability to recover from stress. While I have adapted to some degree, adaptation does not mean absence of harm. Disruption remains disruption, regardless of familiarity. The cumulative effect is ongoing exhaustion and heightened sensory stress.

The flat also suffers from extremely poor heating. During winter, indoor temperatures have been low enough that I have spent extended periods shivering. Living in persistent cold affects physical comfort, sleep, and mental wellbeing. It also increases the effort required to complete basic daily tasks.

Taken together, these conditions create an environment that is actively hostile to someone with autism, sensory sensitivity, tinnitus, and chronic fatigue. Home should be a place of refuge and recovery. Instead, it is a source of ongoing stress and vigilance.

I value nature and quiet, but I do not feel comfortable going outside. The noise, the crowds, and the sense of being watched or judged make leaving the flat emotionally taxing. This further limits access to restorative experiences and contributes to isolation.

Housing instability combined with an unsuitable living environment has placed me in a prolonged state of insecurity. The threat of losing my home, layered on top of daily environmental stressors, has significantly reduced my ability to cope. This situation is not sustainable and represents one of the most severe pressures in my life.

Chapter 12 — Work Inaccessibility And The Cost Of Volunteering

Paid employment is not currently accessible to me. This is not due to a lack of desire to contribute, but because the structure and expectations of most work environments are incompatible with my health, neurodivergence, and limited capacity. The combination of chronic fatigue, sensory sensitivity, fluctuating functioning, and ongoing instability makes sustained paid work unrealistic.

I do, however, volunteer for three hours a week at a mental health charity that supports people through musical expression. My role involves assisting with recording sessions, participating in group jams, and contributing to lyric writing activities. This work is meaningful to me and allows me to contribute in a way that aligns with my skills and values.

Even this small commitment often pushes me to the edge of my capacity. Three hours a week may appear minimal, but the energy required extends far beyond the time spent on site. Preparation, recovery, and the emotional effort involved significantly increase the overall cost.

The most difficult aspect of this work is travel. Public transport is extremely challenging for me as an autistic person. Busy platforms and bus stops, close physical proximity to others, unpredictable delays, route changes, and strikes all create intense stress. Time spent waiting is particularly draining. Travelling requires constant alertness and emotional regulation, and often leaves me exhausted before I arrive.

During travel, I frequently feel scrutinised or judged by others. This heightens anxiety and contributes to masking and self monitoring. By the time I reach my destination, a large portion of my energy has already been spent.

Within the volunteering role itself, the flexibility is essential. As a volunteer, I am able to decline tasks that would cause undue stress. If I am not able to attend on a particular day, I can stay home without fear of punishment or formal consequences. This level of autonomy is the reason I am able to participate at all.

This stands in contrast to paid employment, where absence, reduced productivity, or refusal of tasks often carry penalties. In such environments, my capacity limitations would quickly lead to burnout, disciplinary action, or dismissal. The risk associated with attempting paid work is therefore high.

Volunteering allows me to contribute on my own terms, but it comes at a cost. It consumes a significant portion of my limited energy and leaves little capacity for other responsibilities, creative work, or recovery. Despite this, it remains one of the few ways I am able to engage with society in a meaningful way.

The fact that three hours of supported, flexible activity represents my upper limit is not a personal failing. It reflects the reality of my current capacity and the cumulative impact of the pressures described throughout this document.

Chapter 13 — Navigating Bureaucracy And Institutional Oppression

A significant portion of my time and energy is spent navigating bureaucratic systems. These systems are complex, slow moving, and difficult to engage with, particularly for someone with limited capacity, neurodivergence, and ongoing health problems. The effort required to access support often becomes an additional burden rather than a source of relief.

Processes are fragmented across multiple departments and services. Each interaction requires repetition of personal history, explanation of symptoms, and justification of need. Forms are lengthy, language is opaque, and expectations are rarely clear. Errors or delays are common, and the consequences of mistakes can be severe. This creates a constant sense of pressure to perform correctly while already exhausted.

Waiting is a central feature of this experience. Appointments, assessments, referrals, and diagnostic procedures are often separated by months or years. For example, I have been waiting over two years for a hearing assessment related to my tinnitus and have still not been given an appointment. Investigations into my swallowing difficulties have been spaced out over long periods, leaving me to manage unsafe symptoms on my own in the meantime. Referrals to specialist services such as Speech and Language Therapy have involved extended delays after the need was clearly identified.

These periods of waiting are not neutral. They involve living with unresolved symptoms, uncertainty, and risk. They also involve carrying the knowledge that even when an appointment eventually occurs, there is a possibility of being dismissed, minimised, or offered inappropriate treatment. This anticipation erodes mental wellbeing and contributes to chronic stress.

I first raised the possibility of autism and sought assessment in 2008. At that time, and for many years afterward, I was repeatedly told that adult neurodivergence was not diagnosed by the NHS. As a result, I was assessed and treated primarily through a narrow anxiety and depression framework. It was not until 2020, following a severe mental health crisis in which autistic traits were explicitly identified as contributing factors, that I finally received a formal diagnosis. This prolonged delay had significant consequences for how my difficulties were understood, addressed, and supported.

Accessing help often requires persistence that exceeds my available resources. Follow ups must be chased. Information must be clarified. Mistakes must be corrected. The responsibility for maintaining momentum rests almost entirely on the individual seeking support. When capacity is low, this can result in care stalling or disappearing altogether.

Before being admitted to hospital for severe swallowing difficulties in February, I sought help through my GP. I attended two appointments in an attempt to be taken seriously. In both cases, my concerns were dismissed and minimised. The seriousness of the situation was not acknowledged, despite the fact that eating is essential to survival. It was only after the situation escalated that I received urgent care.

These experiences create a sense of institutional oppression rather than support. Systems that are nominally designed to help instead place the burden of navigation, persistence, and self advocacy on those least able to sustain it. The result is delayed care, prolonged suffering, and increased harm.

Navigating bureaucracy has become a form of unpaid labour that consumes time, energy, and emotional resilience. It is not incidental to my situation. It is one of the mechanisms through which hardship is maintained and compounded.

Chapter 14 — Institutional Gaslighting: When Systems Deny Suffering

Many of my interactions with healthcare, benefits, and support systems have involved a consistent pattern of minimisation and denial. My experiences are frequently reframed, softened, or treated as less serious than they are. This does not usually happen through overt hostility. It occurs through dismissal, inappropriate reassurance, and the failure to acknowledge the severity or persistence of what I am living with.

Symptoms are often treated in isolation, stripped of context, or reduced to secondary effects of something else. Chronic exhaustion is attributed solely to mood. Swallowing difficulties are treated as reflux. Sensory issues are downplayed because I can still communicate clearly. In each case, the reality of the problem is narrowed until it becomes easier to ignore.

This pattern creates a situation in which I am required to repeatedly assert the legitimacy of my own experience. When my descriptions do not fit familiar diagnostic categories or expected narratives, they are treated with scepticism. Over time, this undermines confidence and creates doubt about whether it is worth speaking up at all.

Being told, implicitly or explicitly, that I am coping better than I am has been a recurring experience. This often stems from my ability to articulate my situation calmly and coherently. That presentation is mistaken for stability. The effort and cost behind it are rarely recognised.

Institutional gaslighting also occurs when harm is reframed as adaptation. Being told that I will get used to symptoms, discomfort, or deprivation shifts responsibility away from systems and onto the individual. It implies that endurance is the solution, rather than change. This framing ignores the cumulative toll of living under sustained strain.

When concerns are minimised or dismissed, escalation becomes the only route to care. Symptoms must worsen. Crises must develop. Only then does the system respond with urgency. This creates a perverse incentive structure in which suffering must reach a breaking point before it is acknowledged.

The psychological impact of this pattern is significant. Repeated invalidation leads to frustration, anger, and exhaustion. It also contributes to withdrawal, as engaging with systems becomes emotionally costly. Over time, this dynamic erodes trust and reinforces the sense of being unseen.

Institutional gaslighting is not a single incident, but a repeated experience that shapes how I relate to support systems. It compounds existing difficulties and adds an additional layer of harm. Understanding this pattern is essential for understanding the depth and persistence of the struggles described in this document.

Chapter 15 — The Hidden Labour Of Survival

Much of the effort required to live under these conditions is not visible. It does not appear on forms, schedules, or assessments. It takes place quietly and continuously, consuming energy without producing outward markers of progress. This hidden labour is central to my daily existence.

Each day requires constant management of symptoms, environments, and risks. Decisions that others make automatically must be considered carefully. What to eat, how to eat it, when to leave the house, whether I can tolerate noise, light, or social contact, and how much energy remains are all active calculations. These decisions are made repeatedly, often while already exhausted.

Managing appointments, referrals, forms, and follow ups requires sustained attention and organisation. Remembering deadlines, tracking correspondence, and correcting errors all demand cognitive effort. When systems are slow or unresponsive, the work does not pause. It expands. The responsibility for keeping things moving rests with me, regardless of my capacity at the time.

A significant amount of energy is spent preventing deterioration rather than achieving improvement. Maintaining a baseline of safety involves pacing, avoidance, preparation, and recovery. Small gains require disproportionate effort. Setbacks are costly and take time to recover from. This creates a sense of treading water rather than moving forward.

Emotional regulation is another form of hidden labour. Anxiety, frustration, and fear must be contained in order to function at all. Masking distress, maintaining composure, and presenting as capable require ongoing internal effort. This work is rarely recognised and often mistaken for ease.

The labour of survival also includes adapting to loss. Adjusting to reduced capacity, sensory decline, and physical changes involves grief as well as practical adjustment. Letting go of expectations, ambitions, and spontaneity is not a one time process. It must be repeated as circumstances change.

Because this labour produces no tangible output, it is often overlooked. From the outside, it may appear that little is happening. In reality, a great deal of effort is being expended simply to remain stable. The absence of visible collapse is taken as evidence that things are manageable, rather than as proof of constant work.

The hidden labour of survival shapes how much I am able to give, plan, and hope. It limits access to rest, creativity, and connection. It is not an optional burden. It is the cost of continuing under conditions that do not allow for ease or recovery.

Chapter 16 — Disability, Value, And Recognition

My disability is not primarily physical. It arises from the interaction between my internal reality and a social system that assigns value almost exclusively through extractive productivity. Worth is measured by output, speed, and economic yield, rather than depth, care, or contribution that does not translate neatly into profit. Within this framework, many forms of human value are rendered invisible.

I possess internal value that is real and generative. It exists in creativity, insight, care, attention, and the ability to contribute meaningfully when conditions allow. These qualities are not abstract ideals. They are practical and lived. However, because they do not align with narrow productivity metrics, they are not recognised as valid forms of contribution.

Survival within this system requires self reduction. It demands that I compress my identity, my capacities, and my ways of being into forms that are easier to measure and manage. This requirement conflicts directly with my core values and with the realities of my neurodivergence and health. The effort to conform to these expectations is itself disabling.

Support systems often frame disability as something that must be corrected, rehabilitated, or overcome. This framing assumes that the primary problem lies within the individual. In my experience, the greater problem lies in the refusal of systems to accommodate difference without penalty. When recognition is conditional on conformity, support becomes another mechanism of harm.

What I require is not correction, but recognition. Recognition of the fact that my capacity is limited and fluctuating. Recognition of the contributions I am able to make within those limits. Recognition that survival itself requires labour under current conditions. Fair support for what I do contribute, and freedom from punishment for what I do not, would represent a meaningful shift toward justice.

Disability, in this context, is not simply a matter of impairment. It is produced by the mismatch between human variation and inflexible systems. When those systems refuse to adapt, the cost is borne by individuals. This cost accumulates quietly, shaping lives in ways that are rarely acknowledged.

Understanding disability as a relationship rather than a defect allows for a more accurate reading of my situation. It explains why effort does not reliably lead to stability, why engagement does not guarantee improvement, and why resilience has limits. It also clarifies why recognition, rather than pressure, is the most appropriate response.

This perspective does not deny difficulty or suffering. It situates them within a broader context. It affirms that the struggles described throughout this document are not failures of will or character, but the predictable outcome of systems that value extraction over care.

Chapter 17 — The Emotional Landscape: Grief, Fear, And Persistence

Living under sustained pressure produces an emotional landscape that is complex and difficult to articulate. It is not defined by a single feeling, but by the coexistence of grief, fear, endurance, and quiet determination. These emotions are not reactions to isolated events. They arise from prolonged exposure to instability, loss, and uncertainty.

Grief is a constant presence. It is not limited to the loss of physical abilities or opportunities, but extends to the gradual erosion of ease, spontaneity, and possibility. There is grief for the body I once trusted, for the senses that once brought clarity and pleasure, and for the future that now feels narrower and more fragile. This grief is ongoing and cumulative. It does not resolve, because the losses continue.

Fear operates alongside grief. It is rooted in real threats rather than imagined ones. The fear of losing my home. The fear of further health decline. The fear of being left without support. These concerns are not abstract anxieties. They are grounded in lived experience and reinforced by repeated encounters with systems that are slow, conditional, or dismissive. Living with this level of uncertainty keeps the nervous system in a heightened state of alert.

Alongside grief and fear, there is persistence. This persistence is not heroic or triumphant. It is practical and restrained. It appears in the continued effort to engage with care, to maintain routines where possible, to contribute through volunteering, and to articulate my reality clearly. Persistence here does not mean thriving. It means continuing despite depletion.

There is also frustration and anger, though these emotions are often contained rather than expressed. They arise from being required to justify suffering, from watching support arrive late or not at all, and from being asked to adapt endlessly to conditions that are actively harmful. Holding these emotions without allowing them to overwhelm daily functioning requires effort.

Despite everything, there remains a desire for meaning, connection, and dignity. This is not optimism in the conventional sense. It is a refusal to reduce life solely to survival. Even under strain, there is an awareness of value, both personal and relational. This awareness provides a reason to continue engaging, even when the cost is high.

The emotional impact of these conditions cannot be separated from the practical realities described throughout this document. Emotions are shaped by material conditions, systemic behaviour, and lived constraints. They are not signs of weakness or instability. They are appropriate responses to prolonged adversity.

This emotional landscape defines how I move through the world. It influences decisions, limits capacity, and shapes expectations. Understanding it is essential for understanding my current state of existence. It is the inner counterpart to the external pressures already described, and it carries its own weight.

Chapter 18 — The System Vs The Self: Final Reflections

The conditions described in this document are not temporary disruptions. They form the structure of my current life. Health decline, sensory loss, fatigue, financial precarity, housing insecurity, environmental hostility, and systemic delay interact continuously. Together, they create a level of pressure that is sustained rather than episodic.

Throughout this document, a consistent pattern emerges. Effort does not reliably lead to stability. Engagement does not guarantee support. Articulation does not ensure recognition. The systems I am required to navigate are fragmented, conditional, and often misaligned with the realities of neurodivergent and chronically strained lives. The result is a persistent mismatch between what is needed and what is offered.

There is a significant gap between how I appear and what I experience. I am able to communicate clearly and present as composed. This has often been interpreted as evidence of capacity or resilience without cost. In reality, this presentation is the result of long term adaptation and effort. It masks the extent of depletion rather than negating it.

The self that exists within these systems is required to shrink. To simplify. To become legible at the expense of accuracy. This pressure to self reduce is not benign. It erodes dignity and obscures value. It also creates a false narrative in which survival is mistaken for coping and endurance is mistaken for ease.

What this document shows is not a failure to try. It shows repeated engagement, compliance with treatment, persistence through delay, and ongoing effort under constraint. The limitations I face are not the result of unwillingness or neglect. They arise from the interaction between real human limits and systems that do not accommodate them.

The question at the heart of this document is not whether I am doing enough. It is whether the structures surrounding me are capable of recognising and responding to reality without requiring collapse as proof. Stability, safety, and recognition are not excessive demands. They are prerequisites for recovery and participation.

This document stands as a record of lived truth. It is written with clarity and restraint, not exaggeration. It does not seek sympathy. It seeks understanding grounded in fact. The pressures described here are ongoing, cumulative, and real.

The tension between the system and the self remains unresolved. Until recognition replaces suspicion and care replaces attrition, that tension will continue to define my life. This document exists so that this reality cannot be ignored, simplified, or rewritten.