

# **Cluster Headache: Making Sense of the Idiopathic**



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**Independent Study Project  
in Social Anthropology  
- 151802039 -**





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# Table of Contents

Abstract & Acknowledgements	5
Prologue	6
Introduction	7
<b>Communicative Difficulties: Problems between Sufferers and Others</b>	<b>10</b>
- “Acceptance is more than helpful. It is essential.”	
11	
THE SOCIAL: STIGMA AND ACCEPTANCE	
- “Sometimes I just want people to believe that its true ...”	
15	
THE MEDICAL: (MIS)DIAGNOSIS & ITS LANGUAGE	
<b>Some Languages of CH: Meanings &amp; Positionings</b>	<b>19</b>
- Suffering & Sagehood	
20	
- “... Dollars, not bodies”: The Beast & The Warrior	
25	
Conclusion	30
Appendices & Bibliography	31

## **Abstract**

Cluster Headache is a rare, idiopathic neurological condition considered to be “the most painful condition know to medical science.” Drawing on 6 months email correspondence with twelve

sufferers, observations of a Cluster Headache forum and other online materials, this paper follows the ways that Cluster Headache sufferers *communicate* their condition to others and to themselves. The canopy of this active verb allows me to: 1) situate sufferers within a matrix of difficult social and psychological relations; and 2) explore their creative strategies for navigating this new world. As Cluster Headache reopens the problem of meaning and threatens to confuse one's identity, then to endure is to forge understandings where there are none. This paper is stamped with tentative optimism, wishing to bear aloft the spirit of human perseverance whilst respecting the gravity of its making; this little-known human despair: Cluster Headache.

## **Acknowledgements**

To all who participated in this study I remain indebted; remaining open to faceless questioning takes unconscionable trust and courage, I truly thank you. Moreover, I would like to thank all those at the CHSG for facilitating this correspondence. I am grateful to Marloes Janson, David Mosse, Kostas Retsikas, Ned Carter Miles, all members of the ISP class and those many others who cared to pass comment and support these ideas. Special thanks to Kit Davis who helped mediate this madness and never failed in making me smile. And finally, Tessa, my partner-in-crime, whose support in this and so much more cannot be valued.

## **Prologue**



I wouldn't call them suicidal thoughts, but at times I envy the dead. These moments, irregular as they are, occur in the grips of "the beast"; moments when living entails unrelenting,

insurmountable pain. I speak of the excruciatingly pain-filled world of *Cluster Headache*, known otherwise as “the most painful condition known to medical science” or “suicide headache”<sup>1</sup>.

I had been a sufferer for 4 years before my parents witnessed one of my headaches. I remember it was the height of summer, the heat was particularly wretched. My attacks usually hit during hours of darkness and so rarely in the apex of the day like this. It came on quick, as often does. Abortive medication stops roughly 80% of attacks provided it is taken in time, but on this occasion I had none.

And so, taking a few consolatory paracetamol, I accepted my fate and committed to the ordeal. Overheating, I stumbled out onto the patio in search of a cool breeze.

I pushed my left palm forcefully against my left temple and with my other hand furiously gnawed my trapezius, pacing all the while. I had delineated an unobstructed route from the garden steps to the backdoor between which I could stagger, bent double, back and forth, back and forth, each metered motion helping order the otherwise capricious, arrhythmic stabbing pains behind the eye. Every so often I would stop at the door and bang my head against it. Each pang overrode the head pain but was shortlived. There are few words, just groans, the occasional whimper and expletive whine as the pain crescendos. “Oh fuck ... please ... please stop!” I wretched as waves of nausea turned my stomach. Dizzy and disorientated I tripped over my feet, grazing my elbow on the sandstone paving. The ritual is always exhausting but produces the desired effect—to exhaust the panic, exhaust the pain.

My parents did not expect what they saw that day. They always knew but now they understood. Intermittently they checked on me, offering water, debating between themselves whether I should be taken to hospital or not. With what energy I could muster I stuttered: “No, no ... it will go ... it will go.” It finally left almost an hour later, just as quickly as it came.

This particular incidence charted 8 out of 10 on my personal pain scale. Most attacks register between 5-7 but in my seven years as a sufferer I have experienced perhaps thirty 9’s, even a handful of 10’s. Fortunately my condition is episodic, and improving; I currently get one or two a day for nearly 2 weeks (one “cycle”), 6 weeks remission, and then it begins over. For chronic sufferers, attacks are often an everyday occurrence. Some of the sufferers featured in this paper endure up to six of these attacks every day.

## Introduction



From hereon I will refer to the condition by its acronym “CH”, the term favoured by sufferers. CH is rare, estimated to affect 0.1 - 0.4% of the global population, over 7 million people worldwide

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<sup>1</sup> NHS 2014

(Fletcher 2015: 1). The average attack lasts 45 minutes (ibid.: 3), so taking a conservative estimation—presupposing one attack every other day per sufferer—I estimate CH causes *at least* 958 million hours of debilitating pain every year. Chronic sufferers, constituting approximately 20% of all diagnosed cases (ibid.: 2), are usually unable to work. All too often their condition comes between them and their employers, colleagues, friends, family, even partners. Those isolated soon become depressed. A recent study in the US found that suicide rates among CH sufferers are twenty times higher than the national average (ibid.: 2).

Owing to the condition's rarity, and its isolated conditionee's need for a compassionate support network, one sufferer, Chris Hannah, founded *The Cluster Headache Support Group* (CHSG): a 501(c)(3) non-profit organisation based in Fountainville, Pennsylvania. Its Facebook groups (public and private) are now some of the world's most active CH forums. With invaluable help from the CHSG team I was able to maintain regular email correspondence with twelve fellow sufferers; all of whom generously allowed me into their lives, remained open to my intimate questioning and dedicated their often scarce pain-free moments to this project. For their trust and commitment I am deeply thankful.

Cluster Headache is *idiopathic*: biomedicine has identified neither a cause nor a cure. The best sufferers can hope for is to find a long-term treatment plan amidst a farrago of pills, prescriptions and practices—allopathic or otherwise—that lessen the frequency and/or intensity of attacks until they eventually subside of their own accord. Even then the headaches may return many years later, the fight is never thought to be entirely over. Because 'the cause is not known and the treatment is inadequate,' Melzack & Wall<sup>2</sup> (1982: 288) would consider CH one of the top priority pain disorders. That CH inhabits a space outside biomedical knowledge is a point that will remain central to our discussion forthwith. All my interlocutors interacted primarily with biomedical healthcare systems, their epistemological uncertainties becoming 'deeply inscribed within the selves and bodies of [these] patients' (Honkasalo 2001: 321). Drawing on 6 months sustained email correspondences, observation of CHSG interactions and other relevant online materials, this paper explores how "clusterheads"<sup>3</sup> *communicate* under this liminal sign; ontogenetic, socio-moral, and psychological implications entirely withstanding.

Approaching the condition via communication is a decision as much methodological as analytical. For want of a traditional field site, my data is largely textual. Whilst unable to attest to the latter half of the Malinowskian tension 'between what people say and what they do' (Kuper 1983: 35), this methodology pays dividends elsewhere. Email correspondence allows participants to consider their responses and actively project versions of themselves. Relieved from my misinterpreting hesitations, winks, or other such gesticulations, their texts are highly constructed

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<sup>2</sup> Exponents of the infamous "gate control" theory of pain, the first to account for both physiological and psychological aspects of pain.

<sup>3</sup> A collective term for CH sufferers, favoured on the CHSG forum.



self-representations: filtered and edited as such. This offers some apprehensible if unforgiving grounding to view the tactical construction of CH understandings, the polished veneer of words casting at least a shadow of their author. Analytically-speaking then, this communication approach can be conceived two-fold. In one sense, it emphasises how CH sufferers animate them-  
“selves” within various *languages of suffering*:

discursive flows and practices encouraging certain *identifications*, forms of *action* and the possibility to give one’s confusing illness *meaning*. In another, it draws attention to a set of problems that CH sufferers face when navigating social existence. “Communication” then, concerns both intra- and inter-subjective dialogues, expressions of suffering *inward* to oneself and *outward* to the world.

It has been repeated a number of times that acute pain ‘resists [...] even destroys language’ (Scarry 2007: 65, Good et al. 1992), a pertinent thesis for CH attacks (expletives notwithstanding). But if attacks are marked by abrupt screams and punctual groans, communicating their severity to non-sufferers is better described as a fumble; gesticulation, metaphor, unwholesome comparison, sentences left ..... Consequently, accounts appear unconvincing to many. Amidst this fraught communication lies the purgatory of isolation: ‘[...] pain sufferers report being baffled about how to communicate about their pain day in and day out, [...] some say this endeavor is more challenging than dealing with the pain itself’ (Jackson 2005: 340).

This paper is bifurcated. The first section considers the aforementioned communicative difficulties as occurring in two analytical realms: the *social* (between colleagues, employers, partners, family members) and the *medical* (in the procurement of diagnosis). I shall address them in this order.

This first section more specifically concerns chronic CH sufferers, but may also resonate with episodics.

In either realm, exasperation at other people’s disbelief unifies these centres of misunderstanding. Consequently, clusterheads faced social stigmatisation and had all manner of relationships poisoned. To be believed often required diagnosis, not only as “hard evidence” but for its ability to help sufferers accept their new boundaries and enact their diagnoses openly. However, certain factors hindered diagnosis with gender-bias and diagnostic terminologies found to be significant obstacles in the examination room. By way of transition and conclusion I recapitulate the social power of biomedicine, this time as the sufferer’s servant rather than their master.

The second section deals explicitly with some languages of Cluster Headache, of which I discuss two discernible styles: a *suffering* language and a *pain* language. These languages partly illuminate problematic issues in the sufferer’s journey but largely find utility as tools. Being the produce of social practices and ideologies, these languages carried their own meanings and subject positions which sufferers utilise for their salutary potential in personal and political

endeavours. Across these languages, sufferers oscillate between subject and object; between resignation and resistance; between warrior and sage, hopelessness and healing.



**- 1 -**

## **Communicative Difficulties:**

### **Problems between Sufferers and Others**

**“Acceptance is more than helpful. It is essential.”**



Social stigmatisation is commonly experienced by those suffering pain disorders. Confusions about the nature of chronic pain conditions have lead anthropologists to liken sufferer's treatment in society to that of liminal objects (Murphy et al. 1988; Honkasalo 2001; Jackson 2005), that is, to be kept at a distance.

Under biomedicine's positive gaze, the physically unmarked becomes the dialectically "marked" (Laclau 1990: 33) and this 'uncertain ontological [and epistemological] status' (Jackson 2005: 321) subsequently incites denigration.

Sarah is a professional chef from Larkspur, California. For 5 months now she has been unemployed due to chronic CH emerging 2 years ago. She suffers attacks once or twice a day, with three days being her longest remission period to date. Sarah sees her 'lonely condition' as just another in an endless string of misfortunes. 3 years ago her disabled father jumped from the Golden Gate Bridge, almost exactly a year to the day before her CHs began—a coincidence which had not escaped her notice. On top of CH, Sarah has now developed a weekly migraine disorder. 'People say that I have a "blackcloud" above me - because my life has been full of sorrow, loss, and now this ...'.

Two main features of a professional kitchen, *heat* and *stress*, are commonly cited as CH triggers. Despite these exacerbations Sarah continued to work for over a year, deciding to keep her condition a secret from employers.

*'I never told anyone. I would be fired. Keeping it a secret became impossible because my main symptom [other than pain] is a SEVERE runny nose. Not a good look for a chef. Ha. When I did explain it in secret to coworkers they were understanding at first..... but sometimes I needed them to cover for me, and they got very uncompassionate, very quickly. I've had to quit 8 jobs in the past two years because of CH [...] I didn't talk to my boss about it, because they don't care. If you are an employee that isn't 'reliable' because in the middle of the day you get a CH and you need to go home- why would they want you? They pick apart your work and find subtle ways to make you feel unwanted that have nothing to do with your illness.'*

It is evidently not for lack of desire that Sarah now feels unable to work; in those pain-free moments one is efficient, reliable, and perfectly "normal." Herein lies the paradox. Chronic CH differs from other chronic pain disorders in that the affliction is not ever-present but scatter-gun in presentation. Working any CH condition, episodic<sup>4</sup> or chronic, into the work environment bears greater challenges than usual for employees and employers alike. The unpredictability of the

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<sup>4</sup> One interlocutor, who only ever suffered 2 cycles in 20 years, told me that the fear of having a CH attack at work was a contributing factor in leaving his high-profile job at the United Nations.

condition throws all hope of consistency out the window, it is never a simple case of allotting one's attack time. In Sarah's case this is more untenable still. One is thought to be irreplaceable during those fast-paced hours of service, taking time out to deal with spontaneous attacks is a bigger ask than in other professions. Under such high stress conditions, Sarah's unreliable attacks were quickly interpreted as personal unreliability, mere excuses, especially when the group's workload increased. As such, employees suffering constant, predictable impairments might be accommodated for in a way CH sufferers rarely can.

Emily is another chronic CH sufferer from Shawnee, Kansas. Emily is prolific blogger, she writes about the untold hardships of suffering multiple pain conditions of which CH is only one. Her posts often bear a courageous truth about her suffering, offering practical techniques and emotional support to help others cope with their confusing condition. Emily is a staunch advocate for chronic headache and migraine conditions; she currently sits as membership chair of the American Headache and Migraine Association and volunteers as President of the CHSG. She recalls her first CH attack for me:

*'CH first appeared on Oct. 17, 1999 just a few days before I was to return to full-time work after several years as a stay-at-home mom. I'd been dealing with a stubborn migraine for more than a day, when CH hit and my world turned upside down.'*

I asked her what she meant by "my world turned upside down," thinking it bore some problematic relation to her imminent employment. Quite to the contrary, Emily mentioned working full-time for many years with CH as a software developer for an IT start-up. She kept oxygen tanks<sup>5</sup> in her office, treating attacks 'in full view' of her co-workers.

*'People get so self-conscious [...] I've never once had anyone treat me badly or make insensitive comments. I've always received full support. Sure, there is stigma, but its clearly not as bad as some people fear. I keep waiting for some idiot to say something stupid just so I can let him/her have it ... but it never happens [smiley face emoji].'*

What might account for this difference in experience? Beside the nature of their work, I found another clear distinction between Emily and Sarah when asking what kept them busy. Having spent many years with a variety of pain conditions, Emily immediately identified herself as disabled. Sarah conversely identified as a professional chef currently unemployed. Speaking of her precedent chronic migraine condition in a blog post, Emily writes: 'I decided to integrate migraine into my life and accept its place as part of my identity. I became my migraine.' Regarding CH more specifically she tells me: '[I] learned how to keep on living even with the pain, to feel comfortable using whatever accommodations were needed (O2 tanks, ice packs, meds, etc.), and to not hide

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<sup>5</sup> high flow oxygen is widely considered the most effective abortive treatment for CH

away. I get out in the world whenever I can, even if it means wearing ice packs and towing an O2 tank along.'

Emily achieves what Sue Estroff (1993) has called *chronicity*: 'a fusing of identity with diagnosis' (ibid.: 251). Within the confines of the English language, this is a particularly challenging identification to articulate. CH - unlike schizophrenia, diabetes, or epilepsy - is conceived in possessive terms; i.e. "I *have* CH", rather than "I *am* ... a schizophrenic, diabetic, or epileptic" (ibid.: 256-258). By *becoming her migraine*, Emily plays at the limits of received expression to demonstrate an acceptance and identification. Popular CHSG term "clusterhead" is a creative means of achieving this same end.

Whilst Estroff maintains that "I am" illnesses are more stigmatised (ibid.: 257), I contend the idiopathy of CH makes this articulation exceptionally important. Since one's questions regularly persist beyond the doctor's office, forums like the CHSG are particularly active. Members frequently trade notes on medications, treatments, even causal theories; moreover, the CHSG private group serves partly as a confessional to vent dissatisfactions with partners, family members, or authorities. To receive (and provide) this all-important support one must express solidarity with the community. Whether explicitly using a term like clusterhead or not, by posting or commenting on forums one implicitly states: "I *have* CH, I *am* one of us." And so, it follows logically that without diagnosis there can be no identification. It is here that Sarah and Emily's divergent identifications may be partially explained.

'I just got diagnosed in October,' writes Sarah, 'so I never told any of my past coworkers. I confided in one that I had nerve issues in my brain and that I suffered from strange symptoms - she accused me of being a junkie.' Sarah's affliction then, considered as an irregular and temporary onset of 'strange symptoms' was her communicative difficulty in this case. The inability to authoritatively name her symptoms left Sarah outside the categorical model of health in the US. Unmoored from a totalising diagnostic label, these bizarre symptoms elicited radical doubt as to any pathological root cause. Unable to legitimise her persistent hardship or meaningfully integrate the phenomena into her identity, Sarah was stigmatised by her employers and co-workers. This latter fact partly explains her previous preoccupation with being 'reliable,' an employment value which subsumed under the legal signifier of "disability"<sup>6</sup> becomes relative not absolute.

Emily learned over time to adopt this no shame policy in her public life. Her ability to own her condition, bearing the paraphernalia of CH suffering openly, protects her from dismissive social attitudes in a way that secrecy does not. The pair differ substantially in their experience of public CH suffering for want of diagnosis, and consequently, identification. But whilst Emily has fewer issues in public life, behind closed doors things were not always so easy. She tells me:

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<sup>6</sup> a label offering legal protection, see Americans with Disabilities Act (ADA) 1990

*'That first year was difficult [...] It took almost 6 months to get an accurate diagnosis and proper treatment. Before that, I was in the emergency room every week when the pain got out of control and I couldn't take it anymore. The only people who truly supported me were my husband and my parents [...] His mother and sister were particularly cruel, accusing me of faking my pain to avoid caring for our children. Because we didn't really understand what was happening, we thought maybe I was suffering from mental illness. My husband and I both felt so helpless. Our kids were only 3 and 7. They were afraid that Mommy was going to die. Both kids are still affected by that trauma. As a result of all the stress, my husband and I almost divorced about 2 years later. It took a lot of work to rebuild our relationship.'*

Again we see a host of inter-personal issues arising in this liminal space between presentation and diagnosis. Biomedical authority retains such a hold on the communication of suffering—especially in the US—that pathological experiences falling in its blindspot produce outright vilification, even from within the family unit. Emily is not the only interlocutor who initially thought her condition a mental illness either. Despite being experienced as searing *physical* pain, the social reality of head pain is so deniable and so often denied that “all-in-your-head” explanations become viable (Jackson 1994), even for the sufferer. However, Emily's story should ultimately make us hopeful. Initially chronic CH, like all chronic illness, feels like an endless string of problems. But once one's suffering is socially and personally accepted, new limits come to be defined and life begins to normalise. As one other sufferer put it: 'The world as we know it has shrunk ... If its not quite yet as normal as I hope, then [my] outlook will change to make the best of the shrunken world left.'

Having now obtained her diagnosis, Sarah can begin the long process of redefining her limits. Right now the process seems overbearing: 'I have never been so low in my entire life. It makes me question everything. I can't take care of myself right now- so how will I be able to sustain my life? I have a lot of big questions, and no answers. It is defeating.' Perhaps then the final words are best left to Emily: 'I would have been dead long ago if I hadn't learned to accept CH as part of my life. Is it unfair? Life is unfair. If we are going to be mentally healthy, then our personal hardships must become normalized.

Fighting against the inevitable is useless and only causes more suffering. *Acceptance is more than helpful.*

*It is essential. Without it, CH will destroy your life.'*

**“Sometimes I just want people to believe that its true  
...”**



**- THE MEDICAL: (MIS)DIAGNOSIS & ITS LANGUAGE -**

*The merest schoolgirl, when she falls in love, has Shakespeare or Keats to speak her mind for her; but let a sufferer try to describe a pain in his head to a doctor and language at once runs dry.*

- Virginia Woolf

As our previous section attests, 'diagnostic manuals [operate] as powerful connecting tissues in and between a large number of social practices and the diagnoses themselves [are] central boundary objects within many communities' (Brinkmann 2014: 637). Frustratingly then, it is not unheard of for CH sufferers to go many years without diagnosis. There are discrepancies between episodic and chronic sufferers on this issue, with episodic sufferers usually withholding doctor's appointments on the basis of longer remissions and therefore less disruption to their lives. Regardless, the absence of diagnostic labels eventually lead to anxieties amongst my interlocutors, often impelling them to hypothesise cataclysmically. Issues of *gender* and *terminology* were raised as some obstacles to obtaining diagnosis. Of the two interlocutors who obtained first-visit diagnoses, both were male and just one achieved diagnosis through purely symptomatic description. The other occurred after the sufferer was hospitalised by an attack, and even then the condition was almost missed; by chance a visiting doctor spotted a singular dilated pupil concomitant with the unilateral presentation of CH and diagnosed the condition. Kempner (2004, 2006) provides an exhaustive discussion of gendering in CH, documenting how the observation of its greater prevalence among men lead researchers to construct CH sufferers as hypermasculine, leonine, "Type A" personalities. Whilst curious as to the implications of this thesis in the doctor's surgery (ibid.: 650), her work does not extend so far. Amongst my limited sample of female interlocutors, 4 out of 6 considered themselves victims of gender bias to varying degrees. Understanding the power of diagnosis to end catastrophising and begin legitimising, sufferers would forcefully direct their physicians toward diagnostic baptism, often succumbing to a common trend in our digital episteme: internet diagnosis.

Whilst CH bears close symptomatic resemblance with other disorders (chronic paroxysmal hemicrania, Tolosa-Hunt syndrome and various trigeminal neuralgias), my interlocutors received some surprisingly erroneous diagnoses or explanations from Bell's Palsy and Multiple Sclerosis, to Stroke, allergies, congestion, '*having periods*', or just told they were '*anxiety and depression related*.' Migraine was a common misdiagnosis among female interlocutors. Despite some overlapping diagnostic criteria, its differences with CH are radical; particularly their vastly differing attack behaviours (lying still vs. restless pacing). Epidemiologists claim migraine has a greater prevalence amongst women (Lipton et al. 2001; NHS 2016a), a bias that female clusterheads felt contributed to their misdiagnosis. One CHSG member writes: 'I can't tell you how many doctors insisted I did not have cluster headaches.... Because I am a female.' Migraine withstanding, amidst



these misdiagnoses we can see other gender-biased diagnoses emerging from the examination room. Sarah felt this victimisation pervaded the entire medical system:

*'Men and women in America who work in the medical fields tend to look at all women as just being "hysterical." Have you ever heard the fact that it takes over FIVE visits for a woman to be diagnosed with heart disease in the U.S.? That's AFTER presenting with symptoms. FIVE VISITS. That is an accurate depiction of what being a woman in the U.S. is like. Our pain isn't "real", and very often not acknowledged until it is too late [...] my country has a serious problem with sexism- such a problem, that is literally killing us.'*

In line with sociological works on “deviant” identities (Goffman 1963, Susman 1994, Clarke & James 2003), it is possible that the marginalised experience of idiopathic conditions plays into other oppressed discourses such as those surrounding gender. We must always remain cautious of virulent reductionism at either extremity. However, derivative debates persist. The ICHD-3 states: ‘For unknown reasons, men are afflicted [by CH] three times more often than women’ (Cephalalgia 2014: 666), however, recent studies suggest the condition may actually favour women over men (Jürgens 2017). In the wake of these unknowns I see no immediate advantages in adding such information to diagnostic manuals for CH. Adding possible disregard to an experience already at the outskirts of social and medical care leaves sufferers increasingly vulnerable. Indeed, one woman’s search for help nearly ended tragically when visiting what she called “an illegal Chinese medicine man”:

*'He operated from home and had no qualifications to do anything. He did a lot of manipulation, give me herbal remedies to relax (i had no idea what i was taking), different types of massage, one day he tried to take advantage of me sexually so i never went back. I was desperate for help and put myself in danger.'*

Are symptoms not enough? Are sex-specific weightings more divisive than conclusive, assumptive rather than attentive? Disposed toward *looking* rather than *listening* in the already precipitous context of a 10/15 minute check-up<sup>7</sup>? Is this “knowledge” about CH ultimately useful afloat an ocean of unknowns? Kempner has already demonstrated how masculine stereotyping and *a priori* gender assumptions have massively limited research into new knowledge, new CH therapies (2004: 222). It seems sensible to reiterate the conclusion of John R. Graham’s essay on headache disorders: ‘[t]his attitude of keeping an open mind until we have more certain markers to identify etiology of these conditions may be the wisest attitude to preserve’ (Graham 1984: 87).

Whilst lost in that whirlwind of misdiagnoses, false assumptions and cruel accusations, Emily went online in search of answers. Matter-of-factly she tells me: ‘At that time OUCH [another

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<sup>7</sup> On average, doctors in the US spend 13-16 mins with patients (Peckham 2016 [Medscape]), dropping to 8-10 mins in the UK (NHS 2016b).

CH forum] also had a presence here in the U.S. I stumbled across their website, diagnosed myself, learned about O2, and then called my doctor. He agreed, set me up with O2 and then referred me to a neurologist for confirmation.’ As they say: “Its easy to get around once you know the language.”

‘Pain sufferers learn that normal, everyday-world language can be a serious stumbling block for communication’ (Jackson 2000: 165). One male interlocutor, who had accrued three precedent misdiagnoses, told me: ‘The sinusitis diagnosis stuck for a while [...] this diagnosis only changed after many visits, when one day I remarked to a doctor that I felt like topping myself during the headache attacks. It was then she looked in her book and realised the similarities in what was happening to me and clusters.’ Indeed, the sensationalised suicide headache label pricks up ears among laymen and doctors alike, certainly it was the only “everyday” term that helped this sufferer.

Diwa is a 28-year-old bookmaker from Antipolo City in the Philippines and has suffered episodic CH for ten years now. ‘I think mine is like the mildest not in terms of pain but at least in terms of how often I experience it.’ Diwa only gets one cluster cycle every other year. Certainly his pattern is so disparate that for many years it was put down to changing climate or stresses. But as the condition persisted Diwa could not ignore the sheer intensity of the pain and began fearing the worst: ‘I was starting to be paranoid and thinking that it was like a brain cancer<sup>8</sup>. I had an idea that it is a CH when I looked it up on the internet my symptoms and how I describe the pain. And finally I visited a neurologist and diagnosed me that I have a CH.’

Diwa's ability to research then communicate in this diagnostic lexicon became essential to obtaining his diagnosis. Diagnostic manuals (Longmore et. al 2014: 461, Cephalalgia 2013: 665-667) favour some specific features for CH diagnosis; unilaterality (often without variation), watery or red eye, rhinorrhoea (runny nose), lasting 15-160/180 mins, once or twice a day with remission periods, and often nocturnal. For many whose experience deviates or whose vernacular jars with this criteria, an appeal to such specificities and their turn of phrase is helpful in jogging physician's memories. Certainly physicians *must* be the final arbiters of one's hypotheses, in the age of “patient-centred medical care” (read: medical consumerism) desperate internet diagnoses can often be mistaken, and costly (Prior 2003). Nevertheless, open access to diagnostic criteria helps facilitate a two-way conversation between sufferer and physician which is especially important in the case of rare disorders like CH. Virtual communities, like the CHSG or OUCH, possess term-specific criteria sheets which can help turn confused sufferers with “strange symptoms” into veritable advocates for the cause.

Being potent symbols of biomedical authority, diagnoses usually socialise one's abnormal experience. Yet people still expect diagnoses to function in certain ways: i.e. “*These symptoms are*

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<sup>8</sup> I found cancer fears to be near ubiquitous among my interlocutors in the period leading up to diagnosis.

the result of *this* underlying cause, it has x, y, or z options for treatment.” Being idiopathic, a CH diagnosis does not function like this. Idiopathy in turn prompts idiosyncrasy. My interlocutors cited differing triggers, found differing medications or treatments effective, and held their own theories about the root cause of their CH. To echo Sarah’s words, it is in this regard that CH is a “lonely condition.” This multiplicity was evident in CHSG interactions where members frequently deployed an “each-to-theirown” philosophy of peer support—the tone between optimism and pessimism often illegible. Since each is indeed “to their own”<sup>9</sup>, *self*-knowledge becomes increasingly essential.

Diwa’s desperate proclamation is the title to this chapter, since despite obtaining diagnosis others still do not believe him. Diwa now rests his hopes on his ability to predict attacks as evidence: ‘I am not wishing it to happen this year just to prove to everyone that it really happens to me every other year, but *sometimes I just want people to believe that its true ...*’ An ability to make claims or predictions about one’s illness serves as marker of legitimacy whilst affording a sense of empowerment. Resultantly, many sufferers keep data on their condition; I was actively encouraged to keep a diary of my headaches by my doctor (see Appendix A). Prediction offers power and proof.

When initially volunteering for the project some interlocutors sent me swathes of “proof” about their condition. This proof was *always* expressed through biomedical terminologies. Interlocutors attached detailed attack diaries, exhaustive lists of medications and dosages, how they reacted to said medicines and a host of other nuances about their CH specifically or the condition generally. Those who felt this gesture necessary often mentioned a history of having their condition delegitimised by others.

One man opened his lengthy thousand-word message with: ‘Are you a sufferer, or just interested in study? I hate it when people say, “It’s a {blank} thing, you wouldn’t understand,” but when it comes to cluster headaches, I’ve found that it’s incredibly difficult to get people to truly understand the pain and debilitation. They always minimize the severity of the condition.’

Drug names, doses, research knowledge, technical terms (“shadows”/“triggers”), diaries, and pain scales all serve to project a certain class of knowledge connoting officialdom, consequently offering aesthetic irrefutability lest one encounters another’s denial. We are beginning to see how language, as embedded in social practices and ideologies, transcends its veridical faults and finds redemption as a *tool*.

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<sup>9</sup> “Idiopathic” derives from the Ancient Greek word *idiopatheia*, literally meaning “one’s own suffering/disease/feeling.”



**-2-**

**Some Languages of CH:  
Meanings & Positionings**

# Suffering & Sagehood



*The sage does not hoard.  
The more he helps others, the more he benefits  
himself, The more he gives to others, the more he  
gets himself.*

- Lao Tzu

Brinkmann (2014) identifies five general “languages of suffering”: diagnostic, moral, existential, religious, and political. Whilst these languages are spoken, they are more than utterances. Being embedded in specific social networks, each language possesses its own meta-narratives, ideologies and subject positions with different opportunities for practice appearing in the process of interpretation. Languages may gesture to specific problems in the sufferer’s journey. For example, my female interlocutor’s frustrations at multiple misdiagnoses sees them deploy a political language of suffering. However, Brinkmann views these languages as tools to be employed pragmatically according to usefulness; ultimately, how do languages enable sufferers to cope with the multiple distresses of suffering? I found two prevalent forms of CH language: a *suffering* language, mediating a life between attacks; and a *pain* language, expressing the excruciating character of attacks. Through these languages sufferers create new meanings about their situation and assume salubrious subject positions, temporary roles harbouring certain beneficial attitudes about oneself and one’s condition.

The previous section affirms the power which biomedicine exercises over the social experience of suffering. Its “diagnostic language”—to use Brinkmann’s term—is so often used out of necessity in the mediation of everyday healthcare and social welfare, but also manifests practical solutions. For all the fineries and failings of the biomedical machine, its authoritative terminology demonstrates utility in relegitimising our CH sufferer’s experience in the face of potential disbelief. Being the most recurrent heuristic device this chapter will investigate some semantic potentialities of diagnostic language when coping with CH.

Neil is a 57-year-old ‘fully disabled veteran’ and ‘chronic, intractable’ CH sufferer currently living in Brooklyn, Michigan. His first CH attack was in 1998 whilst cramming for a Physics exam, its alarming violence merited a call for emergency services. Neil professed the virtue of his military training in enabling him to utter even the smallest words to attending doctors that day. Still his CH was not spotted until he saw his doctor at the Veteran Administration three weeks later. Fortunately, a visiting neurologist from the University of Michigan was sitting in on the

consultation and recognised Neil's condition. Currently Neil endures two attacks a day, rising to six 'during peaks such as Solstice and Equinox.'

In his pain-free moments, Neil busies himself with computer programming, gaming, database development, research, writing, and playing guitar. Neil is a fount of knowledge on many topics besides CH and, drawing from diverse fields of research, would occasionally reference pertinent peer-reviewed studies when answering me. Neil once studied for a PhD in I.T. but couldn't completed it due to illness, although this hasn't stopped him writing research papers for the CHSG. He has even composed a guide to help its members conduct their own research. His passions for research, databasing and quantitative analysis were clearly incorporated into how he dealt with his condition. Neil documents his pain with decimal accuracy (his first attack registering 9.3 on his personal scale) and keeps data on all manner of variables (see Appendix B):

*'In keeping data, there is no wrong on what NOT to keep. Something that may seem unimportant ten months ago, may now be very important. As a thought comes to me on a possible data-point, I start logging... Once you start keeping data (six months is good) then start testing. What happens when I get five hours of deep sleep, what happens when the humidity goes above 40%, or start taking 300mg of a medicine instead of just 250mg. Without capturing these nuances, - you will not know where the answer lies. Granted: some pieces of data may be needlessly kept but no doctor or scientist can say with any level of assurance what causes clusters. Nobody. ...and I try to read all of it.*

Neil emplots himself in a diagnostic language of suffering here. Seeking out and writing research, logging data and experimenting with variables are all practices of medical science. This analytic-cumexperimental mode of attention not only affords intimacy with the biomedical healthcare system, producing information which speaks its native tongue, but also situates Neil in a web of its tacit understandings.

Biomedicine makes a number of assertions about the world, centrally that illness is somewhat causally determined being the result of material events. As Brinkmann notes, such determinism is fundamentally fatalistic in character; one's condition is conceived within a succession of causal processes beyond personal accountability (2014: 644). Returning to CH, this prevents sufferers from indulging moralistic narratives particularly common in cases of idiopathic illness where, from lack of authoritative explanations, sufferers tend to hold themselves either partly or wholly responsible (Honkasalo 2001: 342-343). To borrow from narrative therapy, such explanations help sufferers "externalise": '[to] appreciate that *they* are not the problem, but that "the problem is the problem"' (Brinkmann 2014: 637, original emphasis).

But Neil does not use diagnostic language to find solace in mechanistic laws, rather he inquires into causal relations with a view to finding "the answer." Instead of submitting to diagnostic ideology, Neil retains agency through its practices, pursuing what "no doctor or scientist can say with any level of assurance." Idiopathic illness prompts active investigation more than its

better-understood counterparts. Neil was palpably unimpressed with most doctors, when explaining “the 80/20 rule” to me he wrote: ‘It says that 80% of the people do 20% of the work. ...and 20% of the people do 80% of the work. This is true for doctors, mostly.’ Neil’s diagnostic expression of suffering partly illuminates biomedicine’s epistemological deficiency but his analytical practice achieves something more: it attempts to fill this void whilst simultaneously offering a relieving, distantiated subject position.

Louis Althusser writes ‘[...] the author, insofar as he writes the lines of a discourse which claims to be scientific, is completely absent as a ‘subject’ from ‘his’ scientific discourse’ (1971: 171). Leaving the veracity of this statement aside momentarily, Althusser succinctly articulates a fundamental ideological premise of science, and by extension, the diagnostic language: its claim to objectivity, or better still, its lack of subjectivity. Although never stating it explicitly, Neil’s activities satisfy more than most basic definitions of science. Via experimentation and documentation, Neil makes his “suffering self” into an object, a body of data, upon which some “analytical self” observes from afar. Whilst predominantly identifying as “disabled,” Neil’s pursuit enables him to assume the role of “analyst” or “scientist” and forego this identification temporarily. Moreover, the systematic demand of this virtual corpus draws neater lines through the messy experience of suffering rendering it both external and legible, tamed within categories of Neil’s own choosing. In this sense, the analyst’s coherence is directly opposed to the sufferer’s chaos. But what to make of Althusser’s claim?

This “analytic self” is not subject-*less*, rather it is subject-*elsewhere*. As Neil’s excerpt demonstrates the “analyst’s” data-points must be inspired, constantly in conversation with one’s “pain-free self,” “painfull self,” “suffering self,” or any other “self” for that matter. The analyst role then is neither outside subjectivity nor stand alone. It would be equally misleading to claim the “suffering self” is somehow essential whilst “data-self” or “analyst-self” offer cowardly escape. No, the self is not singular, hierarchical, either present or absent, authentic or inauthentic; rather it is various and *multiple*: ‘you are your data, but your data is just one of the many you’ (Sherman 2015). Multiple subject positions then are at play in this practice of data-collection, conversing and colluding, configuring appropriate intimacy and distance from one’s suffering in the marathon of coping with CH. But what is the relieving property of this *elsewhere* analytical self if not obliterating subjectivity? I argue that the “analyst” possesses a wholly different *project* to the “suffering self.” This project—to borrow a term from existential philosophy— reverses, and therefore, liberates the regular relationship of the person to their suffering. It provides meaning afresh.

Drew Leder (1990) argues that pain disrupts the body-subject’s intentionality, that is, it breaks off its “directedness” (viz. existential relationship) toward the world ‘in all its dimensions’ (ibid.: 74). Elsewhere in Neil’s account of that first attack he writes: ‘I couldn’t manage the concentration level to scream. To scream requires some level of concentration.’ Certainly a

substantial dampening of intentionality accompanies CH attacks, whilst the “pain-full self” predominates interlocutors found it hard to walk, talk, scream or “think straight”. However, whilst the existential-phenomenological term “intentionality” is helpful moving forward, the “analyst” positioning is not addressing the “pain-full self” directly but the “suffering self”: the overall conception of oneself as marked by CH.

In her work with chronic, idiopathic pain patients, Honkasalo (2000) found interlocutor’s would often ruminate on their past selves when narrating their suffering. She contends all idiopathic and chronic pain sufferers have their directedness turned inward toward their past. I detected this trend among clusterheads also. After asking one interlocutor to clarify at what age her CH had started, she wrote:

*‘I was indeed 14/15 when I first started going to the doctors about my headaches. I would get headaches pretty much every day and couldn't concentrate in school, I was moved up in all my sets for main subjects (English, Science and Maths) after I started getting more intense headaches I was moved back down in Maths as I just couldn't process numbers or concentrate at all as I'd usually have to sit out or go home. Thankfully English and Science weren't a problem.’*

This interlocutor takes the opportunity to lament her lost mathematical prowess and demonstrates how illness narratives quickly become about one’s life situation, particularly the delegitimation of their past self (Kleinmann 1988, 1992). In any event, the sufferer’s intentionality is often directed toward *themselves* not others (Buytendijk 1962). In Neil’s case the analyst role reestablishes this directedness toward the world, allowing him to suitably attend to himself whilst simultaneously making it about others. By reestablishing a connection between self and other, the analyst becomes sage.

‘When we lose a person to suicide on the CHSG, I take it extremely personally,’ writes Neil, ‘I try to think of ways to develop new tools for people who suffer from clusters to use.’ His gesture here is quite beautiful. Under the guise of critical thought, science and its objective claims are so often hounded for their hegemonic, normalising tendencies. Whilst these systemic critiques are important, they often neglect to acknowledge the impulse behind the microscope. The impulse to universalise, to act through an “objective” discipline is ultimately to say: how can we relate to others whose situations, worldviews, and life strategies are different from our own? (Jackson 2013: 21). Following this thread we could argue for a manifest allocentrism behind the analytic subject position. I certainly wish to stake this claim in Neil’s case. The “analyst”, as articulated through diagnostic language, offers a new meaning to Neil’s condition. Rather than being a “lonely condition”, Neil’s CH has purpose via this subject position. The “analyst’s” production of knowledge affords control and distance whilst simultaneously retaining social value through its empathetic prerogative. A salvation through semiosis.

“Diagnostic language” occasions several pragmatic opportunities for the idiopathic CH sufferer:



its authoritative terminology allays social vilification; its ideology curtails the moral confusions of idiopathic illness; and in this case reconfigures the suffering experience toward sociality. Whether undertaken rigorously and explicitly *for* others, or approximately just to communicate the specificities of one's condition, this method of attending to oneself opens up the world.

My correspondence with Neil was always warm-hearted, his commentary on the hardships of suffering—CH and otherwise—was always sage-like, at times truly poetic. He sought to help as much as possible, from referencing papers to advising me on future employment (after I shared with him an opportunity that had come my way). Having lost a child some years beforehand, Neil's hard-fought ability to turn privation into philanthropy was inspiring: 'Before [CH], I had a great deal of empathy for people in pain. The death of my child gave me that [...] However, that increased when I became stricken with clusters. Not because of my pain, that is a problem to solve. No, for the people who also have this affliction, I cry.' Whilst Neil's empathy is particular overt, clusterheads frequently cited increased empathy as one way their condition had changed them. This needn't necessarily require a diagnostic language of suffering. Indeed, the call to empathy was far louder in other languages. One particularly impassioned member of the CHSG public forum stated:

*'I know that I was given what I have for a purpose [...] I'm a teacher of life, a survival guide, and the world's probably poorest homeless philanthropist. I'm a healer, I love unconditionally all things and all people. Why me? Because the world needs more compassion. And nothing is more humbling than losing everything, crying out in pain while being hungry and violently ill - and no one caring [...] Because we need more loving kindness in the world, and I needed to really truly understand suffering in order to be a vessel. Does that mean every second of every day I'm thinking about world peace and fellowship? Hell no - about every two and a half hours I'm screaming for my pills. But in the space between, I can be something greater than myself.'*

'I needed to really truly understand suffering in order to be a vessel,' writes our sufferer. What they are a vessel *for* exactly is left ambiguous, but the rhetorical style, allusions to being a healer, having a purpose, and becoming greater than oneself, do not require pleonastic analyses to impress the religious language at play here. The notion that through suffering one is turned toward the Other draws from the suffering of Christ and offers yet another way 'of seeing oneself within a larger horizon of meaning—an *ontic logos*' (Taylor in Brinkmann 2014: 638). Whether becoming "healer" or "sage", on this horizon our sufferers actively acquire new meaning by directing themselves toward others, against all odds.

If empathy toward others is one outcome, then "hardening" of the self is another. These two sentiments often occurred simultaneously, initially seeming contradictory until I realised they operate within two completely different ways of being in the CH world. "In the space between," when relatively at leisure, clusterheads can make meaning out of their suffering through additional empathising. However, when "the beast" calls it finds someone else waiting.

# “... Dollars, not bodies”: The Beast & The Warrior



*God is a concept by which we measure our pain.*

- John Lennon

Shared tropes, rhetorical motifs, and thematic archetypes become especially salient within pain communities; language is deemed insufficient to describe life in the pain-full world yet sufferers must regularly resort to lexical practice. Jackson argues that pain is better expressed as *metaphor*, a strategy allowing for pain to be communicated as embodied experience (2000: 163). An example might be “seeing stars,” which Scarry (1985) explains is not literal but refers to the contents of consciousness which are ‘during those moments, obliterated [...] the name of one’s child, the memory of a friend’s face are all absent’ (ibid.: 30) lost in a vast nothingness associated with Outer space. Establishing broad, multivocal conceptual images not only grants emotive and narrative form to the inexpressible but unites CH sufferers in a mutual poetry, mysterious like their ills: ‘[...] the tacit understanding and acceptance of metaphor creates the intimacy of sharing a private language’ (Kirmayer 1993: 178). This matrix of metaphors, symbols and archetypes also constitutes a “language” in the Brinkmannian sense, that is, certain understandings and practical transformations become available through its use.

CH and its pain have accrued a wealth of metaphors, metonyms and idioms: “the beast”, “the devil”, “the storm” and “suicide headache” being among the more popular (see Appendix D). Descriptions of the pain as: ‘like an icepick’; ‘like lightning strikes’; ‘[a] 600 pound sharp rock digging at the base of my skull’; ‘as if the sun had risen behind my right eye’; ‘like someone is poking a hot metal rod with multiple barbs on it into my eye,’ all serve to paint a hellish mythoscape. Unsurprisingly the CHSG is interspersed with accordant imagery (see overleaf). These images and terms aptly depict a quasi-Judeo-Christian, morbid and occultish universe affirming the ‘living hell’ of CH between sufferers. This system of tropes and symbols partly constitutes the CHSG’s “ideology” (Stromberg 1990: 42) and these basic units mediate its member’s mutual understanding. This ideology encourages a pugilistic subject position to battle this agentive pain creature. Moreover, this emotive religious language pushes a latent political agenda: to garner institutional recognition against the chronic underfunding of CH research.

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Pain, suffering, and religious thought have enjoyed close acquaintance for millennia. As a framework, religious explanation helps confront issues of ultimate meaning in suffering: the problem of Job. Its answers may quietly provide solace or culminate in powerful atonement narratives as exhibited at the close of the preceding chapter. Even famous CH sufferer, Franz Kafka, came to see himself as being ‘tortured by agonies *like a martyr*’ (Kafka in Ekbohm & Ekbohm 2004: 309, my emphasis).

‘What was formerly sin is often now seen as sickness’ writes Taylor (2007: 618) in his treatise on secularism. Whilst today even the explicitly religious place their faith in biomedicine to answer the “hows” of illness, the system is wholly inadequate for answering the “whys”. As such religious languages of suffering persist, especially among clusterheads where even the totality of “hows” remain unanswered. Pain, from the Latin “poena” meaning punishment, is now understood functionally: to indicate bodily malfunctions. In such cases, it means the excellence of our biological design. However, in CH, where no underlying problem appears to exist, pain loses its

functional meaning and consequently reappropriates its oppressive latin derivation, becoming simply evil (Wolterstorff 2007). If the popular conception of CH pain as a “living hell” marks it chiefly outside the paradise of wellbeing, its additional idiopathic character helps push it beyond heterodoxy into active epistemological *deviancy* (Herzlich 1995: 156), accruing the appropriate demonic ornaments. And so, the God-Devil, Good-Evil dialectics persist, even amongst secular clusterheads; perhaps as the last palatable ontological markers of absolute positivity and negativity. By their very definitions, God signifies all that is good, and the Devil all that is bad (theodicies notwithstanding).

Looking at clusterhead’s description of their pain we can descry the agency afforded this evil: ‘like *someone* is poking a hot metal rod’; ‘*someone* having a scalpel twisting my veins like spaghetti’; ‘like I took a couple punches’; even allusion to tools possessing no agency of their own accord: ‘like an *icepick*’ or ‘a *spade* is implanted about 6 inches into my face.’ I found those interlocutors with a propensity to see CH attacks as intentional, demonic entities spoke of an equally mythic attack-response identity: “*the warrior.*” This character was emblazoned on CHSG merchandise, its forum rife with members encouraging one another to “fight” and “stay strong” during attacks.



Combative rhetoric is nothing new in illness-talk. Burnside (1983: 2091) explores the pervasive “*medicine is war*” metaphor, tracing it back to Hippocrates who talks of “the *violence* of disease.” Whilst Burnside’s article is centred on inter-practitioner interactions, this metaphor has permeated society-at-large through doctors visits, advertising, and awareness campaigns: “Join the *fight* against Cancer/Heart disease”, “the body’s *defence* system”, “Heart/Asthma/CH *attack*”. Burnside supposes ‘this metaphor is one that society has encouraged us [doctors] to use, since it fits a comforting notion they have about us’ (ibid.). This may be so, but in the case of CH such comfort is largely absent. Using this language as a springboard, sufferers tend to assume this role themselves.

Discussing the metaphor: “*argument is war,*” Lakoff and Johnson (1980: 4-6) claim we do not just speak of arguments *in terms of* war, but we think of ourselves as *winning* and *losing* them,

that is, we live by the metaphor as a metaphorical concept. The same reasoning can be applied to “medicine is war,” or returning to topic, “CH attacks are war.” In many respects “winning” a CH seems inevitable; all attacks eventually subside. For some, this ability to consistently “win” attacks gave them great pride. Emily tells me:

*I've discovered how strong I am. That really means a lot because I was always viewed as weak and sickly. I recently had an outpatient procedure done that is considered very painful to most people. I found it to be uncomfortable, but not painful.[...]When finished, the doctor remarked that I was “one tough lady.” The everyday discomforts of life just don't register on my pain scale at all.*

Taking Emily's history of suffering multiple pain conditions and their affiliated stigmas into account, we can grasp another significance to her warrior subject positioning. Kemper notes: 'The cluster profile suggests strength and vigor, not the psychological weakness associated with pain conditions (Jackson 2000). Cluster's masculine rhetoric confers status [... CH sufferers] are viewed as strong individuals experiencing serious and important pain [...]' (2006: 650). Whilst the potential to relegitimise oneself and resist oppressive narratives (Kleinman 1992) may be a contributing factor to the pugilistic language of CH pain, a full analysis must realise the broader political context of CH research and also remember what “losing” a CH looks like.

The Will Ervin Headache Research Foundation in Texas was recently established in memory of a chronic CH sufferer who took his life at the age of 24 (Cure Headaches 2015). CHSG staff inform me at least one of their 13,000-strong network takes their life every year. Even during the course of this project the group bid farewell to another clusterhead. Whilst the warrior often wins, to lose is all-or-nothing. For now this warrior spirit, embodied and encouraged by organisations like the CHSG, is one of the few consolations amidst abnormally high suicide rates. Many feel the “suicide headache” label more be appropriate, not least because it holds truth. Sufferers expressed considerable animosity toward the terms “Cluster” and “Headache” feeling neither term nor their combination adequately express the intensity or tragedy of the CH experience. “The most painful condition known to medical science” and “suicide headache” have gained most traction amongst spokespersons discussing CH in the public sphere<sup>10</sup>, these terms speak the language of CH pain for sufferers and certainly turn more heads. Many campaign posters build on taxonomies of pain often comparing CH with childbirth (see below), a social practice carrying particular nociceptive currency and significance in the US (Womack 2009: 107; Jordan & Davis-Floyd 1993) where currently the most private and public medical research funding is issued—estimated at \$119.3 billion per year (Chakma et al. 2014). By comparison, a report dated 2013 found CH had received only \$2 million of US research monies since 1988 (Headache and Migraine

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<sup>10</sup> see Beck (2013) for a typical journalistic piece about CH



News 2013). This neglect was palpable among my interlocutors. ‘Yes I am pissed that there is no known cause,’ writes

Sarah, ‘They say it is the most painful thing to have, yet they don't seem very motivated to help us. They being "big pharma" and the other capitalist-driven mad scientists of my country [USA] who only care about *dollars, not bodies.*’

In light of this information, the impulse toward sensational, theological language finds a *political* as well as expressive impetus. Whilst biomedical institutions project an objective unbiased image, 55% of US physicians say their religious beliefs influence their practice of medicine (Curlin et al. 2005). With 70.6% of all Americans professing Christian faith (Pew 2014), battles against demons, beasts and evil play into dominant moral and emotional currents within the country. The extensive use of religious rhetoric in American politics has set a precedent for public appeal. As trillions are spent fighting the “evil” and “evildoers”<sup>11</sup> in the global war on terror (Crawford 2016), with the majority of Christian churchgoers and 70% of the total population favouring further military interventions (Newport 2016), it is unsurprising to see religious turns of phrase surfacing in the language of CH pain and suffering. Perhaps Lennon is still right: God remains a concept by which we measure our pain.



<sup>11</sup> see President Bush’s speech in the days proceeding 9/11 (Fineman 2004)

# Conclusion



To suffer Cluster Headache is to encounter unknowns and unknowables. To endure Cluster Headache is to forge understandings where there are none.

The first section of this paper provided a broad overview of challenges which arise in the wake of that first attack. From the first shadow to the final orison, neophytes sequester themselves away and stand trial over and over again without knowledge of their crime. As once solid ground gives way under foot, sufferers confront the aporia of this new life and for a time confusion reigns. Former safe havens— the workplace, the family home, the doctor's office— slowly become arenas of hostility as the demanding condition erodes the understanding between the sufferer and their old world. Mounting questions desperately requiring answers are brought before doctors, but the process engenders its own challenges and offers little solace beyond a name. But what's in a name? Sometimes a new beginning. Diagnosis brings institutional perks, granting access to welfare and socialising this new pathology, but it also opens up the sufferer to new understandings. Diagnostic labels re-legitimise the sufferer as a social being now with new—if comparatively limited—forms of life available to them. As Emily and Sarah's respective stories demonstrate, after diagnosis, acceptance is the next essential step.

The second section documents the journey from thereon. CH sufferers demonstrated creative imagination and pragmatic versatility by patching together meanings from existing discursive forms, picking and choosing whichever enabled them to cope with their condition or communicate it effectively to others. I identified the suffering sage and the pain warrior as two archetypal CH coping styles, animated by an empathic allocentrism and a self-sustaining resilience respectively. Whilst minimally defined languages of suffering help frame these narratives (Brinkmann 2014), all expressions of suffering are nuanced with individual specificities and the process must always be intimate, sometimes tantamount reclusive. Negotiating Cluster Headache can be lonely but the internet has provided new opportunities to connect with others, to relate to the hardships of others, to share, to vent, to rant, to guide and be guided across this divide between old and new.

To endure Cluster Headache is to bridge this gap between old and new, to peer through the fractal of suffering and envisage a liveable future. Whether one's life literally or metaphorically hangs in the balance, the languages of CH pain and suffering articulate new understandings; ones where meanings can transform and transfix, where identities can die and be reborn; where the meek become fighters, warriors become sages, and idiopathy begins making sense.

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## Appendix A - "My Headache Diary"

March 7th @ 11.30pm - lasting 30 mins, 4/10  
March 16th @ 12.30am - lasting 45 mins, 6/10  
March 26th @ 5.00am - lasting 40mins, 5/10  
March 28th @ 3.15am - lasting 45 mins, 7/10 ... On both sides at same time.  
April 2nd @ 1:30am Lasted 30 mins, 6/10.  
April 2nd @ 11.00pm. Lasting just over an hour. 8/10.  
April 3rd @ 5.30pm. Lasting 30mins. 4/10. Sumatriptan early.  
April 4rd @ 1.30am. Lasting 40 mins. 5/10.  
One or two non-starters, evenly spaced in here.  
April 13th @ 10.00pm. Lasting 35mins. 6/10. Left hand side.

-----  
May 26th @ between 1-3am. Lasting 15-20 mins.

### GUATEMALA

May 30th @ 5pm. Lasting 20 mins. 4/10.  
May 31st @ 1am. Lasting 20 mins. 6/10.  
May 31st @ 5am. Lasting 15 mins. 5/10  
June 2nd @ 5pm. Lasting 20 mins. 5/10.  
June 5th @ 5pm. Non-starter, took sumatriptan.  
June 6th @ 3pm. Lasting 30 mins. 7/10. Left hand side.  
June 7th @ 8.30pm. Lasting 45 mins. 7/10.

### NICARAGUA

June 25th @ 10.30pm. Lasting 1 hour. Nauseas, almost vomiting. 7/10

### LOS ANGELES

July 1st?? @ 1am. Lasting 15 mins. 3/10.  
July 4th @ 7pm. Lasting 20 mins. 4/10.

### LONDON

July 7th @ 2am. Lasting an hour. 9/10!!!  
July 27th @ 11.45pm. Lasting 45 mins. Left side.

-----  
August 26th @ 11pm. Lasting 20 mins. Took sumatriptan early. Left side. 4/10.  
September 12th @ 6.30pm. On plane. Lasting 15 mins. Suma. Left side.

### IN SICILY

September 14th @ 12am. Lasting 20 mins. No suma. Left side. 4/10.  
September 14th @ 6pm. Lasting 15 mins. No suma. 3/10.  
September 14th @ 8.30pm. Lasting 30 mins. Came on slow, took suma quite late. 5/10.  
September 16th @ 12.30am Lasting 15 mins. 4/10. Left side.

-----  
October 6th @ 8.30pm. Lasting 15 mins. 4/10.  
October 15th @ 5.30am. Lasting 15 mins. 4/10.  
October 15th @ 8.20am. Lasting 30 mins. 6/10.  
October 18th @ 9.50pm. Lasting 45 mins. 8/10! Left side, had shadow on right side an hour prior.  
October 24th @ 6.30pm. Lasting 45 mins. 8/10.

October 25th @ 1am. Lasting 40 mins. 7/10.

October 25th @ 8.20am. Lasting 45 mins. 10/10. Vomiting, sweating.

October 28th @ 12.00am. Lasting 30 mins. 6/10. Both sides then settled left.

October 29th @ 8pm?? Non starter. Sumatriptan.

October 30th @ 1.45pm. Left side. 4/10. Lasting 20 mins.

October 30th @ 7.30pm. Nonstarter. Sumatriptan.

-----  
December 13th @ 9pm. 2/10. Right side.

December 14th @ 2pm. 3/10. ??

December 14th @ 11pm. 3/10. Right side

December 21st @ 10pm. Nonstarter. Sumatriptan.

December 23rd @ 7.15pm. Lasting 1 hour. 5/10. Right side.

December 24th @ 1.45am. Lasting 45 mins. 6/10/ Right side.

December 27th @ 8pm. Lasting 1hr. 5/10. Right side.

January 3rd @ 9.30pm. Aborted using suma.

January 4th @ 8.30am. Non starter.

January 9th @ 9am. 3/10. Took sumatriptan, never paced etc.

February 28th @11.30pm. 4/10. Lasting 15 mins before I fell asleep again. Took sumatriptan, could lie down.

## Appendix B - "Niel's Spreadsheet Template"

Date:

Wake Time: Wake Time (avg)

Nap Time: Nap Time (avg)

Sleep Time: Sleep Time (avg)

Hours Slept (Light):

Hours Slept (Deep):

Hours Slept (REM):

Hours Slept (Total):

CH Windows of Pain:

=====

CH Beginning Time (0000-0400) CH Pain Level ( 0000-0400)

CH Beginning Time (0400-0800) CH Pain Level ( (0400-0800)

CH Beginning Time (0800-1200) CH Pain Level (0800-1200 )

CH Beginning Time (1200-1600) CH Pain Level (1200-1600 )

CH Beginning Time (1600-2000) CH Pain Level (1600-2000 )

CH Beginning Time (2000-0000) CH Pain Level (2000-0000 )

Migraine Windows of Pain:

=====

Migraine Beginning Time (0000-0400) Migraine Pain Level ( 0000-0400)

Migraine Beginning Time (0400-0800) Migraine Pain Level ( (0400-0800)

Migraine Beginning Time (0800-1200) Migraine Pain Level (0800-1200 )

Migraine Beginning Time (1200-1600) Migraine Pain Level (1200-1600 )

Migraine Beginning Time (1600-2000) Migraine Pain Level (1600-2000 )

Migraine Beginning Time (2000-0000) Migraine Pain Level (2000-0000 )

Interictal (Shadow) Windows of Pain:

=====

Interictal Beginning Time (0000-0400) Interictal Pain Level ( 0000-0400)

Interictal Beginning Time (0400-0800) Interictal Pain Level ( (0400-0800)

Interictal Beginning Time (0800-1200) Interictal Pain Level (0800-1200 )

Interictal Beginning Time (1200-1600) Interictal Pain Level (1200-1600 )

Interictal Beginning Time (1600-2000) Interictal Pain Level (1600-2000 )

Interictal Beginning Time (2000-0000) Interictal Pain Level (2000-0000 )

Pain Free Days: Note: I had 28 days in 2016. 14 of those were in the month of August. (Still trying to crack that nut)

Medications:

=====

- Prescriptions with Dosing Information

- Pain Medicine with Dosing information along with Time taken in Four segment as above -

Vitamins taken with Dosing Information

Weather Information:

=====

- High Temp
- Low Temp
- Forecast

Exercise Information:

=====

- Steps - Jawbone
- Steps – Google Health
- Exercise Dates
- Weightlifting
- Treadmill
- Tai Chi

- Coffee Intake:

- Moon Phases:

\*\*\*Status Board with unusual Events (Reference for connecting separate event incase multiple items contribute to clusters)

## **Appendix C - The Kip Scale**

(a CH specific pain scale invented by now-deceased CH sufferer, Bob Kipple)

Pain level 0

No pain, life is beautiful

Pain level 1

Very minor, shadow's come and go. Life is still beautiful

Pain level 2

More persitent shadow's

Pain level 3

Shadow's are getting constant but can deal with it

Pain level 4

Starting to get bad, want to be left alone

Pain level 5

Still not a "pacer" but need space

Pain level 6

Wake up grumbling, curse a bit, but can get back to sleep with out "dancing"

Pain level 7

Wake up, sleep not an option, take the beast for a walk and finally fall into bed exhausted

Pain level 8

Time to scream, yell, curse, head bang, rock, whatever work's

Pain level 9

The "Why me?" syndrome starts to set in

Pain level 10

Major pain, screaming, head banging, ER trip. Depressed. Suicidal.

## **Appendix D - "Conversations While Dancing" by CHSG member**

I've been in the shadow of the beast all day. He's been breathing down my neck, pinching the muscle that runs down the left side. If only I can rest for a few hours before he comes to visit. I'm exhausted.

No such luck. From a deep sleep, I sit straight up in bed and see the numbers on the clock beaming a bright read 11:00. The beast has an impeccable sense of time; he's rarely late.

"Come dance with me," he shouts in his silent tone.

"I don't want to! Leave me to rest."

"But I have missed you. We haven't danced for nigh on a day. Up with you, for I'll not be denied."



The deep sigh leaving my own mouth leaves my ears ringing as gently I swing my heavy feet to the floor. I know he's right. There's no telling him no when he wants to tango.

In the darkness I make my way down the carefully counted stairs to the dance floor in the dining room. The windows are swathed with the heavy layers to drown the outside noise and light.

And so the waltz begins with a slow rocking motion. Side to side, left foot, right foot.

"Dance faster," orders the beast.

"I'm tired and weak," I argue to no avail. "Can't you just leave me be?"

"Not on this night," he whispers just behind my left ear. "I heard you today, you know. Do you actually believe that you could be rid of me with all those bottles of potions and concoctions? Have you learned nothing in our time together?"

"I would try anything to be rid of you."

"Dance faster."

The dynamics of the dance change from the rhythmic rocking to a more lively one-step.

"You can't undo what you don't know. No one knows me. I leave no trace behind that I was here. You're the only one, you and the others that I visit, who can testify to my existence. "

An instinctive step away from the wall and I turn, back and forth across the room, keeping perfect time, changing nothing but the pace. The only sounds in the room are my footfalls on the carpeted floor and my own pathetic whining.

"Why don't you kill me? No, you wouldn't make it that easy for me, would you? You leave that evil deed in my own hands. You just make me wish I were dead. Perhaps I'll hack out my brain. Then what would you do? Would you find another way to torment me?"

He ignores my question as he roars, "Faster!"

So faster I go. Fear steals over me as I do what he commands me.

"Faster. Faster! FASTER!"

"I'm going as fast as I can. I can't take it anymore," I bawl. "Please no more." I drop hard to my knees, clutching my head in my hands. "Please kill me or leave me." Over and over again, I repeat these words. "Kill me or leave."

And then, I feel him pull away. Just as suddenly as he came, he goes. Euphoria comes with the exhaustion. My eyelids are too heavy to lift so I feel my way back to the stairs and up into my room. Never turning on the lights so not to wake my family.

As I gingerly rest my head on the pillow, I peek to see the bright red numbers now read 12:00.

"Sleep," the beast whispers, "for I'll be back at 1:00."

*Author's Note: I have suffered from the condition of cluster headaches, also known as suicide headaches, since I was a teen. Often known as the beast to sufferers, the attacks are usually at night, lasting 20 minutes to one hour. The excruciating pain has been compared to amputation without anesthetic. The typical pacing during an attack is termed "the dance."*

## Appendix E - "Why you not smiling?" by CHSG member

Nothing to smile about at this moment. Should something come along that takes my mind off where I am now I might consider activating the muscles in my head and crack a sly one. But until then it seems a fruitless waste of energy and would imply I'm Ok with the world. Which I am not.

"Can't be that bad?"

What is your definition of bad?

"You know, being really poor or dying, or being alone?"

Interesting notion. I'm not poor, but the future isn't too rosy, which is a worry. I'm not dying, but I die in agony 8 to 12 times a day, everyday. As for loneliness, you have no idea. What's your biggest fear?

"Dying alone and in pain".

Try living alone and in pain. Try being feet away from your loved ones, but in reality being a thousand light years from them. Alone, in excruciating pain, inches from love but miles from salvation. Try living a life with a big fucking bubble around you that shields you from any help or relief, that no-one and no-thing can penetrate. Try looking out from this bubble and watching the world moving on without you. Try to imagine that.

"I don't want too. I couldn't do it, "

You'd be surprised about what you can and can't do. You'd be surprised at how many times you hit rock bottom, scrape along the floor, then pick yourself up and carry on. You say you couldn't do it, but you'd have no choice in the matter. Its that or oblivion. A stark choice not many have to consider too often in their lives. But there are some, like me, that 'consider it' on a regular basis. Every day is a choice between continuing or ceasing the journey.

"So why do you continue?"

A while ago I had no answer. I while ago I was convinced life was over. But I realise now there is still journey ahead of me. For me it's full of storms, but in-between the sun still comes out, the world keeps turning and that "Undiscovered Country", the future, not death, awaits me still. Jumping off the ride when its is still moving doesn't seem all that clever too me. I just have to hold on a bit tighter than most. Sometimes its like gripping onto razor blades. But something deep in my bones tells me it will be worth it, if I just hold on. Everything, life, my affliction, even just being, is transitory, and ebbs and flows with tides and currents few have control over. I have good days and bad days. Who doesn't?

"But don't you find yourself asking Why me?"

Why me? That's a trick question sent to cluster fuck your brain. The obvious answer is fate or some kind of punishment. Something you did or didn't do has caused all this "Skull-Buggery", and this is payback! But its a question that has too many answers to be a very good question to begin with. We all fall into that trap, and its despair to begin with, missing the truth that lies as clear as day in front of our pain closed eyes. The answer to "why me?" is it's the "wrong question". It should be "why not me?" A whole new perspective opened when I worked out that puzzle. So I asked myself the right question, and I got the right answer.

"So? What is the answer?"

Why the fuck not me. :)

"Why are you smiling?"

## Appendix F - Untitled poem by CHSG member

Listen up you fools! I tried it. I took a break in a sun-soaked foreign land. I went to Hell and back and returned again for more. I died in a (car\*) park in Sant Luis in the heat of a burning day. I paced like some mad tourist in circles. I cried for relief. I begged for an end. I demanded oblivion! But the world went on. Went on without me. All Around me. Carried on. Ripped my eye in bright searing light. Raped my ears, with every passing sound. Every 'la, la la la' of their foreign tongue burned me to the core. Every incessant bass of radios played loud beat me. Broke me. They walked on by, oblivious to my torture until I screamed. And how I screamed.

I had to hide. I had to shelter. I could only rest with one hand on my wife's shoulder, and I begged her not to touch me. Time to separate right from left.

And then it passed as all storms do, and blessed relief held me tight until I could breath once more. Much later than normal. Was it the heat? Was it the loss? Was it the impending thought of grief and the final acceptance that I am an orphan? Alone in the world with this fucking disease? Unable to be soothed by any means.

Then I recalled. We are legion. We are more than the sum of parts. We are everywhere. We seep through the cracks of wisdom, as no-one knows our name or its cause. I know you all. And you know me. I am not alone. Each of us sings an incredible tune, as in our harmony, we are one voice. Silently screaming alone in this crowded room.

Listen up you fools.

Life goes on. And so will you.