

Mapping out a critical psychology of 'medically unexplained symptoms':  
Neoliberalism, academic-state-corporate agendas, and the need to justify the  
self and the system

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## Abstract

'Medically unexplained symptoms' (MUS) are positioned in mainstream healthcare discourse as an individualistic psychosocial phenomenon. This positioning occurs through application of a particular variant of the biopsychosocial model that downplays biological influences, foregrounds individualistic psychosocial factors ('maladaptive' patient psychology) with little evidential support, and – of central concern to this article - ignores critically informed social and structural influences in health and illness. A counter-narrative to this, drawing upon critical psychology, is that medically unexplained symptoms as per their current conceptualization serve a number of purposes for mainstream institutions, associated actors and society more broadly. These purposes include reinforcement of, and justification for, a neoliberal agenda of healthcare and welfare retrenchment, in the UK associated with the interests of an 'academic-state-corporate nexus' comprising academics (notably psychiatrists), government officials and actors within the disability insurance industry. It is further argued that dominant discourse around MUS may serve relational, existential and epistemic needs for practitioners and social actors more broadly, alongside fulfilling a need to assert moral value in the face of social injustices that threaten the neoliberal 'just world' view. In other words, the (bio)psychosocial construction of MUS satisfies society's need to shape and ascribe to a shared reality, dominated by a collective belief in a just, meaningful and relatively predictable world that justifies the societal status quo and bolsters the privilege of subjects who benefit from unjust social structures. The construct of MUS may therefore reveal more about the psychopathologies of an exclusionary, ableist society than it does about the psychology of people labelled with MUS. Points raised here are highly pertinent to long Covid, notably cases that can be positioned as 'medically unexplained'.

Key words: medically unexplained symptoms, neoliberalism, biopsychosocial discourse, welfare reform, psy disciplines, epistemic injustice, myalgic encephalomyelitis / chronic fatigue syndrome, long Covid

## Introduction: Preparing the ground for a counter-narrative

### 'Medically unexplained symptoms' at a glance

'Medically unexplained symptoms' (MUS), which appear in mainstream literature under various guises including 'functional somatic symptoms' and 'persistent physical symptoms', describe somatic complaints that allegedly lack demonstrable physical pathology or cannot be wholly explained by physical causes (Chew-Graham et al., 2017; Stanley et al., 2002). MUS are typically conceptualized in dominant clinical discourse as psychosocial entities via application of a biopsychosocial model of health and illness (Deary et al., 2007; Sharpe et al., 1997) which is widely recognized to foreground psychological and social factors, whilst downplaying biological influences (see Geraghty & Blease, 2019 for a detailed account). People labelled with MUS<sup>1</sup> are framed as frequent users of health services and a burden on (medical) healthcare resources (Chew-Graham et al., 2017; Salmon, 2000). Accordingly, dominant biopsychosocial approaches toward MUS tend to discourage biomedical investigations beyond routine bloodwork for people with MUS (Sharpe et al., 1997; Wessely, 1996) and encourage practitioners to (re-)frame presenting 'problems' through a psychosocial lens (Dowrick et al., 2008). In the UK National Health Service (NHS), MUS typically include irritable bowel syndrome (IBS), fibromyalgia, and, of on-going controversy, myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) (NHS, 2021a).

MUS are further theorised in clinical practice through a cognitive-behavioural model (Deary et al., 2007), embedded within a biopsychosocial framework, which frames MUS as being perpetuated by 'dysfunctional' or 'maladaptive' psychology on the side of patients. According to this dominant narrative, which is couched in neoliberal assumptions (see Hunt, 2022a), people with MUS perpetuate their ill-health through unhelpful cognitions and fear-avoidance (Wessely et al., 1989; Knoop et al., 2010). Accordingly, cognitive-behavioural therapy (CBT) and graded exercise therapy (GET) are promoted as 'treatments' for MUS, notably in the case of ME/CFS (Sharpe et al., 2022; White et al., 2011). Some biopsychosocial literature also suggests that people with MUS are motivated by entitlement mindset and secondary gains such as desire for attention, avoidance of obligations and financial support (Wade & Halligan, 2007; see also Halligan et al., 2003; Stanley et al., 2002). These victim blaming narratives appear to have been internalised by (some, not all) clinicians: a considerable body of research demonstrates negative stereotyping and prejudice amongst medical practitioners towards people with MUS (Åsbring & Närvänen, 2003; Raine et al., 2004; see also Anderson et al., 2012; Blease et al., 2017), whereby patients are framed as difficult, demanding, lacking in work ethic and stoicism, exaggerating and 'heartsink'. Such attitudes impact on people with MUS who perceive their moral character to be in question, with documented associated distress (Åsbring & Närvänen, 2002; Dickson et al., 2007; see also Kornelsen et al., 2016). In fact, the

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<sup>1</sup> For linguistic simplicity, although 'people labelled with MUS' is perhaps the most accurate term, 'people with MUS' or 'MUS patients' will henceforth be used throughout. This is with recognition of the debates regarding diagnosis-first language and the term 'patient', and with an awareness of the problematics of using a label such as MUS as if it were an uncontested and incontestable diagnosis. It should also be noted that the author does not support the term MUS, nor does she believe that ME/CFS, fibromyalgia, IBS etc. should be categorized as such; the term is used to reflect dominant applications and as a basis for critique.

biopsychosocial and cognitive-behavioural approaches to MUS have been associated with various psychological and physical harms (Geraghty & Blease, 2019; Geraghty et al., 2019).

A key point of tension between practitioners and patients arises from conflicting models of causation and thus implications for management: people with MUS typically understand their illness in primarily biological terms, whilst practitioners tend to reach for psychosocial explanations in the absence of overt biological markers (Blease et al., 2017). Emergent research on long Covid suggests a similar dynamic in some but not all healthcare encounters (see Hunt et al., 2022; Hunt, 2022b). In fact, sub-groups of the long Covid umbrella are currently without diagnostic biomarker and there are indications that influential biopsychosocial proponents are seeking to frame these sub-groups as a form of MUS (Sharpe, 2021; Verveen et al., 2022; Willis & Chalder, 2021); points raised in this article will therefore likely be of relevance to the clinical trajectory and long-term positioning of long Covid, or at least sub-groups thereof.

### 'The' biopsychosocial model?

Whilst 'the' biopsychosocial model is typically associated with Engel (1977, 1992), there are debates around its status as a model, what Engel may have envisaged any such model to be, and whether the idea of the 'model' originated with Engel. Whilst a biopsychosocial approach assumes an interaction between psychological, social and biological influences in health and illness, the nature of these interactions is not specified by Engel or by successive theorists, leading to suggestions that the model is, at best, "a guiding formulation" (Stam, 2015, p.24) or, at worst, "conceptually underdeveloped or even flawed" (Van Oudenhove and Cuypers, 2014, p.201). In particular, it has been argued that conceptual vagueness allows any pillar to be foregrounded, as per the biases of whomever applies the framework (Ghaemi, 2009; Stam, 2000). This is important, since what is often referred to as 'the' biopsychosocial model may actually be applied in highly differentiated ways (see Hunt, 2022a). Of particular relevance to this article, a variant of biopsychosocial model has been applied to health and social policy as per the interests of actors and power structures implicated in the neoliberal retrenchment of health and welfare sectors, to the detriment of chronically ill and disabled people (see Shakespeare et al., 2017; Stewart, 2016).

Whilst it has been proposed that Engel's ideas represent neither a theory nor a model (Stam, 2000), Engel was clear in suggesting that a biopsychosocial approach could offer a more holistic framework relative to the biomedical model, notably one that was cognisant of the patient's 'social context' (Engel, 1977; also see Hunt, 2022a). Yet, the only contextual (social and structural) factors acknowledged in biopsychosocial theorising of MUS are those which further justify an individualistic and psychologising application of the model. Thus, colluding medical practitioners who supposedly over-investigate their patients, over-solicitous others and support groups, and an allegedly overgenerous benefits system are variously argued to play a role in the perpetuation of MUS (Bentall et al., 2002; Band et al., 2014; Stanley et al., 2002). This selective attention limits acknowledged social factors to the purported problematic social reinforcement of dysfunctional individual psychology, essentially blaming the patient and their support system.

In the above respects, the biopsychosocial model as applied to MUS could be contended to have more in common with Joseph Matarazzo's (1980) understanding of health and illness than

anything Engel envisaged. Matarazzo, who would become President of the American Psychological Association in 1998, drew on the biopsychosocial model (at least in name) to advance his objective of carving out a space for behavioural psychology within medicine, a space that would become mainstream health psychology (see Santiago-Delefosse, 2015)<sup>2</sup>. Matarazzo's brand of health psychology was quantitative, individualist, cognitive-behavioural and couched in neoliberal ideology (Matarazzo, 1980; see also Santiago-Delefosse, 2015), resonating with dominant biopsychosocial discourse far more than anything apparently offered by Engel. In fact, the victim blaming narrative that pervades mainstream health psychology, a narrative challenged by critical psychology (Fox et al., 2009; Murray, 2015), and a narrative evident within dominant biopsychosocial discourse (see Anderson et al., 2012; Horton-Salway, 2002; Shakespeare et al., 2017) is subtly discernible in Matarazzo's contributions. For example, Matarazzo emphasizes the cost of poor health to the US economy, and the "growing recognition that an individual's life-style and related negative habits are responsible for the decline in health for many Americans" (Matarazzo, 1980, p.814), whilst describing health psychology as a discipline that "stresses *individual responsibility*" (p.813, original italics). In a parallel with the ascendancy of the politicized variant of the biopsychosocial model in the UK (see Rutherford, 2007b), Matarazzo's emphasis on self-responsibility in health matters was said to be warmly welcomed given the contemporaneous impetus to reduce healthcare spending (see Santiago-Delefosse, 2015). In Matarazzo's case, a particular variant of biopsychosocial theorising is revealed as socio-economically, politically and historically contingent. In this case also, psychology (or the psy disciplines) may be argued to contribute to the construction of truth discourses that such disciplines claim merely to discover and reflect, by offering solutions to their perspective of socio-economic 'problems' and legitimizing this perspective through appeal to scientific objectivity (see Rose, 1998, 2019; Foucault 1961/1988). This article will elucidate how the same can be argued of dominant biopsychosocial theorising vis-a-vis MUS.

Whatever the truth regarding Engel's project for a biopsychosocial model, it is important to note that critically informed social and structural (socio-structural) factors in ill-health - part of the patient's 'social context' that Engel acknowledged - are not acknowledged in dominant BPS discourse. Chief amongst critically informed socio-structural factors discussed in this article are power dynamics within the clinical encounter, alongside a broader context of oppressive power structures that revolve around welfare reform (see Johansen & Risor, 2017; Rutherford, 2007a; Faulkner, 2016; Stewart, 2016; see also Hunt, 2022a). Such omissions from biopsychosocial discourse are curious, since a wealth of literature highlights the role of power and powerlessness in health and illness (Phelan et al., 2010; McCartney et al., 2021; Wallerstein, 1992), whilst socio-structural factors (such as health and social policy, legislation and macro socio-economic policy) are known to have downstream effects on health (Metzl & Hansen, 2014; Heise et al., 2019). In particular, the impact of welfare reform on chronically ill and disabled people is well documented (Stewart, 2016; de Wolfe, 2012; Garthwaite, 2014; Saffer et al., 2018). Equally, whilst dominant biopsychosocial discourse around MUS, in particular in the case of ME/CFS, has been robustly critiqued for lack of empirical

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<sup>2</sup> Matarazzo had in fact co-authored a 1953 paper (Guze et al., 1953) on a broadly speaking biopsychosocial approach to health and illness; Matarazzo (1980) writes how this paper was not as warmly welcomed as Engel's subsequent papers. Further, Santiago-Delefosse (2015) points out that Grinker (1953) also expounded a comparable approach prior to Engel, but Grinker's work did not produce a comparable academic and social response. This demonstrates how knowledge production and assimilation is socio-historically contingent; perhaps the popularity of Engel's ideas, and the fact they are attributed to Engel, is to some degree related to 'right time, right place' (see Santiago-Delefosse, 2015 for discussion of *kairos*).

underpinning and theoretical coherency (Geraghty et al., 2019; Geraghty & Blease, 2019), the omission of broader socio-structural context in dominant biopsychosocial MUS discourse has received little attention in peer-reviewed literature until recently (Hunt, 2022a, 2022b, 2022c; Hunt, in press; also see Rutherford, 2007a). This article seeks to expand on these contributions via the lens of critical psychology, in particular drawing upon the notion of neoliberal ideology as a means of justifying the self and the system.

## Definition of terms and theoretical positioning

A critical psychology approach (Teo, 2015; Fox et al. 2009), contextualizing health and illness within a broader socio-structural context with particular focus on power relations, is considered necessary to illuminate factors implicated in the construction of MUS and (re)production of MUS discourse that mainstream approaches have hitherto ignored. Critical psychology holds that “concepts used in psychological theories and practices are sources of power” (Teo, 2015, p.246); it follows that biopsychosocial discourse, along with associated practices, has the potential to both empower and oppress. Whilst power is a disputed concept (McCartney et al., 2021), power is defined here broadly as the capacity to influence others’ actions (see Foucault, 1980; Fricker, 2007). Critical psychology problematizes mainstream psychology’s historical tendency to form alliances with the interests of socially powerful groups, to the detriment of marginalized persons (Arfken & Yen, 2014). Whilst well-documented accounts of oppressive alliances exist pertaining to gender and race (Harris, 2009), it could well be argued that psychology has done little to empower chronically ill and disabled people (see Goodley & Lawthom, 2006). Accordingly, this article argues that dominant concepts and theories around MUS are an artefact of academia’s (notably psy’s) alliance with the interests of power structures associated with welfare and disability insurance (income protection or permanent health insurance) industry reforms, within a broader context of neoliberalisation, to the detriment of chronically ill people whom psy professions purport to serve.

To explicate how this alliance has marginalized people with MUS, the article draws on critical (social) psychology’s preoccupation with social constructionism, in assuming that language constructs as well as reflects reality (Teo, 2015; Arfken & Yen, 2014; Murray, 2015). Language combines with manifestations of social power to produce socially dominant discourse, where discourse is understood as “systems of thought, or knowledge claims, which assume an existence independent of a particular speaker” (Stoddart, 2007, p. 203). Dominant discourse represents a series of stories or narratives about a given phenomenon, that may or may not approximate ‘truth’ but nevertheless is taken as truth, largely owing to the entwining of truth claims with social power, thus shaping social (consensus) reality. Language is therefore understood to be a social practice that can empower some individuals and groups whilst disenfranchising others. As will be discussed, a variant of biopsychosocial discourse has constituted MUS as a form of undeserving chronic illness in policing the boundaries between what is a ‘serious medical condition’ and what is a ‘common health problem’ (see Waddell & Aylward, 2010), where MUS are positioned as the latter (Waddell & Burton, 2004).

Discourse harnessed to justify and bolster systems of power can be understood as ideology (Stoddart, 2007); dominant biopsychosocial discourse considered in the context of power structures

that both produce and benefit from such discourse can thus also be considered ideology. Whilst divergent perspectives on defining ideology are acknowledged (see Stoddart, 2007), the term is applied in this article in a spirit of theoretical pluralism. Thus, ideology and ideological power ensuing from and reinforcing biopsychosocial discourse can be understood to some degree through a Marxist lens (an economic class elite lulling the masses into false consciousness through exploitative relations of neoliberal capitalist production), through a lens consistent with the Frankfurt School (emphasizing the role of mass culture and science in bolstering socially unjust narratives), and finally through a post-structuralist perspective (ideological power as diffuse, arising from social relations as well as social structures and thus offering possibilities of multiple forms of resistance). Accordingly, this article explores the role of actors and structures within and associated with the scientific, clinical and academic communities, the government, mass media and corporate realm, in the (re)production of a self- and system-justifying ideology that bolsters currently dominant narratives around MUS. Specific recommendations for resistance are outside the scope of this article (but see Hunt 2022a; 2022b; 2022d; Hunt in press); however, the author considers the application of a critical psychology framework, in constructing a counter-narrative to expose and interrogate hegemonic biopsychosocial discourse, to be a form of resistance in itself.

In elucidating how and why biopsychosocial discourse around MUS persists despite robust challenges to its theoretical and empirical foundations, and despite evidence of patient harm, the article further draws from critical social psychology in its focus on issues of complicity in socio-structural injustice (Arfken & Yen, 2014). For the purposes of this article, 'structural complicity' is understood as a collective (societal) internalisation and (re)enactment of unjust social practices (see Aragon and Jaggar, 2018). As previously mentioned, critical psychology has much to say about the historical complicity of mainstream psychology with oppressive social practices and structures (Arfken & Yen, 2014); this article argues that the (re)production of dominant biopsychosocial discourse around MUS both requires and facilitates the complicity of not only clinicians (largely within psy disciplines) but also other social actors in marginalizing people with MUS. Complicity typically assumes a lack of intention and even awareness in perpetuating injustice (see Aragon & Jaggar, 2018); drawing upon critical psychology's interest in unconscious processes (see Fox et al., 2009; Murray, 2015; Parker, 2015), this article considers clinical and societal complicity through psychoanalytic defence mechanisms (Freud, 1933/1965; Freud, 1936/1957) and the broad lens of the psychology of legitimacy (see Jost & Major, 2001). Here, it will be argued that MUS as per their current conceptualization serve various psychological purposes for mainstream institutions, associated actors and society more broadly. These purposes include reinforcement of and justification for socio-economic policies (notably, in the UK, welfare reform), management of medical and broader societal uncertainty and seeking of moral legitimacy in the face of socio-structural injustices.

Finally, in understanding how biopsychosocial discourse around MUS can impact on the well-being of people labelled with such, the article subscribes to critical health psychology's argument that an individual's health is thoroughly embedded in the socio-cultural and political context in which individuals reside, a context infused with power differentials (Chamberlain & Murray, 2009; Murray, 2015). In particular, the article assumes a central role of power in (re)producing health and healthcare inequities (see McCartney et al., 2021; Phelan et al., 2010; Link & Phelan, 2001). It is argued that the variant of biopsychosocial theorising dominant in MUS practice and policy, arising from and reinforced by an 'academic-state-corporate nexus' (see Rutherford, 2007b), is further



embedded in a neoliberal capitalist project of prioritising the interests of private corporations and the market over respect for human rights, in part via systematic retrenchment of health and welfare provision and creation of opportunities for private profit (Clifford, 2020; Stewart, 2016). Such reforms (structural adjustment programmes) are near global phenomena, notably across Organisation for Economic Co-operation and Development (OECD) member states (OECD, 2009; Garthwaite, 2014; Clifford, 2020), and can be traced back to at least the 1970s but were accelerated by the 2008 global financial crisis and subsequent austerity measures (Clifford, 2020; Sakellariou and Rotarou, 2017). Thus, although this article draws mainly from the current and historical climate in the UK, points raised hold relevance for a wider readership.

Whilst neoliberalism can be conceptualized as an economic policy model, as outlined above, it also manifests as a biopolitical ideology discernible in social practices and the collective consciousness through an emphasis on competition, consumer-citizens, free will, personal responsibility, and self-determination (Adams et al. 2019). Of particular relevance to this article, neoliberalism positions individual responsibility, motivation and autonomy as central to achieving health, whilst blaming marginalized persons as masters of their own fate (Hunt, 2022a; Hunt et al., 2022; Hughes, 2015; Sakellariou and Rotarou, 2017). Neoliberalism thus promulgates a victim blaming ideology that permeates dominant social discourse and social practices, including biopsychosocial discourse pertaining to MUS, as will be demonstrated.

In what follows, macro level structural factors implicated in constructing the current dominant narrative around MUS are discussed, notably a nexus of power structures associated with welfare reform within a broader context of neoliberal retrenchment, reinforced by complicit institutional practices. Within this discussion, ME/CFS is highlighted as a prime target of nexus interests and a blueprint of health and welfare reform policies in the field of MUS. This is followed by a similar analysis at a micro level, specifically the patient-practitioner relationship, which can be understood as an internalization and reproduction of macro level power dynamics. Power relations and structural complicity manifesting within the clinical encounter are then re-positioned within a broader organizational and socio-political context, drawing on psychology of legitimacy (Jost & Major, 2001). Finally, the impact of structural injustices on the overall wellbeing of people with MUS is explored through a lens of power. Throughout, an overt social justice orientation toward research and practice is espoused, with a strong commitment to social change (Teo, 2015), an approach which eschews the 'neutrality ideal' of mainstream science (Harding, 1992).

## Macro level analysis: the political underbelly of MUS

### A nexus of power structures

Disability scholars, disabled activists and allies have long asserted that dominant clinical and societal discourse around chronic illness and disability has been constructed by a complex of interests arising from power structures within a broader global context of neoliberal structural adjustment programmes (Rutherford, 2007a; Jolly, 2012; Berger, 2014; Stewart, 2016). This assertion applies all the more to chronic illness and disability that can be understood as 'contested',

that is, that are associated with medical uncertainty or contestation. In the UK, this complex of power structures involves associations between academic-clinicians (chiefly, psychiatrists), the UK government and the disability insurance industry and has been referred to as an 'academic-state-corporate nexus' (Rutherford, 2007b). More specifically, it has been proposed that the biopsychosocial model as it dominates health and social policy - elsewhere referred to as the Waddell-Aylward biopsychosocial model (Shakespeare et al., 2017) - has been manipulated to further a neoliberal project to reduce state health and social expenditure, increase private profits, and protect the market and interests of the privileged at the expense of chronically ill and disabled people (Jolly, 2012; Berger, 2014; Stewart, 2019). More specifically, it is contended that the interests of the academic-state-corporate nexus result in policies that deprive chronically ill and disabled people of welfare provision, appropriate healthcare and/or private disability insurance income protection, by framing certain health conditions as psychosocial and largely 'medically unexplained' or subjective in nature. Such framing positions health conditions as amenable to 'recovery', and importantly to return to work, via psychosocial healthcare interventions (notably CBT and GET) largely developed by academic-clinicians with an interest in MUS, thus precluding eligibility to longer term welfare provision, private income protection and comprehensive biomedical investigations (Faulkner, 2016; Hooper & Williams, 2010; Rutherford, 2007a; see also Sharpe, 2002; Waddell & Aylward, 2010; White, 2005). Dominant positioning of MUS can therefore be considered profitable for all parties within the academic-state-corporate nexus of associations (see Hunt, 2022a; Hunt in press). This project has been considerably facilitated through the work the Centre for Psychosocial and Disability Research at Cardiff University and its associates (see Rutherford, 2007a; Faulkner, 2016; Stewart, 2016).

Encompassing all facets of the academic-state-corporate nexus, the Centre for Psychosocial and Disability Research at Cardiff University was opened in 2004 and was for some years sponsored by disability insurance giant Unum and directed by Mansel Aylward, formerly Medical Director, Chief Medical Officer and Chief Scientist at the Department of Work and Pensions (DWP). The research produced by the Cardiff centre and associates (Waddell and Burton 2004; Waddell and Burton 2006; Waddell and Aylward 2005; Waddell and Aylward 2010), some of which was commissioned by the DWP, catalysed reform of the state welfare system and disability insurance industry policy on income protection. Notably, the 2005 monograph 'The Scientific and Conceptual Basis of Incapacity Benefits' (Waddell and Aylward, 2005) prepared the ground for the 2006 Welfare Reform Bill and the 2007 Welfare Reform Act which, together with the so-called Freud report (Freud 2007), carved out the design for the 2008 Work Capability Assessment (WCA) (Stewart, 2019a, 2019b, 2022).

The WCA, accompanying the transition from Incapacity Benefit (IB) to Employment and Support Allowance (ESA), was designed to limit the number of successful claimants, notably through drawing on a Unum-adopted biopsychosocial model grounded in 'disability assessment medicine' (Aylward 2003; see also Stewart, 2016). This disability assessment medicine approach was predicated upon the belief that increased rates of benefits claims in the UK, US and beyond were due to a historical 'indiscriminate acceptance' within medical practice of 'subjective' health conditions as grounds for disability and work incapacity (Aylward, 2003). It followed that a more stringent approach to assessing such conditions was required, an approach where prognosis or diagnosis would be downplayed and the input of general practitioners (GPs) would be limited (Aylward and LoCascio 1995; Aylward, 2003; see also Stewart, 2016, 2019b; Shakespeare et al., 2017). The WCA is associated with enormous suffering among chronically ill and disabled people

(Barr et al. 2016; Stewart, 2018; Pring, 2017). In 2015, the media reported that more 80 people per month were dying after having navigated the WCA and being denied incapacity benefits (Ryan, 2015; Butler, 2015; see also Stewart, 2019b). Moreover, the same variant of biopsychosocial model as underpins the WCA was acknowledged by erstwhile Minister for Welfare Reform Lord David Freud, during debates leading up to the 2012 Welfare Reform Act, to inform assessments for Personal Independence Payment (PIP), which gradually replaced Disability Living Allowance (DLA) as part of the Act's provisions (Freud, 2012; also see Faulkner 2016). The profoundly detrimental impact of this transition on disabled people has been discussed both in published research and press report (Saffer et al., 2018; Ryan, 2016; see also Roulstone, 2015). Thus, this politicized variant of biopsychosocial model has informed a large portion of the UK social security system.

Aylward's directorship of the centre was accompanied by orthopaedic surgeon Gordon Waddell's placement as honorary professor. Waddell had a particular interest in back pain and related disability, and much of the thinking that pervades dominant biopsychosocial discourse around MUS appears to have arisen from Waddell's thinking in this field (Waddell, 1987, 1999, 2002; see also Hunt, 2021a, 2022a). Of particular note, Waddell suggested that back pain should not cause long term disability, that too much rest was harmful, and that a rehabilitative approach (notably with 'controlled exercises') was necessary and sufficient to facilitate recovery and return to work. Waddell's work on back pain also distinguished between what he considered an illness (a psychosocial and cultural entity) and a disease (a biomedical entity), considering back pain to be the former (Waddell, 1987, 1999, 2002); parallels with the biopsychosocial model of MUS and associated discourse (Deary et al., 2007) are evident (see Hunt, 2021a, 2022a, 2022c). Waddell ostensibly drew on a biopsychosocial model in developing his work and, despite the previously outlined divergence in thinking, Engel's biopsychosocial model is also referred to throughout the Cardiff centre's papers (see Waddell & Burton, 2004; Waddell & Aylward, 2010). In a similar vein, the Cardiff centre's work drew parallels between their variant of the biopsychosocial model and the World Health Organization's (WHO) model of disability, the International Classification of Functioning, Disability and Health (ICF), which describes itself as biopsychosocial (WHO, 2002). However, the ICF model is significantly more contextualist, acknowledging not only social factors, but also structural factors such as institutions and macro level policies - factors that underpin dominant biopsychosocial discourse and practice, and factors biopsychosocial discourse around MUS ignores. It could be contended that the Cardiff academics sought to legitimize their work through association with models that already sat favourably in the collective consciousness (see Shakespeare et al. 2017), again highlighting the centrality of language and discourse in shaping social reality. Whilst Waddell's work on back pain offered a distinction between illness and disease, the Cardiff centre's work further developed this distinction in a way that would hold profound repercussions for state healthcare and social policy and provision, as will now be discussed.

### Language games and the neoliberal collective consciousness

The framing of MUS as a form of undeserving chronic illness and associated disability was greatly facilitated by a largely arbitrary, but politically strategic, division between what Waddell and Aylward refer to as and 'severe medical conditions' and 'common health problems' (Waddell & Aylward, 2010; Waddell & Aylward, 2005). They argue that the that workers' compensation and social security benefits were originally designed for people with "severe medical conditions and

permanent impairment" (Waddell & Aylward, 2010, p.6), whilst common health problems are considered to be "similar in nature and sometimes even in degree to the bodily and mental symptoms experienced at times by most adults of working age" (Waddell & Aylward, 2010, p.6). 'Common health problems' are further defined as mental health, musculoskeletal and cardio-respiratory conditions that are "characterised more by symptoms and distress than by consistently demonstrable tissue abnormality" and are thus considered "subjective health complaints" (Waddell & Burton, 2004; Waddell & Aylward, 2010, p.7). These referenced papers, produced by the Cardiff centre, clarify that 'common health problems' are another term for MUS or 'functional somatic syndromes', notably drawing from the work of psychiatrists Simon Wessely and Peter White, who have a particular interest in what they prefer to call CFS. The positioning of MUS as something that most people experience at some point in their life represents an example of using language to construct a social reality whereby certain groups of people are legitimized, whilst others are epistemically and socially marginalized and stigmatized.

In setting the stage for a societal scapegoat, common health problems are also positioned as responsible for increasing state expenditure in the welfare sector and increased loss of productivity (see Waddell & Burton, 2004; Waddell & Aylward, 2010; YouTube, 2010). Upward trends in incapacity benefits claims are noted, alongside increased rates of sickness absence and long-term work incapacity, before stating that the majority of sickness absence, long-term incapacity and also ill-health retirement are caused by common health problems as opposed to severe medical conditions (Waddell & Burton, 2004). By then claiming that "incapacity is not inevitable" (Waddell & Burton, 2004, p.50), common health problems are constituted as a socio-economic 'problem'. (It is noteworthy that the word 'problem' even appears in the construct itself, in contrast to 'severe medical conditions'). Further, by emphasising the fact that some people with 'severe medical conditions' can and do work (Waddell & Burton, 2004) and downplaying the severity of common health problems, those who are positioned in the latter category are implied to be individually culpable and morally deficient. Unsurprisingly, disability studies scholars have argued that the distinction between common health problems and severe medical conditions invokes the 'deserving and undeserving poor' division (Stone, 1984 cited in Shakespeare et al., 2017), thus promoting a victim blaming narrative that may be associated with negative societal attitudes towards disabled and chronically ill people (Shakespeare et al., 2017).

The positioning of MUS as an undeserving form of chronic illness and associated disability is further facilitated by the Cardiff centre's implicit appeal to a collective consciousness permeated with neoliberal values and assumptions. The Cardiff academics position disability as it pertains to 'common health problems' within a framework of "conscious choice" (Waddell & Aylward, 2010, p.21), where allegedly controllable psychological factors (notably dysfunctional beliefs and fear-avoidance) are posited to influence disability (Waddell & Burton, 2004). Receipt of benefits and 'decisions' around being unable to work are equally conceptualized as "free choices" (Waddell & Aylward, 2010, p.22), whilst effort and motivation are expected to lead to recovery, notably through compliance with cognitive-behavioural rehabilitation strategies such as GET and CBT (Waddell & Burton, 2004). In parallel with dominant biopsychosocial discourse around MUS, 'social' factors are acknowledged within this discourse only as they serve the individualist and neoliberal narrative of agency and free will, for example, social reinforcement of 'illness behaviour' via sick certification and/or over-indulgent clinical attitudes (Waddell & Aylward, 2005; Waddell & Burton, 2004). The suggestion that psychological factors such as effort and motivation influence disability (Waddell &

Aylward, 2010) implies that disabled people may be unmotivated or lazy; chronic illness and disability are thus framed as a personal or moral failure. Neoliberalism in the realm of disability policy has been said to create a hierarchy of disabled people whereby only a portion are deemed worthy of state support, whilst the larger portion (now considered not really disabled) are re-framed as undeserving and fit to enter the labour market – or invalidated as scroungers and malingerers where disabled people fall short of neoliberal exigencies (Soldatic, 2020; Hughes, 2015). The Cardiff centre's neoliberalist, individualist narratives around MUS ('common health problems') embody this dynamic, bolstering a hierarchy of deservingness and perpetuating the marginalization and stigmatization of those deemed undeserving.

It is noteworthy that the academic-state-corporate definition of disability represents another example of how language can be understood as a social practice that may be entwined with oppressive social practices, and also highlight how language can be applied as a device to illuminate or obfuscate meaning (see Teo, 2009). Whilst 'disability' is typically conceptualized in mainstream health psychology literature as per the biomedical model (understood as limited functioning and restricted participation) and in disability studies literature broadly as per the social model (understood as a form of social oppression imposed on chronically ill people), 'disability' as constructed in politically motivated discourse appeals to an ableist, neoliberal rhetoric. That is, whilst broadly aligned with the medical model's definition, the term is imbued with moralizing overtones with the suggestion that an enabling environment (an overly generous social security system and colluding clinicians), alongside the individual's "conscious choice, effort and motivation" (Waddell & Aylward, 2010, p.21), play a significant role in disability. It then follows that when influential biopsychosocial proponents profess to be sympathetic to the 'disabling' nature of MUS, or describe ME/CFS or other so-called MUS as a 'disabling' condition (see Sharpe et al., 2022; White et al. 2017), it is not completely clear as to how this should be interpreted.

There are evident parallels between the Cardiff centre's discourse around common health problems and dominant (biopsychosocial inspired) social and clinical discourse around ME/CFS (see Hunt, 2021a, 2022a), notably around the need for effort and motivation in overcoming dysfunctional beliefs and fear avoidance through psychosocial interventions (see Picariello et al., 2017; Burgess & Chalder, 2005). In this respect, it is noteworthy that 'chronic fatigue syndrome' is mentioned in the Cardiff centre's work within the context of these common health problems (Waddell & Burton, 2004). Equally noteworthy is that 'chronic fatigue syndrome' is located under the rubric of mental health, despite a burgeoning body of biomedical research suggesting otherwise (see: Cortes Rivera, 2019). Further, a parallel can be drawn between the moralizing connotations of 'common health problems' in the Cardiff centre's output, and the (bio)psychosocial construction of 'CFS': both have been framed - implicitly or explicitly - as essentially healthy people who simply cannot cope with the vicissitudes of life (Wessely, 1997; Aylward, 1998; Waddell & Burton, 2004; YouTube, 2010). In fact, associations (ideological and working alliances) exist between the Cardiff academics and influential ME/CFS academic-clinicians (largely psychiatrists), whilst ME/CFS could be considered a blueprint for welfare reform and disability insurance policy reforms, which have impacted detrimentally on the wider chronic illness and disability communities. It is to this 'blueprint' that the discussion now turns.

## ME/CFS as prime political target

Although ME/CFS was formerly known as ME and was recognized by the World Health Organization (WHO) as a neurological condition in 1969 (see WHO, 1992), a group of eminent academics, who can be considered a key component of the academic-state-corporate nexus, played a central role in framing the condition as a primarily psychosocial entity under the term 'chronic fatigue syndrome' (Hooper & Williams, 2010; see also Geraghty & Esmail, 2020). In fact, ME/CFS can be considered a blueprint for welfare reform, with evident involvement of all facets of the nexus (for examples see Jackson, 1995; Halligan et al., 2003; Sharpe, 2002; Waddell & Burton, 2004; White, 2005). Papers issuing from the Cardiff centre, under Aylward's directorship, draw from the work of 'CFS' academics (psychiatrists) Peter White and Simon Wessely, notably around the 'subjective' nature of MUS and CFS (see Waddell & Aylward, 2010) and give special acknowledgement to contributions of the same academics (see Waddell & Burton, 2004). Moreover, various publications demonstrate ideological and/or working alliances between academics with an interest in 'CFS' and the Cardiff centre researchers (e.g. White, 2005; Halligan & Aylward, 2006; Halligan et al., 2003). Additionally, prior to the emergence of the Cardiff research centre, a number of ME/CFS academics are known to have communicated with UK government (DWP) officials - including Mansel Aylward - on the subject of ME/CFS, notably during the 1990s (see Eliot Smith, 2015 for data from The National Archives relevant to this article). Some of the documented correspondence reveals concerns raised by White and Wessely over the positioning of CFS (as they prefer to call it) in the then upcoming DWP Disability Handbook, the guide for non-medical decision-makers regarding eligibility to Disability Living Allowance. Both the possibility that ME might be considered a neurological disorder (Wessely, 1993) and the possibility that ME might be separated from CFS and positioned as a permanent or progressive disability (White, 1993) raised strong objections (see appendix figures A1, A2, A3, C1, C2, D1; see also Hunt, 2021a).

Notable within these exchanges is the suggestion, from White in communication with Aylward (the latter then on the Disability Living Allowance Advisory Board or DLAAB), that the separation of ME and CFS would "enhance disability" (White, 1993; see also appendix, figure A3). White explains this by suggesting that people who believe they have ME believe they have a "totally physical condition, probably related to immune dysfunction or persistent viral infection for which no treatment is available" (1993). In contrast, White contends that both physical and psychological factors maintain ME/CFS, and that "treatments and rehabilitation programmes" (graded exercise and cognitive-behavioural therapy, which White helped to develop) were already available for 'CFS'. Another way of understanding this is that preserving a space for ME (understood as a neurological disease as per the WHO classification) both in the DWP Disability Handbook and in the collective clinical and social psyche, would likely lead to positioning the illness as deserving disability (a 'serious medical condition' as opposed to a 'common health problem') that would not be amenable to the processes of psychologisation and politicization evident in the case of ME/CFS and MUS more broadly. The subsequent conjoining of ME with CFS (as CFS/ME) in historically dominant discourse (see CFS/ME Working Group, 2002; NICE, 2007/2018), followed by biopsychosocial proponents' omission of ME to produce the historically dominant term 'CFS' (see Sharpe et al, 1997; Picariello et al., 2017) is an example of how language, combined with social power, produces discourse that in turn shapes social reality. In this case, the entity by the name of 'ME', a WHO-designated neurological condition with a body of biomedical research suggesting neuro-immuno-endocrine

abnormalities (see Cortes Rivera et al. 2019 for an overview), is eclipsed by a psychosocial story about 'CFS'. In a parallel with the 'common health problems' construct, 'chronic fatigue' suggests something that most healthy people experience at some point in their life. Yet, in stark contrast, ME/CFS has been associated with a lower health-related quality of life than (for example), cancer and chronic renal failure (Falk Hvidberg et al. 2015). Perhaps unsurprisingly, research suggests that patients find the term CFS reductive and that clinicians may consider CFS a less serious diagnosis relative to ME (Nicholson et al., 2016; Jason et al., 2002).

For Wessely's part, documented exchanges with Aylward and other government officials reveal the possible origins of a number of now dominant truth-claims about ME/CFS (see appendix figures A1, A4, C1, C2; see also Hunt, 2021a). Firstly, the suggestion that benefits receipt might perpetuate disability can be found in Wessely's communications with UK government officials (Wessely cited in McGrath, 1993), later reiterated in the Cardiff centre's work driving welfare reform policy (Waddell & Aylward, 2010). Secondly, claims about the 'ME lobby' (the suggestion that people with ME/CFS prefer activism-militancy to scientific evidence), is evidenced in Wessely's early communications with Aylward (Wessely, 1993, see appendix figure A1), duly picked up by Aylward (Aylward, 1993; see appendix figure A2) and later widely promulgated by the UK press (Anthony, 2019; Liddle, 2019; McKie, 2011)<sup>3</sup>. Moreover, the (bio)psychosocial appeal to the reported high costs of ME/CFS and, more broadly, MUS healthcare as a justification for psychosocial theorising and practice (Chew-Graham et al., 2017) – costs that have been overstated in some cases (Chew-Graham et al., 2017; Tuller, 2019) – is an appeal evident in Wessely's communications with Aylward (Wessely, 1993), again repeated by the Cardiff academics (Waddell & Burton, 2004; Waddell & Aylward, 2010). As Waddell once said: "It is all about money. The main thing was to persuade the treasury that there was an opportunity for keeping costs down, particularly over the longer term" (Waddell cited in White, 2005, p.219; see also Faulkner, 2016). Still further, the (bio)psychosocial claim that ME/CFS is not perpetuated by persistent viral or post-viral sequelae can be observed in a presentation made by Wessely to the DLAAB during Aylward's involvement in the board in the early 1990s (Wessely cited in McGrath, 1993; see appendix figure A4). In advancing this claim, Wessely was supported by another academic, Professor Thomas of the Royal Free Hospital, who additionally claimed that the 1955 viral outbreak of ME at the Royal Free (henceforth sometimes known as 'Royal Free disease' but also earning the first description as ME), was in fact 'mass conversion hysteria' (Thomas cited in McGrath, 1993; see appendix figure A4).<sup>4</sup> Finally, the downplaying of biological influences and foregrounding of psychosocial factors has been complemented by a 'failure to cope with everyday life' and 'illness as an avoidance of taking accountability' story line (Wessely, cited in McGrath, 1993; Thomas, cited in McGrath, 1993). This story line bears resemblance to Wessely's contemporaneous work on the purported parallels between neurasthenia and ME/CFS (Wessely, 1990, 1994, 1997), which appeared to make a big impression on Aylward, who later expressed a very similar viewpoint (see Aylward, 1998).

It is pertinent that neurasthenia, broadly designating the inability of otherwise healthy people to cope with the pressures of modern life (Wessely, 1990, 1994, 1997), is also highly resonant of Aylward's definition of common health problems (YouTube, 2010). In making analogies between CFS

<sup>3</sup> Michael Sharpe also drew on the 'ME lobby' trope in his contribution to UnumProvident literature (Sharpe, 2002; also see appendix figure B1)

<sup>4</sup> Thomas' framing of ME as mass hysteria echoes the psychiatric re-construction of the Royal Free outbreak by McEvedy and Beard (1970).

and neurasthenia (Wessely, 1990, 1994, 1997), and in positioning CFS within the 'common health problems' category (Waddell & Burton, 2004; Waddell & Aylward, 2005, 2010), CFS - and by extension ME/CFS - is framed as an inability to cope with life, a framing that has found its way into the clinical imagination (Raine et al. 2004; Chew-Graham et al., 2009; Chew-Graham et al., 2010). It is also pertinent that in drawing such analogies, the psy disciplines (here, psychiatry) can be seen to discursively construct a 'problem' that can only be solved with the input of psy disciplines. That is, psychiatry is shown to contribute to the construction of knowledge (truth claims) that the discipline claims merely to discover and reflect. This 'knowledge' positions psychiatry as prime candidate to solve the alleged problem, whilst psychiatry's appeal to its (purported) foundations upon scientific objectivity enhances its expert status (see Rose, 1998, 2019; Foucault 1961/1988). However, this article has already demonstrated that in the case of MUS, the influence of the psy disciplines is bolstered by other power structures such as the state. In fact, this power complex has been further reinforced by the third facet of the academic-state-corporate nexus, in whose discourse all of the above-mentioned truth claims about ME/CFS can be found: the disability insurance industry.

Growing alliances between academia and state officials were likely further bolstered, and academic-state narratives further reified, by contemporaneous shifts within the disability insurance industry. During the early 1990s, whilst the UK government sought ways to reduce welfare spending by cutting disability-related benefits (in part by inviting officials from Unum to provide consultancy), Unum and other disability insurance companies were finding that they were losing profits due to increasing pay-outs for difficult to treat yet debilitating illnesses such as ME/CFS and fibromyalgia (see: Rutherford, 2007a). The UK government, then under John Major's prime ministership, responded to this by drafting in a Unum representative (Dr John LoCascio) to provide consultancy to then Minister for Social Security Peter Lilley on how to reduce state expenditure. As previously outlined, one way to counter this loss of profits, whilst simultaneously cutting state (biomedical) healthcare spending and creating profitable roles for developers and providers of psychosocial rehabilitation programmes, was to re-frame medical conditions as primarily psychosocial entities. ME/CFS appeared to be a prime target for psychologisation within the disability insurance industry, having been described in Unum documentation as "neurosis under a new banner" (Jackson, 1995, p.17; see also Hooper & Williams, 2010). This description was accompanied with the warning that: "UNUM stands to lose millions if we do not move quickly to address this increasing problem" (Jackson, 1995, p.4). The alleged 'increasing problem' formed part of the agenda of the Woodstock meeting, held in the UK (near Oxford) in 2001 on the subject of 'malingering and illness deception', and funded by the DWP (see Halligan et al. 2003). The gathering represented all elements of the academic-state-corporate nexus (Rutherford, 2007a; Hunt, 2021a; see also Marks, 2021): DWP officials, Cardiff academics, at least one Unum representative, and ME/CFS academic-clinicians (psychiatrists) were among the attendees. In this regard, it is highly pertinent that some ME/CFS academics have documented associations with the insurance industry (Sharpe, 2002; Hooper & Williams, 2010; Marks, 2017). For example, as has been discussed elsewhere (Hooper & Williams, 2010; Hunt, 2021a; see also appendix, figure D1), Michael Sharpe has provided consultancy for Unum and contributed to company literature, advising how to effectuate a return to work and thus preclude disability insurance claims as well as benefits eligibility (Sharpe, 2002; see also appendix figure B1).

Whilst these accounts relate to the current and historical climate in the UK, it is worth noting that events beyond the UK have indubitably facilitated (bio)psychosocial hegemony pertaining to



ME/CFS and MUS on a national and international level. Notably, in the US, the Centers for Disease Control and Prevention (CDC) has been accused of significantly downplaying biological origins of cases of ME/CFS, perhaps most memorably in the Lake Tahoe outbreaks in the mid-1980s (see Johnson, 1996). This, accompanied by the CDC 1988 working case definition report which introduced the term 'chronic fatigue syndrome' (Holmes et al., 1988), likely created the optimum conditions to achieve a similar process of psychologization on the other side of the Atlantic. Further discussion of these politics is beyond the scope of the article and the reader is directed to other resources (see Dimmock & Lazell-Fairman, 2015; Johnson, 1996; Tuller, 2011).

Before widening the lens to consider broader structural complicity with this nexus of associations, it is noteworthy that the now infamous PACE trial (White, et al., 2011), which sought to compare the effectiveness of standard medical care alone with standard medical care plus CBT, GET and pacing, can be understood to embody these academic-state-corporate alliances. The trial was part funded by the DWP with Aylward's assistance, with Wessely and Aylward on the Trial Management Group and Trial Steering Committee respectively (see Marks, 2017; Faulkner, 2016). The robust criticisms to which PACE has been subjected will not be repeated here (see *Journal of Health Psychology*, Spring Edition, 2017 for a detailed account), other than to reiterate that independent data re-analyses suggested that the level of effectiveness of CBT and GET was approximately two-thirds lower than originally reported (Wilshire et al., 2017). Concomitant charges of methodological and ethical flaws of the trial from a considerable portion of the international scientific and patient communities (see Tuller, 2018; Wilshire et al., 2017; Marks, 2017) were not sufficient for the research to be retracted and biopsychosocial hegemony within the field of ME/CFS and MUS persists (Chalder et al., 2022; Sharpe et al. 2022; RCP, 2021). This persistence is all the more extraordinary since the landmark revision of the UK National Institute for Clinical Excellence (NICE) guidelines on diagnosis and management of ME/CFS, which repudiated GET and downgraded CBT from clinically proven treatment to unproven but potentially supportive adjunct (NICE, 2021; see also NICE 2020). The political significance of such psychosocial interventions is underscored when considering the climate of increased welfare conditionality in the UK and beyond (see Garthwaite, 2014; Hunt, 2021a; see also appendix, figure D1), where eligibility for benefits is increasingly conditional upon particular conduct; in the case of disability and incapacity for work benefits, 'conduct' includes engagement in rehabilitative healthcare interventions. (Similar conditionality is written into some income protection insurance policies). CBT and GET are chief among these healthcare interventions for MUS, and conditionality has been largely supported by actors within the academic-state-corporate complex, including – in the case of permanent disability and medical retirement – some of the PACE trial researchers (Sharpe et al., 1997; Wessely et al., 1989; see also Waddell & Burton, 2004; Waddell & Aylward, 2005).

From a critical psychology perspective, persistence of (bio)psychosocial discourse and re-shaping of social reality around MUS, in the face of so little empirical support and evidence of patient harms (see Geraghty & Blease, 2019; Geraghty, Hann & Kurtev, 2019), demonstrates both how social reality is shaped by power structures and how truth claims are historically, socially and politically contingent (Fox et al., 2009; Murray, 2015; see also Foucault 1961/1988; Rose, 1998). To further understand the persistence of biopsychosocial hegemony, despite wide-ranging and robust challenges to theoretical foundations and empirical support, it is necessary to consider the issue of complicity, and what drives or facilitates complicity on an individual and collective level.

## Landscapes of complicity

Social and epistemic injustices in the realm of MUS (again notably in the case of ME/CFS) have been bolstered by complicity from within other mainstream institutions, where landscapes of complicity particularly include the arenas of public research funding, academic publishing, the mass media and healthcare policy development. In these cases, institutional complicity might be the first term to come to mind; however, following Aragon and Jaggar's definition (2018), it is here suggested that such cases, whilst arguably representing institutional injustice, represent a form of complicity that might be understood as a localized (institution-specific) form of structural complicity. Manifestations of such complicity are numerous and examples follow.

The majority of public research funding in ME/CFS has historically been allocated to psychosocial, as opposed to biological research, and notably to psychosocial research that is consistent with the academic-state-corporate interests already discussed. Simultaneously, an ever-increasing body of biomedical research (Cortes Rivera et al., 2019), largely funded by charities, continues to be downplayed by biopsychosocial proponents (Chalder et al., 2019; Sharpe, Chalder & White, 2022). This skewed narrative around ME/CFS has been reinforced by biases within academic publishing, where editors of respected medical journals have declined to retract psychosocial studies widely considered to be flawed (Tuller, 2018; Tuller, 2019). The UK press, with a few notable exceptions, has historically painted a highly stigmatizing picture of people with ME/CFS whilst presenting a biased perspective on research (Anthony, 2019; Knapton, 2015; McKie, 2011; Pemberton, 2011). Some research has suggested that healthcare practitioners source some of their information about MUS from the media (Chew-Graham et al., 2008); this highlights how dominant discourse, even in healthcare settings, may have as much to do with distribution and use of power in shaping a social reality than it has to do with 'truth'. The historical bias of the UK press is perhaps unsurprising given that the Science Media Centre (SMC, see SMC, 2020), which provides the UK media with science-related briefings, has observable alliances with (bio)psychosocial interests. For example, the SMC (notably via its director Fiona Fox) played a role in promoting and defending the PACE trial, whilst Wessely has been involved with the SMC as trustee and scientific advisor (Faulkner, 2016; Maxwhd, 2022; Hooper & Williams, 2010). Similarly, biases within academic publishing may be reinforced by the presence of influential (bio)psychosocial proponents on the editorial boards of, or involved in bodies associated with, journals where (bio)psychosocial research on MUS is published (see Tuller, 2022; Hughes & Tuller, 2022). In a similar vein, NHS policy and discourse pertaining to MUS has historically reflected psychosocial interpretations (NHS, 2021a; NHS, 2021b), perhaps unsurprising since influential biopsychosocial proponents, notably psychiatrists, have been involved at clinical and policy-development levels within the healthcare system (Hooper & Williams, 2010; also see Geraghty & Esmail, 2020). Finally, it has elsewhere been proposed that the publication trajectory of, and responses to, the revised NICE guidelines for the diagnosis and management of ME/CFS represent an example of structural complicity (see Hunt, 2022c).

All of the above instances of complicity, as previously discussed, can be located within a neoliberal collective consciousness that prizes individual (patient) responsibility in 'recovering' from

chronic illness, largely through hard work and positive mindset. The same collective consciousness has given rise to successive welfare reforms and retrenchment of the public healthcare arena, and to the academic-state-corporate agendas which dominate mainstream thinking on MUS. Here, the definition of structural complicity as the internalization and reenactment of unjust practices (see Aragon & Jaggar, 2018) is applicable: actors who view and treat MUS as a psychosocial entity may have no ill-intent, but are simply re-producing the dynamics of oppressive power structures on a micro level. This is not to downplay responsibility and culpability on the part of a small group of actors, whose involvement may be better described as collusion (that is, intentional) than complicity.

Whilst the possible professional, political and/or financial interests to be served for some actors by bolstering the status quo in the field of MUS have been discussed, this article argues that the current dominant narratives around MUS also satisfy fundamental collective and individual psychological needs. Fulfillment of such needs may be factor in complicity and thus in the persistence of socio-structural injustices sustained by people with MUS (see Hunt, 2022c; Hunt in press). The article therefore turns to a micro level analysis of MUS healthcare encounters to explore how biopsychosocial discourse around MUS may serve clinicians, before locating these encounters within a broader structural context.

## Micro level analysis: The quest for personal legitimacy

### Clinical power struggles

Health psychology and sociological literature has examined power relations in MUS clinical encounters from the perspective of patients and practitioners (Åsbring & Närvänen, 2004; Johansen & Risor, 2017; Nettleton, 2006). However, biopsychosocial discourse ignores the role of power in contributing to health or ill-health, and in constructing health-related discourse. These omissions are curious, since biopsychosocial theorising typically reinforces the assumed social and epistemic privilege of practitioners over patients (see: Stanley et al., 2002), whilst concern over the relative power of patients in healthcare is an implicit or explicit theme in some biopsychosocial literature (Salmon, 2000; Stanley et al., 2002; Wessely, 1997). This concern is reflected in clinicians' perspectives on MUS healthcare encounters, as captured by research.

A meta-ethnographic synthesis of 13 qualitative studies exploring GPs' perception and management of MUS (Johansen & Risor 2017) sheds some light on the psychology of practitioners and points towards how psychosocial framing may serve psychological needs of clinicians. In this synthesis, epistemological incongruence, the lack of fit between practitioners' (biomedical) training models and the presentation of patients in clinical encounters, was found to threaten the assumed authority of practitioners and influence power dynamics in the clinical encounter. Studies included in the synthesis variously highlighted practitioners' perceived threat to professional identity, discomfort with the perception that the balance of power favoured patients, and acknowledgement of inability to solve patients' problems, alongside associated feelings of frustration, fear, inadequacy and helplessness (see Åsbring & Närvänen, 2003; Wileman et al., 2002). Such feelings suggest that

dominant approaches to MUS healthcare may be disempowering to clinicians as well as to patients. Other research suggests that the challenge posed by people with MUS to the epistemic privilege of practitioners as enshrined in the 'sick role' (Parsons, 1951) is related to negative stereotyping of patients by practitioners (Raine et al., 2004). It might thus be suggested that the well-documented negative stereotyping and stigmatization of patients by medical practitioners, through application of (bio)psychosocial theorising, is to some degree a response to feared loss of expert status and associated social power, a defense against both medical uncertainty and fear of losing moral legitimacy (see Åsbring & Närvänen, 2003; Wileman et al., 2002).

A study by Wileman et al. (2002), exploring GPs attitudes towards the management of MUS in primary care (notably through a lens of the 'problem of power') supports the above suggestion, whilst highlighting how dominant discourse around MUS can be understood as socially (in this case, clinically) constructed. The study illustrates how GPs actively sought out individualistic psychosocial influences in patients' cases whilst downplaying biological factors and without contemplating the broader social context of health and illness. This social context likely includes the practitioners' behaviour: the same study demonstrated instances of clinicians framing patients as attention-seeking, self-indulgent, lacking in work ethic, labelling patients as 'frustrating' and 'heartsink', with such clinical prejudice to be found in wider MUS literature (Åsbring & Närvänen, 2003; Chew-Graham et al., 2009; Chew-Graham et al., 2010; Raine et al., 2004). Notably, GPs demonstrated no awareness that their own attitudes toward patients might be a psychosocial contributor toward patients' presenting issues, for example toward patient distress. Whilst patients were positioned by GPs as lacking insight into the purported psychosocial nature of their illness (thus adding to the narrative of maladaptive psychology), GPs demonstrated no insight into the possibility that polysymptomatic clinical presentations might be explained biologically.

Importantly, according to Wileman et al. (2002), MUS were framed by GPs as less serious and less worthy of clinician attention relative to other patient issues, thus justifying the collective clinical stance toward MUS: "the majority of people who come to the GP do not have serious illness [...] And that is I suppose what being a GP is; you have to sift out between what is serious and what is not" (GP6 cited in Wileman et al., 2002, p.181). Here, Waddell and Aylward's binary distinction of serious medical conditions and common health problems can be discerned; such binaries have been argued to be a way of managing anxiety (see Shildrick, 2020). Binaries are constructions of sharply demarcated boundaries, where boundaries are in fact indistinct and permeable, and oppositional structures whereby one side of the binary is typically positioned as favourable, and the other side is, quite literally, 'othered' (see Goodley, 2018). Binaries may thus be employed to create certainty and meaning where there is none, and to bolster positive self-concept and in-group cohesion. In the case of MUS, by framing this clinical entity in psychological terms (which cannot be 'objectively' proven or disproven), by positioning as less deserving (less serious, less worthy of clinical attention), and by constructing moralizing stories about patients' characters, clinicians are able to reclaim epistemic authority and moral legitimacy in the face of medical uncertainty and poor clinical outcomes.

Whilst mainstream literature in the field of MUS suggests themes of intolerance of uncertainty and a search for a moral legitimacy among people with MUS (Wessely, 1994, 1997; Tucker, 2004; Nettleton, 2006; Chalder et al., 2019), the above research findings suggest that such themes might apply just as much to clinicians. Yet, in contrast to the largely unsubstantiated yet pervasive psychologization of people with MUS in biopsychosocial discourse, the psychology of practitioners

and impact on patient health outcomes in biopsychosocial literature is afforded little to no mention. Further examination is thus indicated of what underpins and reinforces practitioner psychology – in particular defensive practice as indicated here - in the realm of MUS.

### Desperately seeking psychic equilibrium?

The above discussion suggests that psychologization of people with MUS may represent a clinical defence against threats posed by MUS to medical certainty, epistemic authority (clinical expertise) and clinicians' desire to preserve moral legitimacy in clinical encounters. Defensive behaviours can be understood through a number of lenses; consistent with critical psychology thinking, a psychoanalytic perspective is turned to in the first instance (see Ror Malone & Friedman, 2015; Goodwin, 2017).

From a psychoanalytic (psychodynamic) perspective (Freud, 1933/1965; Freud, 1936/1957), and applied on a micro level of analysis, ego defences employed by clinicians may include denial (denying the patient's suffering, rejecting the possibility of biological underpinning), rationalization (positioning the psychologization of patient concerns as consistent with evidence-based practice), displacement and projection (frustration at the practitioner's self is displaced onto the patient, the practitioner's lack of insight is projected onto the patient). A further ego defence, discernible in GP behaviours of separating 'serious' from 'non-serious' conditions (Wileman et al., 2002), is that of splitting (Klein, 1946). This defence is theorised to protect the ego against anxiety arising from 'ambivalence', the acknowledgement that 'good' and 'bad' frequently exist within the same subject (i.e. acknowledgement of uncertainty). Splitting describes a process of separating 'good' (positively valenced associations) and 'bad' (negatively valenced associations), introjecting the 'good' and projecting the 'bad' onto something or somebody else. According to Klein, the anxiety that leads to splitting is "felt as fear of annihilation (death)" (Klein, 1946, p.4) and is related to the death instinct and the absolute dependency that all humans experience at birth. Since caregivers are inevitably unable to meet every need of the baby, and unmet needs are experienced as a threat to survival, the developing ego splits the caregiver into two separate objects – good and bad – with the 'good' object serving as a safeguard during periods of heightened uncertainty or anxiety. Splitting may therefore meet existential needs, that is, the need for safety and security, and Klein believed this defence often persisted into adulthood, arising when the subject feels powerless. In the realm of MUS, the binary of 'common health problems' (not worthy of biomedical care and welfare provision) and 'severe health conditions' (worthy of such) is a further example of clinical and societal splitting, allowing clinicians and other social actors to justify the neglect and marginalization of 'common health problems', including MUS, by positioning them unworthy, or otherwise negatively valenced. It follows that clinicians and others who engage in such splitting position themselves within the 'worthy' binary category, a positioning that may meet self-esteem needs, facilitating the preservation of moral legitimacy whilst also ensuring a precarious sense of safety in distancing the 'worthy' self and in-group from the fate of people who are othered.

Although (critical) psychoanalytic thinking, perhaps surprisingly to some readers, has much to offer a critically-informed analysis (see Goodley, 2011; Goodwin, 2017; Ror Malone & Friedman, 2015), it is possible to understand intrapsychic dynamics through other theoretical perspectives. For

example, through a lens of cognitive dissonance (Festinger, 1962), reducing the salience of dissonant cognitions through cognitive re-appraisal increases cognitive consistency and thus lessens associated discomfort. Through this theoretical lens, the clinician's recognition (or cognition) that a patient is genuinely suffering, juxtaposed with the acknowledgement (cognition) that there is no established biomedical treatment available, creates dissonance. This dissonance may be resolved by working on the former cognition to re-gain cognitive consistency or consonance: 'this patient isn't genuinely suffering, they are exaggerating'. Yet another way of theorising this anxiety and the ensuing psychological dynamics is through a Rogerian lens (Rogers, 1951/2003). Here, it would be theorised that the clinician's self-structure as expert and as helper-healer is not congruent with their experiencing (medical uncertainty, being unable to help the patient), with incongruence causing anxiety. According to Rogers, distortion or denial of experiencing often ensues, in an attempt to protect self-structure and maintain a precarious form of congruence (see Rogers, 1951/2003). No matter what the theoretical lens applied, dominant biopsychosocial discourse around MUS can be said to assist clinicians in maintaining a precarious sense of psychological stability (psychic equilibrium, cognitive consistency or congruence), allaying anxiety ensuing from unconscious or preconscious intrapsychic conflict.

Intrapsychic defences among clinicians may be reinforced by structural and institutional factors that impact on clinical practice and policy, factors which also represent the neoliberalization of healthcare. In public health service settings such as the NHS, time-limited and increasingly manualized interventions, focus on outcomes as opposed to process and therapeutic relationship, and overarching audit culture may create an environment where practitioners feel under pressure to 'deliver' as per the terms of their employment, even when it sits at odds with truly patient-centred care (Proctor et al., 2019; Cheshire et al., 2017). This is particularly evident in the UK Improving Access to Psychological Therapies (IAPT) mental health initiative, which is unashamedly underpinned by government policy consistent with the interests of the academic-state-corporate nexus, that is, to reduce state expenditure on health and welfare, largely through return-to-work initiatives (Layard, 2007). In UK primary care, the Quality and Outcomes Framework or QOF (NHS Digital, 2022; see also Cheshire et al., 2017), represents a further structural constraint to socially just practice and a further example of neoliberalization of healthcare. QOF is a pay for performance scheme which financially incentivises GPs to provide quality care to people with most medically legitimised conditions, but not to people with 'contested' conditions such as MUS (see NHS Digital, 2022 for a list of QOF supported conditions). Research has revealed that this framework may encourage GPs to de-prioritise people with MUS (Hannon et al., 2012). Further, since mental health diagnoses such as depression are eligible for QOF 'points' (extra income for GP surgeries), such policy might also encourage clinicians to psychologize patients and re-frame MUS as a psychosocial entity. From a psychoanalytic perspective, the clinical moral imperative to help the patient, frustrated by the reality of structural constraints and above-noted epistemological incongruence, may result in moral anxiety that can be defended against through adhering to dominant biopsychosocial theorising. From a behavioural perspective, such structural and institutional factors create a network of contingences that could be said to reinforce practitioners' adherence to dominant biopsychosocial discourse and practice.

A further institutional influence that likely reinforces clinical defences as outlined above, particularly defensive behaviour vis-à-vis threats to epistemic authority, is that of professional training. There appears to be little emphasis on critical reflexivity (as opposed to reflective practice) during clinical training, both in the psy disciplines and beyond (GMC, 2022; BPS, 2017; also see Hunt

in press). This may be in part due to a foregrounding of the scientist or scientist-practitioner model. Here, a largely positivist notion of a neutral observer is foregrounded; if clinicians believe that they can be 'objective' in the sense of a value-free, independent observer, critical reflexivity becomes redundant (see Harding, 1992). The widespread assumption of, or collective striving towards, a position of disembodied neutrality in mainstream sciences has been conceptualized in feminist scholarship as the 'god-trick', the pretense of seeing everything from nowhere (Haraway, 1988). Such assumptions may encourage a lack of epistemic humility, whereby other perspectives (such as those of patients) are more readily dismissed. Subscribing to the 'neutrality ideal' (Harding, 1992) and associated self-positioning as an objective scientist may serve not only epistemic but also relational needs for clinicians: increasing self-esteem and self-efficacy through self-positioning as expert, fostering a sense of belongingness and cohesion within the mainstream scientific community, and assisting in the construction of an identity that sits favourably in the collective consciousness.

The above analysis suggests that micro level phenomena (clinical encounters and clinician psychology) cannot be separated from its structural context (training and organizational policy, further embedded within the creeping neoliberalization of healthcare). Indeed, the definition of structural complicity as assumed in this article (see Aragon & Jaggar, 2018) highlights how individuals reproduce oppressive architecture on a micro level by "habituating the cognitive, affective and active practices that it normalizes" (Aragon & Jaggar, 2018<sup>5</sup>). The previous macro level analysis revealed that this architecture includes a broader structural (national, global ideological) context of retrenchment of health and welfare sectors that indubitably reinforce clinical behaviour. However, it would be unfair and inaccurate to frame clinicians as the only social actors implicated in the internalization and reenactment of injustices committed against MUS patients. Structural complicity, as already defined, implicates all social actors in these processes. The article thus now turns to an exploration of how complicit behaviours manifesting in (micro level) clinical encounters can be understood not only as an internalization and reenactment of meso and macro level oppressive practices, but also as a context-specific manifestation of broader structural complicity, of collective societal strategies employed to defend against acknowledging injustice.

## Macro meets micro: Justifying the self and the system

Critical psychology holds that individual subjectivities are constituted through socio-structural context (see Murray, 2015; Fox et al., 2009). Accordingly, the (likely unintentional) oppressive practices evidenced in clinical encounters can be understood as reinforcing and reflecting broader societal manifestations of oppression. Indeed, it would be unfair and inaccurate (at least, in most cases) to ascribe a *mens rea* to clinical complicity in the marginalization of people with MUS (see Aragon & Jaggar, 2018 for discussion of culpability in structural complicity). That is, clinical complicity with injustices sustained by MUS patients can be understood as a context-specific form of structural complicity. Moreover, the psychological needs likely fuelling and fulfilled by clinical complicity may also be conceptualized as driving societal manifestations of complicity. This suggestion will now be illustrated through the following exploration of victim blaming and scapegoating, phenomena evident in the clinical and broader social sphere, and strategies by which

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<sup>5</sup> Owing to the version of record of this cited source being paywalled, this quotation has been taken from the accepted manuscript; page numbers are not available.

social actors may deflect discomfort generated by their complicity in injustice, or deny the existence of injustice altogether.

MUS research reveals that patients perceive being blamed by clinicians (see Anderson et al., 2012 for a qualitative meta-synthesis on ME/CFS), whilst discourse analysis demonstrates how medical doctors may draw upon psychosocial theorising in MUS to preserve their 'expert' status and avoid the discomfort of medical uncertainty by shifting health-related accountability onto patients (Horton-Salway, 2002). More broadly, it has been noted that psychosocial explanations are often used to deflect away from medical failure to diagnose and treat certain conditions (Yardley, 1996). A parallel process can be evidenced in academic-state-corporate discourse pertaining to MUS, which draws upon individualistic and frequently moralizing psychosocial narratives about patients (Jackson, 1995; Halligan et al., 2003; Waddell & Aylward, 2010; White, 2005). In a similar vein, mainstream (health) psychology has been critiqued by critical psychologists for promulgating victim blaming through an over-emphasis on individual factors in health and illness, whilst ignoring socio-structural context (Murray, 2015; Fox et al., 2009). In all cases, responsibility (blame) for health status is shifted onto chronically ill and disabled people, whilst those who ascribe blame seek moral legitimacy through claims of following the 'evidence base'. In the realm of MUS, clinical framing of patients as lacking in work ethic and stoicism (see Åsbring & Närvänen, 2003; Chew-Graham et al., 2009; Chew-Graham et al., 2010; Raine et al., 2004) runs parallel to the neoliberal rhetoric observed in government narratives around disability (Rutherford, 2007a). These victim blaming dynamics and neoliberal assumptions can also be discerned in theoretical frameworks informing 'treatments' for MUS.

The influence of neoliberal ideology in cognitive behavioural discourse around MUS can be observed, for example, in how the 'problem' is located squarely within the individual, through ascribing the perpetuation of MUS to alleged maladaptive patient psychology (Deary et al., 2007; Sharpe et al., 1997; Wessely et al., 1989). As has been argued elsewhere, there is no reflexive recognition of the broader social problem, including policies of welfare reform and healthcare spending cuts that the models help to justify (see Hunt, 2022a). The cognitive-behavioural emphasis on effort and motivation in 'overcoming' unhelpful cognitions and maladaptive behaviours, and thus overcoming MUS (e.g. Burgess & Chalder, 2005) is highly consistent with neoliberal exigencies (see Adams et al., 2019). Specifically, the type of subjectivity constituted through CBT is a neoliberal one, involving "radical abstraction of self from context, an entrepreneurial understanding of self as an ongoing development project, an imperative for personal growth and fulfilment, and an emphasis on affect management for self-regulation" (Adams et al. 2019). Although cognitive-behavioural thinking dominates (bio)psychosocial discourse in the realm of MUS, thinking from other theoretical approaches – notably positive psychology – is perceptible in the dominant biopsychosocial stance.

Although a separate theoretical tradition to cognitive-behavioural approaches, the positive psychology movement may well have influenced dominant psychosocial thinking – and bolstered victim blaming tendencies - in the field of MUS and more widely in the realm of contestable chronic illness and disability. This approach to psychology (Seligman & Csikszentmihalyi, 2000; Peterson & Seligman, 2004), developed under the leadership of another former president of the APA, Martin Seligman, sought to shift the lens of scrutiny from psychopathology (psychology's traditional focus) towards positive affect and human flourishing. In fact, positive psychology is influenced by cognitive psychology, in assuming that thoughts can be managed to regulate affect (Sugarman 2015; Binkley



2013). Importantly for points raised in this article, seminal work on positive psychology demonstrates thinking highly consistent with neoliberal values (see McDonald & O'Callaghan, 2008; Binkley, 2013), notably the project of "making normal people [sic] stronger and more productive" (Seligman & Csikszentmihalyi, 2000, p.8). Moreover, it has been argued that some of the foundational ideas in positive psychology, in particular pertaining to purported 'character strengths' and 'virtues' such as work ethic (Peterson & Seligman, 2004; Seligman & Csikszentmihalyi, 2000), are evocative of neoliberal narratives concerning welfare reform policy within the UK, US and beyond (McDonald & O'Callaghan, 2008). Positive psychology thinking has also crept into the realm of MUS, for example through the suggestion of biopsychosocial proponents that 'The Lightning Process', a 'neuro-physiological training programme' inspired by positive psychology among other influences (Parker et al., 2018), is an effective treatment for adolescents with mild to moderate ME/CFS (Crawley et al., 2018/2019). It should be noted that such suggestions are accompanied with very little empirical support, with various methodological and ethical problematics within studies being highlighted (Hughes, 2019; Marks, 2021; Tuller, 2021). Importantly, like cognitive-behavioural approaches, positive psychology may promote victim blaming. In the latter's case, in holding that the cultivation of character strengths and virtues such as courage, wisdom and persistence can lead to improved health and life satisfaction (Peterson & Seligman, 2004), positive psychology positions those who do not or cannot 'improve' as morally deficient. Victim blaming likely satisfies various psychological needs for those who those who engage in it.

Some researchers propose that victim blaming is driven by attributional biases, not least a belief in a just world (Lerner & Miller, 1978; see also Sheikh & McNamara, 2014), a tendency to hold people personally accountable for their misfortunes, satisfying the need to believe in a just, relatively predictable and thus 'safe' world. These needs, in turn, can be understood as driven by a fundamental human need to maximise perceived control, certainty and (self)-efficacy (Langer, 1975). Alternatively, or in a spirit of complementarity, victim blaming can be conceptualized as a strategy to shift the spotlight of scrutiny away from more legitimate causes of 'misfortune', pertinently, socio-structural injustices and underpinning oppressive power relations (see Ryan, 1971). Of particular relevance here, Ryan (1971) argues that whilst victim blaming is motivated by desire to maintain the status quo, notably in the interests of those who engage in victim blaming, it can also don the mantle of genuine concern for those who are blamed. This, it is argued, is typically achieved by offering a perfunctory nod of acknowledgment to socio-structural injustices, whilst declaring a wish to help the individual overcome their 'problem', thus locating the 'problem' squarely within the individual (Ryan, 1971). This approach could well describe mainstream clinical and therapeutic management of all health concerns, and most certainly describes political, clinical and social framing of MUS (see Deary et al., 2007; Halligan et al., 2003; Sharpe, 2002; Waddell & Aylward, 2010; White, 2005; see also Hunt in press). In all cases, victim blaming likely serves particular psychological needs: avoidance of accepting personal or collective responsibility for complicity or collusion in social injustices (preservation of moral value), maintaining a 'just' and predictable world view (satisfaction of epistemic and existential needs) and distancing the self and in-group from the fate of 'others' such as people with MUS (satisfaction of existential needs).

It is noteworthy that the themes of seeking control and preserving moral legitimacy are evocative of the dual model of scapegoating (Rothschild et al. 2012; also see Hunt, 2022c; Hunt in press). Although a separate phenomenon from victim blaming, scapegoating offers another way to understand how certain actors and collectives might gain from biopsychosocial discourse around

MUS. Rothschild et al. (2012) argue that scapegoating, the process of attributing disproportionate blame for a negative outcome to a particular (out)group, is psychologically motivated by the dual need to maintain perceived moral value and to maximise perceived control in the face of negative outcomes. More specifically, scapegoating involves delineating a clearly identifiable and external cause for a negative outcome, thus maintaining a collective sense of order and control, whilst defending against personal and social accountability for the outcome. These dynamics are observable in the clinical, political and broader social arena. In the social policy sphere, and from the perspective of the wider disability community, it has been argued that many disabled people have become the scapegoat for economic austerity, chiefly through a 'neoliberal politics of resentment' (Hughes, 2015), that includes over-exaggeration of the 'problem' of malingering and benefit fraud, the grading of disability to create categories including 'not really disabled', and lack of attention paid to structural drivers of inequality (Briant et al., 2013; Soldatic, 2020). Echoes of this dynamic can be discerned in the case of MUS: as certain disabled people are discursively constructed a drain on the economy (see Hughes, 2015; Soldatic, 2020), MUS patients are discursively constructed (by researchers, clinicians, government and disability insurance officials) as a drain on healthcare resources and social security provisions in an increasingly overburdened health and social system (Chew-Graham et al., 2017; Payne, 2016; Sharpe, 2002; Waddell & Aylward, 2010; see also Rutherford, 2007a). In both cases, chronically ill and disabled people are explicitly or implicitly held responsible for negative outcomes that are largely due to broader systemic failures, a dynamic which epitomizes scapegoating.

There is debate as to whether scapegoating should be theorised and analysed on the level of the individual or as a collective phenomenon, on the level of the group (see Rothschild et al., 2012). Certainly, (individual) ego defences, as already discussed in the context of clinical encounters, can also be applied to scapegoating and to some degree victim blaming: in particular, splitting, displacement and projection have been discussed in these contexts (see Goodley, 2011; Hollander, 2017; Marks, 1999; Rothschild et al., 2012). In these cases, the ego defences mentioned could be understood both as individual and collective defences, in seeking to meet both individual and collective epistemic needs (need to know, need for certainty, predictability and meaning), need for self-legitimacy (need to preserve moral value, need for self-esteem) and existential needs (need for safety, need to manage fear and threat). However, some theorists – chiefly social identity theorists – argue that scapegoating should be approached on the level of the group, particularly since it is suggested that relational needs are satisfied, such as gaining or preserving group cohesion (see Rothschild et al., 2012). This suggestion is consistent with the previous discussion regarding complicity, where it was suggested that ascribing to biopsychosocial discourse around MUS may serve a relational need, the need to belong to a particular community of thought and to subscribe to a shared social reality. Considered altogether, these motives can be located in what has been termed to psychology of legitimacy (Jost & Major, 2001), in particular in system justification theory (Jost & van der Toorn, 2012).

System justification theory posits that, beyond a tendency to justify the self and one's group, people are motivated to defend the status quo, even when that status quo is socially unjust, in order to fulfil particular psychological needs (Jost & van der Toorn, 2012; Jost & Major, 2001). These needs can be classified as epistemic (the need to for certainty, meaning and predictability), existential (the need for security and safety) and relational (the need to belong, the need to ascribe to a shared reality). Further, and consistent with prior discussion of ego defences as playing a possible role in

complicity, system justification motives are speculated to occur both consciously and unconsciously (see Jost & van der Toorn, 2012). In particular, the suggestion of epistemic need fulfillment in complicity in the marginalization of MUS is supported by research suggesting that attributing patients' symptoms to psychosocial causes (despite so little evidence of psychosocial causation) increases clinicians' sense of competence (Dowrick et al., 2008). In fact, research indicates that justifying the system correlates positively with general well-being, even among less advantaged groups (see Osborne et al., 2019); this suggests that resistance to modifying such a world view would be considerable. Through a critical psychology lens, psychology of legitimacy has been invoked to illuminate why people may do nothing in response to injustice, or why injustice is not perceived (Arfken & Yen, 2014).

Dominant biopsychosocial discourse around MUS may thus be argued to fulfill deep-rooted psychological needs not only for clinicians but also for social actors more broadly. That is, the construction of MUS as per biopsychosocial discourse satisfies society's need to create and ascribe to a shared reality which is dominated by a collective belief in a just, meaningful and relatively predictable world, thus fulfilling relational, epistemic and existential needs and the need to assert moral value in the face of inequity and injustice. In this respect, it is noteworthy that some (bio)psychosocial narratives that have emerged in the field of MUS and have been weaponized against patients, such as ME/CFS being a cultural phenomenon and a way of avoiding responsibility with concomitant 'gains' (Huibers and Wessely, 2006; Stanley et al., 2002), may in fact better apply to clinicians, actors implicated in the academic-state-corporate nexus, and society more broadly. It is also pertinent that system justification pertaining to various forms of inequality has been found to be positively associated with endorsement of neoliberal values (see Bettache & Chiu, 2019), again emphasising the need to consider the structural (here, ideological) context in which individual and group psychology play out.

Before moving to consider to individual consequences of socio-structural injustices (here, the marginalization of certain chronically ill and disabled patient groups), it is interesting to consider that neoliberalism could be argued to satisfy the very needs that are thwarted by contested and contestable chronic illness. That is, endorsement of neoliberal values – at least superficially – meets epistemic, existential and relational needs, by offering both a worldview and collective rules for living that ostensibly provide explanations and justifications for chaos, uncertainty and injustice, whilst allowing those who endorse neoliberalism to affiliate in a shared sense of deservingness. On the other hand, chronic illness – especially that which is contested and neglected – plunges many sufferers into uncertainty, chaos, increasing isolation and the irrefutable recognition that life is neither just nor controllable. In many ways, chronic, incurable and largely untreatable illness represent a threat to the neoliberal order and to the satisfaction of fundamental psychological needs that neoliberalism could be said to serve; this may go some way to explaining the systematic disbelief, dismissal and stigmatization to which many chronically ill and disabled people are subjected.

## Individual consequences of socio-structural injustice

Structural injustices carry repercussions for individual health and life chances; although this has received very little attention in the realm of MUS, it can be inferred from a close reading of

extant literature combined with wider critical research. Most of the MUS literature on injustice and patient harm focus on meso and micro level phenomena, notably healthcare policy, explanatory models and clinical encounters (Geraghty, Hann & Kurtev, 2019; Blease et al., 2017; Geraghty & Blease, 2019). However, this article has demonstrated that macro level injustices pertaining to neoliberal retrenchment of health and welfare sectors have given rise to and reinforced such policies and models. Further, this article has revealed an academic-state-corporate nexus of associations which, via policies, legislation and the (re)production of clinical and social discourse, has promulgated diffuse structural injustices that manifest at every level of analysis. These macro level and diffuse structural injustices may impact directly and indirectly on the well-being of people with MUS.

An indirect pathway of harm can be discerned in how being positioned as having an 'undeserving' chronic illness creates barriers to accessing legitimized disability status and subsequent financial support and social accommodations, depriving people of rights, resources and opportunities that would otherwise be accorded to them (see Hale et al., 2020). A process of marginalization may be initiated, likely exacerbated by pre-existing sociodemographic disadvantage (Phelan et al., 2010) and particularly in the case of intersected disadvantage (Turan et al., 2019). However, there is a dearth of intersectional research in the field of MUS, which needs to be addressed. A more direct pathway of structural harms can be speculated through research where participants report that grappling with a hostile social security and unaccommodating healthcare system impacts detrimentally on their psychological and physical health, notably through the stress engendered (de Wolfe, 2012; Hale, Brough et al., 2021; see also Hunt 2022a). Indeed, it is noteworthy that common clinical presenting 'problems', typically conceptualized through an individualistic psychological lens (such as low self-esteem, depression, low self-efficacy, and suicidality), may on closer examination represent the downstream effects of disempowering interactions with healthcare practitioners, embedded within a hostile and disempowering healthcare and social security system (Devendorf et al., 2020; Edwards et al., 2007). The detrimental impact on physical health in such cases may be understood through a lens of allostatic load and/or biological embedding, whereby stressful events – including discrimination and related experiences of disempowerment – can be understood to quite literally "get under the skin" (Heise et al., 2019, p.2449; see also McEwen, 1998; Pascoe & Richman, 2009). In this regard, the disempowering nature and impact of stigma and epistemic injustice, two forms of injustice researched in the field of MUS, are of interest.

Both stigma and epistemic injustice have been discussed in the realm of MUS (e.g. Anderson et al., 2012; Åsbring & Närvänen, 2002; Blease et al., 2017; Buchman et al., 2017). Whilst an increasing body of research in MUS explores stigma on a micro level (Anderson et al., 2012), stigma and associated constructs such as discrimination can impact as structural phenomena, for example via discriminatory socio-economic policies as already discussed. In broader (non-MUS) research, structural stigma has been associated with poorer health and reduced life chances (Hatzenbuehler et al., 2013) and it has been noted that structural injustices likely have a biological impact over time, again through a lens of allostatic load or biological embedding (Heise et al., 2019). This suggests that more research on structural (notably macro level) injustice in the realm of MUS is necessary, along with a consideration of how such injustice may directly impact on a biological level. Healthcare-related harms in the realm of MUS have also been theorised through a lens of epistemic injustice (Blease et al., 2017; also see Buchman et al., 2017). Here, the potential of epistemic injustice to

generate harms via inadequate or inappropriate healthcare provision and, in some cases, loss of patient trust and reluctance to engage with health services has been highlighted (Blease et al., 2017). Further, it is pertinent that such harms have been related to biopsychosocial practice and policy as it dominates ME/CFS healthcare (Geraghty & Blease 2019). However, epistemic injustice, like stigma, can also be understood on a macro level, whilst a direct impact on the body of such injustice over time may be speculated; this will now be considered.

Through a macro structural lens, epistemic injustice can be understood as arising from and facilitating a neoliberal project of retrenchment of health and welfare sectors, a project consistent with the interests of the academic-state-corporate nexus of alliances. Indeed, neoliberalism in this context could be conceptualized as a hermeneutical framework and driver of hermeneutical injustice, limiting the discursive, clinical and social space to particular set of value and assumptions. This limited space gives rise to 'conceptual impoverishment' (see Carel & Kidd, 2014) vis-a-vis the experiences of chronically ill and disabled people who do not conform to the ideal neoliberal subject, and such conceptual impoverishment fuels testimonial injustice. That is, the testimonies of chronically ill and disabled people do not 'fit' within the dominant hermeneutical framework, and are thus dismissed or distorted, leading to well-documented negative stereotyping, victim blaming and gaslighting. A similar argument might be forwarded regarding ableism, inextricably bound up with neoliberalism, and defined as "a cultural imaginary and social order centred around the idealised able-bodied and -minded citizen who is self-sufficient, self-governing and autonomous" (Goodley, 2020, 366-367). Further theorising and empirical research along these lines may give rise to a "deeper sense of *structural epistemic injustice*" (Carel & Kidd, 2017, 344 original italics), identified by the cited scholars as an important consideration for future research. This will inevitably be important for understanding epistemic injustice as it applies to long Covid: whilst events earlier on in the pandemic indicated that long Covid might be subject to less negative stereotyping and disbelief relative to patient groups such as ME/CFS (see Hunt et al., 2022), it has also been recognised that long Covid is at risk of inheriting the landscapes of exclusion navigated by people with MUS, landscapes drenched in seemingly immutable neoliberal and ableist ideology (Hunt, 2022b). Moreover, drawing from stigma and discrimination research (Heise et al., 2019; Pascoe & Richman, 2009), it may be speculated that epistemic injustice – both transactional and structural (see Fricker, 2017) - impacts directly on a biological level, as a chronic, uncontrollable stressor conceptualized through the lens of allostatic (over)load or biological embedding (see Hunt 2022a, 2022b). Epistemic injustice in the realm of MUS and long Covid may thus be theorised to add directly to illness burden, by 'getting under the skin' (see Heise et al., 2019).

Of particular interest from a critical theory perspective, both epistemic injustice and stigma can be understood as an oppressive application or manifestation of power (see Fricker, 2007; Link & Phelan, 2001). Indeed, a conceptual overlap between epistemic injustice and stigma has been noted, largely owing to shared patterns of social power, oppression and domination (Buchman et al., 2017). This supports the critically oriented argument that perceived and actual disempowerment may impact deleteriously on health and life outcomes (Wallerstein, 1992; McCartney et al., 2021; Hatzenbuehler et al., 2013) and points to a need for more research into how stigma, epistemic injustice and other forms of disempowerment are experienced by people with MUS. In particular, research into the experiences of people with MUS who can be positioned at the intersection of multiple forms of social disadvantage is recommended to explore how intersected social

disadvantage might interact with epistemic and broader social injustices. For example, research on epistemic injustice might follow examples set by stigma research in understanding such injustice as intersectional (see Turan et al., 2019). To summarise, recognition of the socio-structural context, including social determinants or influencers of health, intersected social positionality of both patients and clinicians, and overarching political and ideological factors, is typically lacking in mainstream psychology and broader health-related literature, and this is sadly exemplified by the case of MUS. A critical psychology approach offers a counter-balance to the dominant individualistic approach, shining the spotlight of scrutiny on phenomena hitherto overlooked.

## Where to go from here?

As previously noted, actors involved in the politicization and psychologization of ME/CFS are also involved in the clinical positioning of long Covid (see Sharpe, 2021; Verveen et al., 2022; Willis & Chalder, 2021). Further, there is some suggestion that this involvement extends to social policy: a UK All-Party-Parliamentary Group (APPG) session on 'Long Covid and employment' in June 2021 (APPG Coronavirus, 2021) included presentations from Unum's head of public policy Simon Hodgson and from Professor Kim Burton, co-author of some of the previously outlined DWP-commissioned research produced in collaboration with the Cardiff research centre (Waddell & Burton, 2004; Waddell & Burton, 2006). For further context, Burton has authored numerous academic articles embracing a (bio)psychosocial approach to 'common health problems', contributed to publications representing the academic-state-corporate nexus of alliances (e.g. Halligan & Aylward, 2006) and also acts as Expert Advisor to the DWP. During the June 2021 APPG, Burton suggested there would be a role for 'work-focused healthcare' in long Covid (APPG Coronavirus, 2021); whilst it is not entirely clear what this refers to, it may be synonymous with 'work-focused rehabilitation programmes' that Burton has supported for 'common health problems' (Waddell & Burton, 2004) which, for conditions such as ME/CFS, has historically included CBT and GET. The probability of a tidal wave of post-viral (or on-going viral) disability has been noted (Hansard, 2021; Davis, 2022), raising questions of how society will accommodate this in the long-term and it has been cautioned that the clinical and societal positioning of long Covid may be influenced by political and economic agendas (Perego et al., 2020; also see Hunt et al., 2022; Hunt, 2022b). With the extra burden placed on the health, social system and wider economy by the covid-19 pandemic, and further austerity looming in the UK and beyond (Moore, 2021; Sharma et al., 2021), the scapegoating, stigmatization and marginalization of chronically ill and disabled people may well increase. This is particularly the case where those people are experiencing anything that can be positioned as 'medically unexplained' and thus susceptible to framing as per dominant psychosocial representations of MUS. Therefore, sub-groups of the long Covid umbrella that lack biomarkers ('objective' markers) may be especially at risk; in particular, there is a possibility that these sub-groups will be positioned as 'common health problems' for the purposes of health and social policy. It has been noted that societies are occasionally susceptible to periods of 'moral panic', where one group is constituted as a threat to mainstream agendas and interests (Briant et al., 2019; see also Stewart, 2022). The socio-economic repercussions and collective psycho-emotional impact of the pandemic may well lead to such moral panic, and it is reasonable to suggest that chronically ill and disabled people, particularly

those with politically and socially contestable conditions, will be positioned among the prime candidates for society's scapegoat.

Given that the documented landscapes of institutionalized discrimination and oppression, long since navigated by people with MUS and others in the chronic illness community, have arisen largely due to the historical dismissal and devaluing of chronically ill and disabled people's testimony and experience, it is crucial that society heeds the epistemic contributions of these marginalized groups. This extends to long Covid, which is currently at risk of inheriting such landscapes (see Hunt, 2022b). Power structures implicated in the systematic marginalization of people with MUS should be brought to mainstream attention, with a view to garnering greater resistance to psychosocial hegemony. In this regard, it is pertinent that a large portion of the literature (both 'grey' and peer-reviewed) on the subject of power structures driving these discriminatory landscapes is produced by disabled people and independent researchers, many of whom are unpaid (e.g. Stewart 2016, 2018, 2019a, 2019b, 2022; Clifford, 2020; Benstead, 2019; Faulkner, 2016; also see Hale, Benstead et al., 2021). This is also the case specifically within the field of MUS, and with consideration of the implications for long Covid, where the author of this article has contributed a modicum of literature to the field (see Hunt, 2020, 2021, 2022a, 2022b, 2022c; 2022d; Hunt, in press). It could be contended that much of the remaining literature is written by academics taking a scholar-activist stance highly consonant with that of critical psychology and other critical disciplines (e.g. Rutherford, 2007a; Shakespeare et al., 2017). Finally, The National Archives data (see appendix A) and Unum documentation (see appendix B) that have been used to formulate some of the arguments advanced in this article, have been made available by chronically ill and disabled people. The National Archives data are made available by a UK barrister who is also a person with ME (Eliot Smith, 2012/2016); since some of the data had been closed owing to their sensitive nature, Eliot Smith succeeded in having some of the data released using the Freedom of Information Act. The Unum documentation is an example of a broader set of historical resources made available by a person with ME (see Maxwhd, 2022).

Despite the above, the author's experience (as an unpaid, independent disabled researcher), is not only that much of this literature is overlooked by mainstream actors, but that epistemic injustice is also rife in the least expected places. That is, whilst it might be expected that a community of patients, researchers and clinicians working toward the same broad objective would yield guaranteed allies for marginalized patient-researchers, the author's experience is that (wrongful) epistemic appropriation is disturbingly common. This suggests a need for reflexivity and humility at all levels within knowledge-producing arenas. Need for (critical) reflexivity extends to research and clinical tools and frameworks; the author has elsewhere proposed that the biopsychosocial model – if it is to be used at all in the realm of MUS - should be informed by a critically reflexive, structurally competent ethos (Hunt, 2021b, 2022a). The fundamental nature of the needs satisfied by biopsychosocial discourse as theorised here suggests that any attempts to disrupt biopsychosocial narratives around MUS, and those emerging around long Covid, will meet with considerable mainstream resistance. This is surely all the more reason to acknowledge and value the epistemic contributions of marginalized groups who, in the author's experience, have often survived through developing novel forms of resistance. In knowledge-producing arenas such as academic publishing, structural discrimination and epistemically unjust policies - such as the fact that most open access, rapid review journals charge processing and publication fees that exclude many marginalized researchers – require critical scrutiny. More broadly, persisting with the historical

tendency to prize ableist and disabling credibility hierarchies and networks of privilege within knowledge-producing arenas will result in the persistence of discriminatory landscapes for people with MUS and ensure that long Covid meets with the same fate.

## Summing up

The article has espoused a critical psychology perspective in exploring the construction of MUS as a purported psychosocial entity, the complicity of mainstream actors, institutions and broader structures in (re)producing dominant discourse around MUS, and the impact on people labelled with such. MUS as per their current conceptualization can be argued to serve a number of purposes for mainstream institutions, associated actors and society more broadly, purposes that may drive complicity in the marginalization of people with MUS. These purposes include reinforcement of and justification for socio-economic policies (notably, in the UK, welfare reform), management of medical and broader societal uncertainty and seeking of moral legitimacy in the face of socio-structural injustices.

Psychosocial framing of MUS is consistent with a neoliberal ideology that permeates discursive, clinical and social spaces and offers health-privileged (or healthcare-privileged) people a means by which to protect and justify that privilege<sup>6</sup>. Dominant constructions of MUS, and (bio)psychosocial discourse more widely, serve mainstream social actors and structures in justifying and defending the status quo (the self and the system) in the face of overt injustice and inequity, and rendering complicity in such injustice unproblematic. Indeed, the (re)production of (bio)psychosocial discourse around MUS both requires and facilitates complicity in marginalizing this group of chronically ill and disabled people. Dominant discourse in this field draws on decontextualized narratives that foreground individualistic psychological theorising, downplaying biological research findings and – of central relevance to this article - ignoring critically informed social and structural influences in health and illness. This discourse has been revealed as an artefact of academia's (chiefly psy's) alliance with the interests of power structures associated with welfare and disability insurance industry reforms, within a broader context of neoliberalization, to the detriment of chronically ill people whom psy professions purport to serve.

In this regard, dominant biopsychosocial discourse pertaining to MUS and any health condition that can be positioned as such (including sub-groups of the long Covid umbrella), could be considered at one and the same time a diffuse socio-structural phenomenon and a totalizing system, akin to a *dispositif* or apparatus of neoliberal governmentality, and thus a manifestation of biopower (see Foucault, 1975/1995, 1980; Rose, 1998, 2019; Tremain, 2001). Indeed, this article has revealed how power-knowledge is strategically (re)produced in facilitating the construction of a 'problem' to be managed (here, MUS), and in designating authorities to manage the 'problem' (here, an assemblage of clinicians, benefits assessors, actors with academic-state-corporate agendas and particularly from the psy disciplines), largely via normalizing technologies (here, CBT and GET). Such technologies facilitate the regulation of patients, assessed by degree of conformation to the ideal neoliberal subject, here, by degree recovery and productivity. By donning a mantle of scientific objectivity, appealing to 'expert opinion', and claiming to discover what in actuality they construct,

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<sup>6</sup> People who lack various forms of social privilege may also, in some circumstances, tend toward justifying an inequitable system (see Osborne et al., 2019); discussion is beyond the scope of this article.



(bio)psychosocial proponents attempt to naturalize and materialize socio-political constructions such as 'common health problems', 'chronic fatigue syndrome' and 'medically unexplained symptoms', and seek to legitimize an ideology that carries profoundly socially unjust consequences.

The account of MUS offered in this article has highlighted key tenets of critical theory more broadly, and of critical psychology thinking more specifically. Chief among these tenets is how psychology practice, discourse and concepts can oppress as well as empower, how dominant discourse arises from the intersection of language, truth claims and power, how such discourse constructs as well as reflects the collective consciousness and consensus reality, and how complicity reflects and reinforces unjust practices. Importantly, and relatedly, this account underscores the critical assumption that the individual subject is constituted by, and inseparable from, the broader socio-structural context.

Finally, it is hoped that the value of critical psychology as an oppositional device is showcased by this article. Not only does critical psychology expose and interrogate systems of power and oppression that harm marginalized groups, but it can also be applied to shift the lens of scrutiny away from the moralizing psychologization of chronically ill and disabled people and toward a consideration of the psychopathologies of an exclusionary society. This approach creates a counter-narrative, an opportunity for a counter-hegemony, that represents both a form of resistance to, and a critical interrogation of, oppressive manifestations of social power. Indeed, critically oriented theorists have argued that dominant constructions of marginalized groups often reveal more about privileged subjects than they do about marginalized subjects (Wilkinson & Kitzinger, 1996); this article strongly supports that argument (see also Hunt in press). In particular, it has been contended that social discourse ostensibly pertaining to disability and impairment is, in actuality, about non-disabled people; it has been argued to bolster the privileged status of abled people and to defend against threats posed by the disabled body to the collective abled psyche (see Mintz, 2002; Marks, 1999). Accordingly, many of the dominant stories told about MUS likely reveal more about those who (re)produce these stories than they do about patients, and the article concludes by elaborating on this point.

Whilst tales have been told about MUS as a social epidemic (Stanley et al., 2002), it could well be argued that the real social epidemic is neoliberalism, entwined with the need to justify the abled subject and an ableist society. Similarly, whilst ME/CFS (allegedly in parallel with neurasthenia) has been framed as a way to "give legitimacy to distress that would otherwise be unacceptable to the patient" (Wessely 1994, p.192), and as means to absolve the sufferer from moral responsibility (Wessely, 1994, 1997), it might be more persuasively contended that dominant conceptualizations of ME/CFS and MUS represent a way to give legitimacy to an oppressive status quo and those who benefit from it, whilst absolving complicit actors from blame. That is to say, the stories of discomfort with uncertainty, lack of insight into the condition, and difficulty taking personal accountability, routinely (re)produced about patients (Stanley et al., 2002; Huibers & Wessely, 2006; Chalder et al., 2019), may apply better to clinicians and social actors more broadly (see Hunt in press). In short, so-called 'maladaptive' psychology in the realm of MUS may be a real phenomenon, but such psychology - particularly as it impacts deleteriously on the wellbeing of others - is typically not to be found within the patient community, but rather within an abled and largely ableist collective consciousness. The psychological, political, professional and financial investments in the status quo, as discussed in this article, suggests that mainstream resistance to counter-narratives will be fierce.

However, the foundations of (bio)psychosocial hegemony have been revealed as socio-politically and discursively constructed and can therefore be deconstructed in a myriad of ways. Critical psychology offers many valuable tools in this regard.

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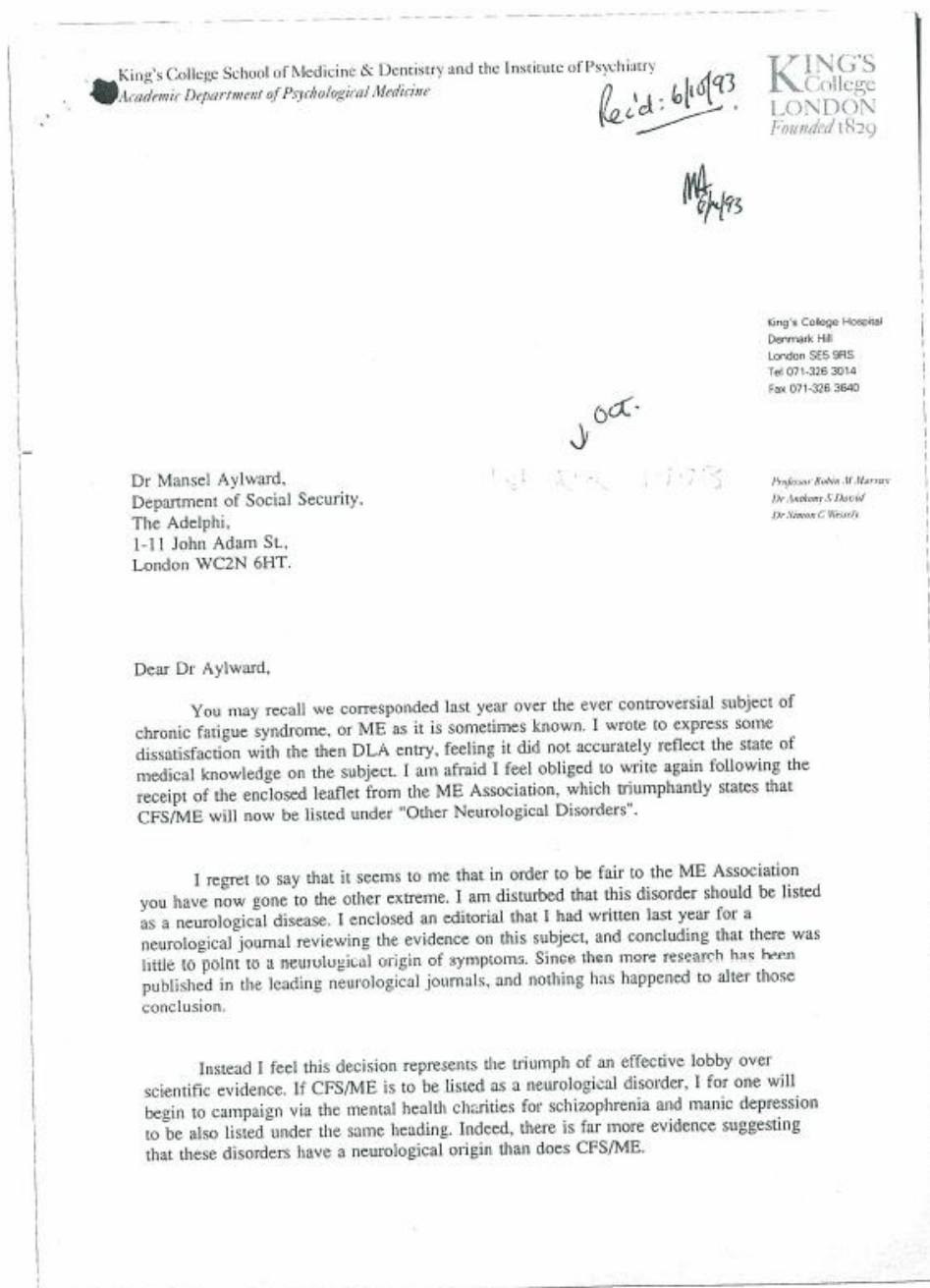
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## Appendix A: Data from The National Archives

Note: The National Archives data as presented below are accessible via Valerie Eliot Smith's blogsite (Eliot Smith, 2015). The data is also available on request to The National Archives <https://www.nationalarchives.gov.uk/>

**Figure A1**

*1<sup>st</sup> October 1993 Letter from Simon Wessely to Mansel Aylward*



I also feel that this decision, if it has been made, reflects an undesirable stigmatisation of psychiatric disorders. The main difference between CFS and the major psychiatric disorders is neither aetiological, nor symptomatic, but the existence of a powerful lobby group that dislikes any association with psychiatry.

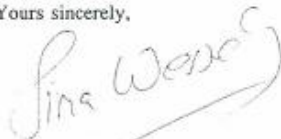
It is also a most unfortunate message to send sufferers. It colludes with the erroneous belief that this is a severe disorder of neurological functioning, for which there is little effective treatment, and a poor prognosis. It will discourage any sensible efforts at rehabilitation. As we, and now many other groups, have shown that the **only** determinant of outcome in this condition is strength of belief in a solely physical cause, then it will also itself contribute to disability and poor outcome. I cannot believe that is the intention of the Department, if only on grounds of cost!

I believe that the Department is making an error if it accepts the partisan views put forward by pressure groups as a basis for making medical decisions. I also believe that it is a decision that the Department will come to regret, since it seems likely the result will be an ever increasing stream of claims for permanent benefits in people who might otherwise have had a chance of recovery.

I am sorry to write to you again on this subject, and I know all too well how your spirits may well sink at receiving another letter on the topic. I also know from personal experience that coming to any decision on this subject that conflicts with the "party line" is not a recipe for a quiet life. Nevertheless, I would value your comments.

With kind regards,

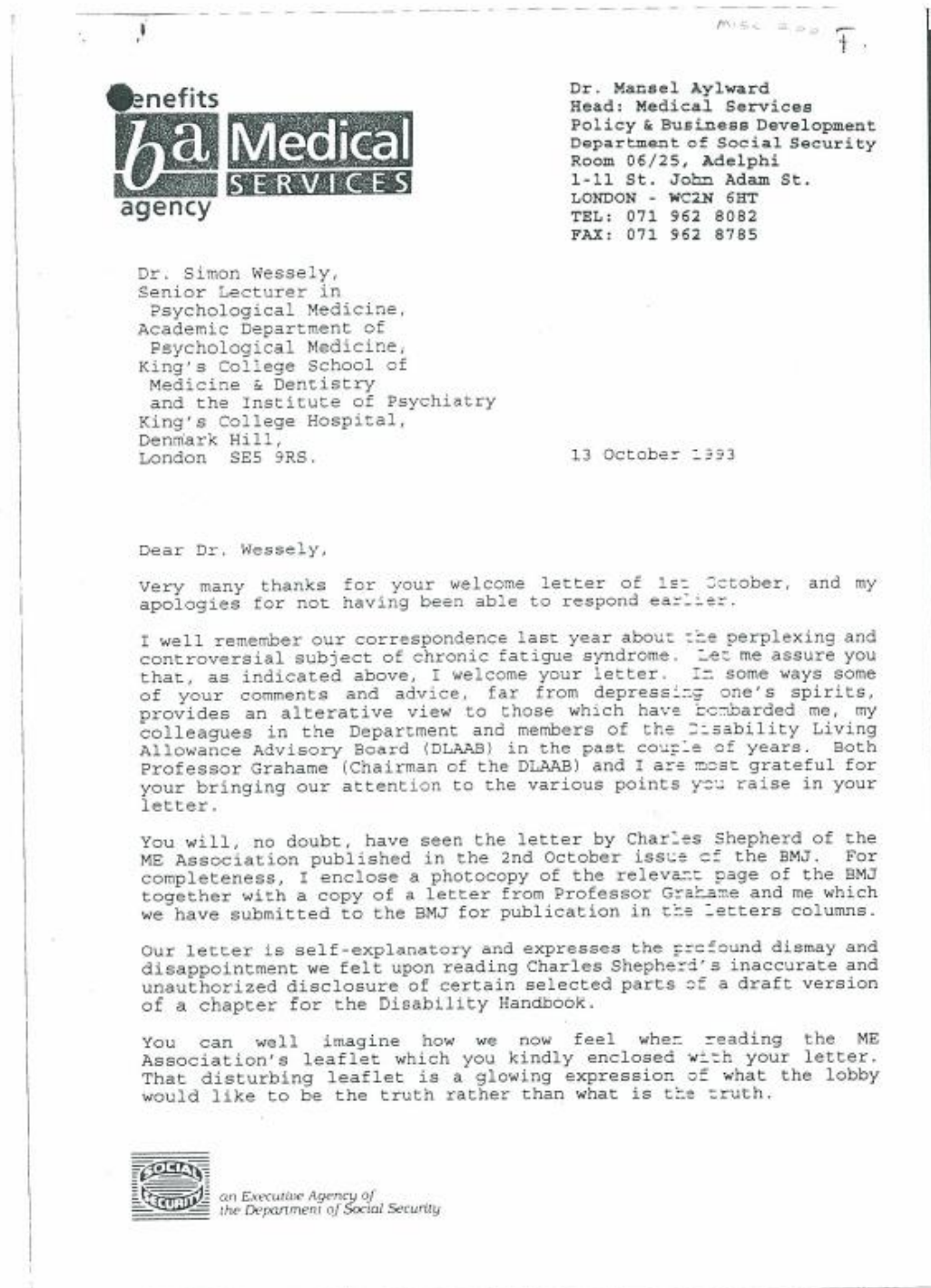
Yours sincerely,

A handwritten signature in dark ink, appearing to read 'Simon Wessely', written in a cursive style.

Dr Simon Wessely,  
Senior Lecturer in Psychological Medicine.

Figure A2

13<sup>th</sup> October 1993 letter from Mansel Aylward to Simon Wessely



The draft version of the Handbook's chapter was sent to groups representing people with ME as part of the customary confidential consultation procedures followed by the DLAAB when soliciting the views of interested parties on provisional revisions of the text of the Disability Handbook. The DLAAB, and the DLAAB alone, is charged with advising the Secretary of State on the contents and format of chapters for the Handbook. The DLAAB has not yet reached a decision on the final text of the chapter mentioning ME which it will recommend to the Secretary of State for inclusion in the Handbook.

A plenary session of the DLAAB will take place at 10.00a.m. on Tuesday, 2nd November at Richmond House when the Minister of State, The Rt. Hon. Nicholas Scott MBE MP, will be attending. Among other matters on the agenda will be a talk by Professor Thomas of the Royal Free Hospital on the subject of chronic fatigue syndrome. Professor Thomas's contribution will also assist the DLAAB in its deliberations on the final text of the chapter concerned with ME. Both Professor Grahame and I would be delighted if you could attend too. If you are able to come could you please get in touch with Dr. Mida McGrath (Tel: 071 962 8045) at the above address who will be pleased to give you details of the agenda and copy you with the relevant papers.

I am sure that the matters you raise, and in particular your views on the listing of chronic fatigue syndrome under "Other Neurological Disorders", will serve to fuel the debate at that meeting.

With kind regards,

Yours sincerely



Dr. Mansel Aylward



Figure A3

10<sup>th</sup> November 1993 Letter from Peter White to Mansel Aylward & Rodney Grahame

17/11

*The Medical College of Saint Bartholomew's Hospital*

University of London

Department of Psychological Medicine

Head of Department: Professor Ted Dinan MD PhD

10 November 1993

NA 157xi

Mr Rodney Grahame  
and Mr Mansel Aylward  
Disability Living Allowance  
Advisory Board  
London WC2N 6HT

Dear Mr Grahame and Mr Aylward,

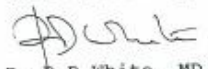
Description of ME in Disability Handbook

I read your letter in the British Medical Journal of 23 October this year. I was worried to learn that the Disability Handbook "will probably conclude that myalgic encephalomyelitis is a separate entity within the group of disorders encompassed by the chronic fatigue syndromes and that some affected people remain disabled, make little or no progress, or even deteriorate over time".

I am a psychiatrist who has been studying fatigue, particularly fatigue following infections like glandular fever, for nine years. From my own work, as well as my reading of the world literature, I would not agree that there is a consensus that "ME" and the chronic fatigue syndrome are separate conditions. Because of my research and clinical experience of helping to reduce disability in the chronic fatigue syndrome, I suggest that separating the two conditions may enhance disability. The reason for this is that those who believe in the separate existence of "ME" believe this is a totally physical condition, probably related to immune dysfunction or persistent viral infection, for which no treatment is available. On the contrary, I think the present evidence suggests that the chronic fatigue syndrome is a genuine discrete syndrome and treatments and rehabilitation programmes are available which address both the physical and psychological factors that maintain this syndrome.

For this reason, I would ask you to reconsider separating the two conditions. I would be happy to have further discussions with you about this.

Yours sincerely,



Dr P D White, MD MRCPsych  
Senior Lecturer and Honorary Consultant Psychiatrist

St. Bartholomew's Hospital  
West Smithfield, London EC1A 7BE

Telephone 071-601 6138  
Fax 071-601 7969

**Figure A4**

*Minutes of talk given by Peter Thomas and Simon Wessely on ME and CFS, 2<sup>nd</sup> November 1993  
plenary session of DLAAB, recorded by McGrath*

CHRONIC FATIGUE SYNDROME

SUMMARY

OF THE TALK GIVEN BY PROFESSOR P K THOMAS CBE DSc MD FRCP  
AND DR S WESSELY BM BCh MRCP MRCPsych on 2.11.93.

AT A FULL BOARD MEETING HELD IN RICHMOND HOUSE IN THE  
PRESENCE OF THE RT HON NICHOLAS SCOTT MBE MP.

Professor Thomas:-

1. The term Myalgic Encephalomyelitis (ME) was introduced at the time of the epidemic in the Royal Free Hospital in 1955. There can be no doubt that this epidemic represented mass conversion hysteria. The epidemic was triggered by a small number of cases of genuine neurological disorder, such as MS or post infective acute disseminated encephalomyelitis. In 1962 when Professor Thomas started working in the Royal Free Hospital there were still a number of symptomatic cases. The dominant symptoms were weakness, fatigability and muscle pain.
2. The cases now seen in the UK are a variety but one thing is certain they do not have Encephalomyelitis. This term means inflammation of the brain and spinal cord, for which there is no evidence whatsoever. Their symptoms are Myalgia, Fatigue and some Psychiatric symptomatology.
3. Fatigue is a symptom in a wide variety of conditions and it is vitally important to establish a precise diagnosis. Many cases have been labelled as having ME when the diagnosis on further investigation was found to be eg Myasthenia Gravis, Hypothyroidism, Brain tumour, Occult infection, Metabolic neuropathies etc.
4. There are different types of fatigue. Fatigue is the inability to maintain the necessary output of force by muscles. a). Peripheral Fatigue that is due to problems with the muscles themselves, the neuro-muscular junction or with the spinal cord.  
b). Central Fatigue refers to difficulty in maintaining an output of muscle force because of problems in the activation of the nerve pathways that run from the brain to the spinal cord.



c). Objective Fatigue is something that can be demonstrated by physiological recordings, which measure the declining force from the muscle.

d). Subjective Fatigue refers to the situation where the delivery of the required force cannot be maintained because of uncomfortable sensations, not in the muscles themselves but in an indefinable way that affects drive and motivation.

5. The features of the chronic fatigue syndrome are multifarious and variable between different parts of the world. They have also changed over time. Definition thus becomes a problem, however symptoms should have persisted for at least six months. This is arbitrary but it does exclude patients who have the fatigue that normally follows many acute illnesses.
6. The dominant symptom is FATIGUE, both mental and physical. They are unable to work and many spend most of the day in bed or resting elsewhere. They have great difficulty in undertaking even mild exercise. Careful studies, in particular by Professor Richard Edwards in Liverpool and by a group in Sydney, Australia have shown unequivocally that the fatigue these patients experience is SUBJECTIVE. That is they have no muscle weakness, there is no difference between normal and CFS subjects in the decline and recovery of muscle force/contraction.
7. The second important symptom is MYALGIA or muscle pain. Characteristically this follows exercise rather than occurring at the time, it is the same as the pain which is suffered by physically unfit people after exercise. These patients are not active and therefore experience post-exercise myalgia after quite mild activity. It is related to muscle damage during what is called eccentric contraction. MUSCLE BIOPSY shows no abnormalities other than those related to the effects of inactivity ie type 11 atrophy of muscle fibres. The symptoms of CFS are therefore NOT due to neuromuscular dysfunction.
8. MENTAL FATIGUE is associated with emotional disorder. All studies have emphasized the high rates of psychological disorder in patients with CFS. Major or minor DEPRESSION is the commonest, however the following occur as well, somatization disorder, anxiety, hypochondriasis, hyperventilation and a few hysterical conversion syndromes. There is no psychiatric disorder in 23% of cases. CFS IS NOT DUE TO MALINGERING. It must be pointed out that fatigue is a symptom of depression and can be the initial symptom of depression.

One feature that tends to distinguish patients with CFS from other patients with depression is a lack of self blame or self deprecation which is often a conspicuous aspect. Patients with CFS are desperate to find some reason outside themselves which has caused their symptoms.

9. CFS is NOT related to chronic viral infection, previous claims have been shown to be faulty.
10. Prognosis is not clearly understood and is determined by many factors, such as :- Psychological, social and cultural influences.  
Certain factors are associated with a poor prognosis, these are:- long duration of illness, high emotional distress, illness beliefs eg viral persistence or muscle disease, and poor clinical management.
11. Clinical management MUST include identification of the underlying depression and persuasion of the patient to accept this explanation. It must be treated as it could lead to suicide.  
ACTIVE management is important, with graded rehabilitation towards achievable targets. Graded exercise does and will help. Patient support groups do not help as they tell patients that at all costs they must avoid exercise as it will make them worse which is totally untrue.  
There is no difference between ME and CFS except in the patient's belief.

Dr Simon Wessely:-

1. There is no evidence of primary muscle dysfunction ie it is not a neuromuscular disorder or a neurological disorder. There is no evidence of inflammation of the CNS. There is no evidence of hysterical or feigned origin to symptoms.
2. It is associated with high rates of psychiatric disorders which are well in excess of what might be explained as a reaction to physical illness.
3. There is little evidence that it is due to a persistent virus. The only infective association is that it may be triggered by the Epstein Barr virus. Post viral fatigue after other viral illnesses should not last longer than six months.

The prognosis for those who acquire the label of "ME" is at the moment poor. The only three prognostic studies conducted to date all suggested that poor prognosis, and failure to improve, is closely related to illness beliefs of a solely physical origin to symptoms.

5. It seems likely that the greater the disability, the more likely is the disorder to be associated with either misdiagnosed psychiatric disorder or poor illness management. Many are iatrogenic ie Doctors contribute in perpetuating the disease and its symptoms.
6. TREATMENT is difficult, extraordinary sensitivity is necessary. Great flexibility is essential in treating these patients, each case is different. It is a treatable disorder but its management is deplorable at present, the worst thing to do is to tell them to rest. Rehabilitation is essential, exercise is good for these patients, prolonged inactivity causes adverse physical and psychological consequences. Most cases can be expected to improve with time.
7. As regards benefits:- it is important to avoid anything that suggests that disability is permanent, progressive or unchanging. Benefits can often make patients worse.

Dr M McGrath  
Secrétaire DLAAB

## Appendix B: UnumProvident documentation

Note: the following documentation is made available by Maxwell Head:

[https://issuu.com/maxhead/docs/unum\\_cmo\\_report\\_2002/18](https://issuu.com/maxhead/docs/unum_cmo_report_2002/18)

**Figure B1**

*Michael Sharpe's contribution to 2002 UnumProvident 'Trends in Health and Disability' brochure (Sharpe, 2002)*

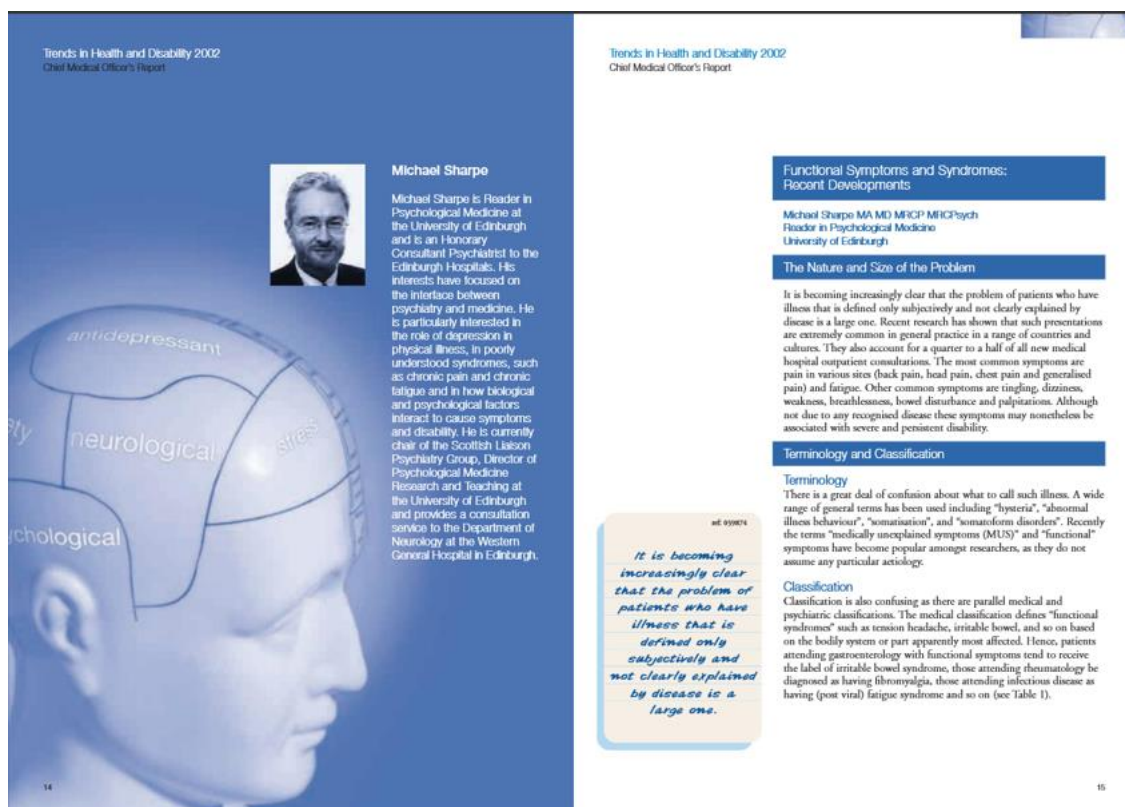


Table 1: Common medically defined functional syndromes listed by medical speciality

Gastroenterology	Irritable bowel syndrome (IBS), non-ulcer dyspepsia (NUD)
Gynaecology	Pre-menstrual syndrome (PMS), chronic pelvic pain (CPP)
Rheumatology	Fibromyalgia (FMG)
Cardiology	Atypical or non-cardiac chest pain; benign palpitation.
Respiratory medicine	Hyperventilation syndrome (HVS)
Infectious diseases	(Post-viral) fatigue syndrome (CFS)
Neurology	Tension headache
Dentistry	Temporal-mandibular joint dysfunction, atypical facial pain
ENT	Globus syndrome
Allergy	Multiple chemical sensitivity

There has recently been increased awareness that these individual "functional syndromes" are not as separate as they seem. There is not only overlap in the symptoms patients report but also in associated characteristics and response to treatment (see below). It has therefore been proposed that these conditions be considered together as a "general functional somatic syndrome". Whilst this may be too extreme a view, substantial commonality between them is now generally accepted.

patients may become chronically disabled because of a treatable but untreated psychiatric disorder.

The psychiatric classifications provide alternative diagnoses for the same patients (See Table 2). The majority, but not all patients will meet criteria for depressive or anxiety disorders and most of the remainder of those for the so-called somatoform disorders of which hypochondriasis (severe anxiety about disease) and somatisation disorder (a long term tendency to present repeatedly with a range of medically unexplained symptoms) have most clinical utility.

Table 2 : DSM-IV and ICD-10 categories for medically unexplained syndromes

DSM-IV	ICD-10
Somatoform disorders	Somatoform disorders
Somatisation disorder	Somatisation disorder
Undifferentiated somatoform disorder	Undifferentiated somatoform disorder
Conversion disorder	
Pain disorder	Persistent somatoform pain disorder
Hypochondriasis	Hypochondriacal disorder
Body dysmorphic disorder	
Somatoform disorder NOS	Somatoform autonomic dysfunction
	Other somatoform disorders
	Somatoform disorder unspecified
	Dissociative (conversion) disorders
	Disorders of movement and sensation
	Other neurotic disorders
Neurasthenia	
Depressive disorders	Depressive disorders
Anxiety disorders	Anxiety disorders

Neither classification is ideal. However, the psychiatric classification has important treatment implications. Because patients present somatically (and may not want a psychiatric diagnosis) this may be missed. Hence, patients may become chronically disabled because of a treatable but untreated psychiatric disorder. This is not an uncommon finding both in clinical practice and in IMEs. We need better classifications – in the meantime, the best practice is to always seek evidence for and record diagnoses from both medical and psychiatric systems for example "irritable bowel syndrome with anxiety".



## The Aetiology of Functional Syndromes

The best ways of understanding such syndromes is to consider a range of biological, psychological and social factors. Table 3 illustrates such an approach to chronic fatigue syndrome.

Table 3: Possible causal factors in chronic fatigue syndrome

	Predisposing	Precipitating	Perpetuating
Biological	Genetic Previous depression	virus	HPA axis disturbance inactivity
Psychological	Personality (perfectionism)	response to stress	disease attribution, avoidant coping style
Social		stresses	life conflicts, iatrogenic factors

## Biological factors

Recent research using functional brain imaging (PET and fMRI) has started to identify altered brain functioning in patients who have functional syndromes (as well as in those with depression and anxiety). This does not mean the patients have brain disease, but that their experience of symptoms has a neurophysiological correlate. On the one hand this is merely evidence of mind-brain identity, on the other hand it does remind us that these symptoms are not purely psychological phenomena but that they have a biological reality, albeit a potentially reversible one.

## Psychological factors

Whatever their biological basis, there is strong evidence that symptoms and disability are shaped by psychological factors. Especially important are the patients' beliefs and fears about their symptoms. Research in several functional syndromes has found that a strong belief and preoccupation that one has a "medical disease" and a helpless and passive attitude to coping is associated with persistent disability (as it is in recovery from acute medical condition such as myocardial infarction). The presence of depression is similarly associated with greater disability and worse outcome. Some persons appear to exaggerate symptoms but this is often hard to prove.

there is strong evidence that symptoms and disability are shaped by psychological factors.

social factors are almost certainly of great importance in shaping functional illness

Although harder to research, social factors are almost certainly of great importance in shaping functional illness. Relevant factors include the information patients receive about the symptoms and how to cope with them. This information may be helpful or may stress the chronicity of the illness and promote helplessness. Such unhelpful information is found in "self-help" (!) books and increasingly on the Internet (see for example [www.mcasassociation.org.uk](http://www.mcasassociation.org.uk)). Unfortunately, doctors and especially "specialist private doctors" and complementary therapists may be as bad. Other social factors that perpetuate illness are anger with the person or organisation the illness is attributed to, or toward the insurer for not believing them. It has been pointed out that: "if you have to prove you are ill you can't get well". Both State and private insurers pay people to remain ill. Litigation for poorly understood and functional illness appears to be on the increase and a recent large study from Canada provided evidence that it does increase the duration of so-called whiplash symptoms.

## Treatment

## Evidence based treatment

Recent systematic reviews of randomised controlled trials have confirmed that psychologically informed rehabilitative treatments (often called cognitive behaviour therapy or CBT) and "antidepressant" drugs have some effectiveness in treating most functional syndromes. There is however a great shortage of skilled providers of CBT in particular and rehabilitative facilities in general.

## Obstacles to recovery

In practice, even if treatment is available, there may be obstacles to recovery. Over time, the patient's beliefs may become entrenched and be driven by anger and the need to explain continuing disability. The current system of state benefits, insurance payments and litigation remain potentially major obstacles to effective rehabilitation. It is often unrealistic to expect medical treatment alone to overcome these. Furthermore patient groups who champion the interest of individuals with functional complaints (particularly for chronic fatigue and fibromyalgia) are increasingly influential: they are extremely effective in lobbying politicians and have even been threatening towards individuals and organisations who question the validity and permanence of the illness they champion. Again the ME lobby is the best example.

The current system of state benefits, insurance payments and litigation remain potentially major obstacles to effective rehabilitation.

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*Possible new functional syndromes are likely to include those associated with pollution of the workplace... and work stress*

Functional symptoms are not going to go away. They will be driven by factors such as work stress and disaffection, information about new illness from the media and the Internet and the persisting stigma of psychological problems. However, the form that they take is likely to continue to change. Although there are a limited number of symptoms that people can have, there are an almost infinite range of factors that these symptoms can be attributed to. Such illness attributions tend to be to external factors and often those, which individuals feel fearful of, wronged by and which are outside their control. Possible new functional syndromes are likely to include those associated with pollution (chemical, biological and radiological) of the work place and work stress, and perhaps now in relation to "terrorism" and fear of terrorism.

A shift towards a more consumer-based approach to health is also likely to increase the prominence if not the prevalence of such syndromes as the authority of medicine to define what is a legitimate illness is diminished. Indeed, increasingly consumer oriented and privatised doctors will collude with the patient's views that they have a disabling and permanent disease. In other words, it may be difficult for those who wish to champion rehabilitation and return to work to "hold the line" without seeming to be "anti-patient".

The demands such persons make on health service, social benefit systems, and insurers are likely to increase. An increase in insurance claims is to be therefore anticipated.

#### What can be done?

Generally  
It will be imperative that health and social policy addresses this problem. Benefits and medical services need to be more rehabilitation orientated. This will not be easy. However, there are glimmers of progress.

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*Benefits and medical services need to be more rehabilitation orientated.*

An example is recent developments in the politics of CFS. After a failure of patient organisations to accept a report on the condition produced by the Royal Colleges, the previous CMO for England set up a working party that included both patient advocates and professionals. The meetings were difficult and there was a failure to agree the final report. Nonetheless, the current Chief Medical Officer released the report early in 2002 ([www.doh.gov.uk/cmo/chmcreport](http://www.doh.gov.uk/cmo/chmcreport)). It is "mixed", in terms of the relationship of its contents to the research evidence as opposed to advocacy – but does accept the

increasingly strong evidence for rehabilitation. Furthermore, one of the

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*As long as the economy remains strong and skilled workers are sought after, it will be in employers' interests to rehabilitate sick but valued employees.*

major patient charities (Action for ME) is aligning itself with a more evidence-based approach. These are early days but if this convergence of rehabilitation oriented clinicians and a patient advocacy group is successful, there could be very positive implications for patients and for insurers.

There is a major need for effective rehabilitation for treatable patients. Existing pain and rehabilitation services would provide a useful basis. However, their capacity and skills are currently far too limited. Funding of rehabilitation by commercial bodies has begun in the UK (with organisations such as PRISMA) and is likely to continue. As long as the economy remains strong and skilled workers are sought after, it will be in employers' interests to rehabilitate sick but valued employees.

#### By the insurance industry

From the insurance point of view, efforts need to be made to minimise the risk of their policyholders getting ill and to minimise the obstacles to their recovery. There are implications for pre-acceptance medical assessment and for the work practices of employers. When policyholders do fall sick with a functional syndrome it is likely to help if both insurer and employer maintain a positive relationship with the claimant. An early but positively planned return to work (even in a very limited capacity) is desirable. If the claimant becomes hostile toward employer or insurer the position is likely to be difficult to retrieve.

Much could be gained from having an early biopsychosocial assessments of patients that ensured the identification of psychiatric as well as medical diagnoses. There is also a need to minimise iatrogenic harm both from family doctors who misguidedly encourage the patients to "take time off" at the insurer's expense and from certain "specialists".

For those with established disability an increased availability of rehabilitative treatment facilities is highly desirable. The NHS is not likely to pay for these.

#### Summary

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*How much is it costing you doing nothing?*

The problem of medically unexplained or functional illness is a large one. It is not going to go away and it is likely to get bigger. Social factors are more likely to influence the trends in the prevalence, presentation and cost than are medical developments. Both health services and insurers now need to take a more positive approach. To those who say that this will cost money I would reply – how much is it costing you doing nothing?

## Appendix C: Further data on academic-state alliances

### Figure C1

*Self-authored blogpost on ME/CFS academic-state alliances*

Available at: <https://www.healthcarehubris.com/post/spotlight-on-me-cfs-who-is-lobbying-whom-part-one>

#### **Spotlight on ME/CFS: Who is lobbying whom? Part one**

4 October 2022

I have already written a little on some of the ME/CFS-related academic-state exchanges that can be found in [The National Archives](#), data from which is made available on Valerie Eliot Smith's excellent [blogsite](#) - see [here](#) and [here](#) for access to files. (Valerie is a person with ME and a UK barrister who used the Freedom of Information Act to release data pertaining to ME/CFS).

By 'academic-state', I mean the association between the UK government and certain actors within academia, largely but not exclusively psychiatry. These alliances have been further bolstered by comrades within the disability insurance industry, creating a multi-faceted power structure that has constructed a highly persuasive story about a psychosocial entity by the name of 'CFS'. At least, highly persuasive, if eminence-based propaganda is your bag.

My previous writings on these alliances can be found [here](#), [here](#), [here](#) and [here](#), inspired largely through a critical psychology and disability studies lens. Valerie Eliot Smith has also discussed facets of these alliances on her blogsite. In this blogpost, I'm going to relay some of The National Archives data relating to what might be considered an academic lobbying of the UK government – largely the Department of Work and Pensions (DWP) - on the subject of ME/CFS.

Since I cannot offer hyperlinks to each individual communication referenced here (the two data pdfs on Valerie's blogsite each contain hundreds of scanned documents), I will add references to the pieces I discuss at the end of this post. Although I will use the term DWP throughout for simplicity, this department was called the Department of Social Security until 2001 when it was replaced by the DWP.

The following account is necessarily selective, and documented exchanges exist before the selected starting point for this particular account.

#### **ME and the DWP Disability Handbook**

Let's start with psychiatrists Simon Wessely and Peter White, who were both most unhappy at the suggestion, back in 1993, of a possible re-positioning of ME as a discrete neurological condition within the context of UK government health and social policy. (Maybe we should say re-repositioning, since ME was recognised as a neurological condition in 1969 by the World Health Organization, before two other psychiatrists, McEvedy and Beard, re-framed it as hysteria). The health and social policy issue concerned the then upcoming revised chapter on ME/CFS in the DWP Disability Handbook, a guide for non-medical decision-makers regarding eligibility for Disability Living Allowance (which would later be phased out as part of the 2012 Reform Act and gradually replaced by Personal Independence Payment).

In a nutshell, the handbook chapter looked set to position ME as a separate clinical entity to CFS, where ME would be recognised as neurological (as opposed to psychosocial or psychiatric). Further, the chapter looked set to emphasise that ME could result in severe and progressive disablement.

The implications of this for the UK government, for psychiatry and the disability insurance industry are profound: ME would no longer be within the reach of psychiatry and their psychosocial 'treatments', whilst



the UK government and insurance industry would be faced with increased costs in the form of long-term benefits and private income protection respectively (see here for a [summary](#) of the political backdrop).

The UK ME Association had announced the provisions of this revised chapter to their members in autumn 1993, including in the form of a leaflet, prior to its official publication. This had apparently caused dismay in some quarters, including on Wessely's part.

#### **Wessely's letter to Aylward, 1st October 1993 (Wessely, 1993)**

Wessely wrote to express his disgruntlement on this matter to Mansel Aylward, one of the authors of the original Disability Handbook and involved in its revision, who would also enjoy a distinguished career at the DWP as Chief Medical Officer, Medical Director and Chief Scientist. (It should also be noted that Wessely and Aylward had engaged in prior exchanges regarding the first version of the Disability Handbook in 1992, which are not documented here).

In an October 1993 letter to Aylward, Wessely encloses the ME Association's leaflet, and argues that the decision to position ME as neurological is underpinned with very little empirical support. Instead, Wessely suggests that: "this decision represents the triumph of an effective lobby over scientific evidence" (note the beginning of the 'ME lobby' narrative). Wessely then suggests that if ME was to be considered neurological in origin, he will campaign for schizophrenia and manic depression (now usually known as bipolar disorder) to be considered similarly. He goes on:

"I also feel that this decision, if it has been made, reflects an undesirable stigmatisation of psychiatric disorders. The main difference between CFS and the major psychiatric disorders is neither aetiological, nor symptomatic, but the existence of a powerful lobby group that dislikes any association with psychiatry."

Here, the 'anti-psychiatry' trope that figures in some of Wessely's [writings](#) can be discerned. This trope, unsurprisingly given the links between Wessely and the Science Media Centre - with Wessely variously serving as science advisor and trustee - has found its way into the UK press (see [here](#) and [here](#)).

Here too, a now common psychosocial narrative, that of a neurological (biological) positioning of ME/CFS reflecting mental health stigma, is also evident. Wessely's [early work](#) on ME/CFS – notably where he attempts to draw parallels to neurasthenia – is spattered with suggestions that people with ME/CFS seek a biological understanding of their illness as a means to escape the stigma of mental health. That people with ME/CFS might seek a biological understanding of ME/CFS because there is a biological basis to the condition, and because psychosocial framing might lead to harmful 'treatment', does not seem to occur to Wessely.

Finally, Wessely writes that Aylward's department (the DWP, then DSS) is sending out a "most unfortunate message" that "colludes with the erroneous belief that this is a severe disorder of neurological functioning" and goes on to caution Aylward of the repercussions of considering ME as a disability: "I cannot believe that is the intention of the Department, if only on grounds of cost!" This cost is clarified as the "ever increasing stream of claims for permanent benefits in people who might otherwise have had a chance of recovery". Since this purported recovery would be positioned as a result of interventions that Wessely has spent much of his career developing, considering ME (or ME/CFS) as a severe and permanent form of impairment would indubitably also cost Wessely's career dearly. Little wonder Wessely also demonstrates concern that a neurological understanding of ME (or ME/CFS) "will discourage any sensible efforts at rehabilitation."

It is hard not to read this letter as a form of lobbying. Wessely's assertion that he will campaign if he does not get his way, his use of emotive language, metaphor and appeal to scientific legitimacy ("the triumph of an effective lobby over scientific evidence"), alongside a rather rhetorical drawing of Aylward's conclusion for him ("I cannot believe that is the intention of the Department") demonstrate Wessely's ability for persuasive communication, if not activism. It is therefore interesting that Wessely and chums have apparently been so invested in constructing or reinforcing the 'lobby-activist-militant' trope about patients (see [here](#), [here](#) and [here](#)).

## Interlude

The day after the date of Wessely's letter to Aylward, Dr Charles Shepherd of the ME Association had a letter published in the BMJ (British Medical Journal). The letter, among other things, reiterated the ME Association's announcement to their members that ME would be conceptualised as a neurological condition in the upcoming Disability Handbook (imagine the level of Wessely's disgruntlement at this point).

Aylward – who was presumably already pretty impressed by Wessely's persuasiveness - and Professor Rodney Grahame, then Chairman of the Disability Living Allowance Advisory Board (DLAAB), duly wrote the BMJ to express their dismay that Dr Shepherd would announce the outcome of the revised chapter whilst it was still a provisional draft. In the letter, published 23 October 1993, the Grahame and Aylward appear to try to smooth over the debacle by stating:

"It [handbook chapter] will likely conclude that ME is a separate entity within the group of disorders encompassed by the Chronic Fatigue syndromes, and that some affected people remain disabled, make little or no progress, or even deteriorate over time. However, the revised chapter will also provide information about the majority of people affected by ME in whom disablement is neither severe nor permanent". (Grahame & Aylward, 1993)

This prognostic suggestion could well be construed as extremely optimistic; one [systematic review](#) suggested that for 14 studies of CFS the median full recovery rate was 5%. On the other hand, the acceptance that some people remain disabled or even deteriorate over time could well be argued to be an improvement over the dominant clinical standpoint today. However, it would seem that this 'compromise' positioning was not good enough for some, including Peter White. We'll revisit that shortly. First, this post turns briefly to Aylward's response to Wessely's letter.

### **Aylward's response to Wessely, 13th October 1993 (Aylward, 1993)**

Aylward thanks Wessely for his "welcome letter", which he describes as an "alternative view to those which have bombarded me, my colleagues in the Department and members of the Disability Living Allowance Advisory Board (DLAAB) in the past couple of years". (Some of these 'bombardments' are documented in The National Archives data and consist of disabled people with ME and their allies asking for a more accurate and less stigmatising representation of their illness in official documentation).

Aylward, seemingly very keen to demonstrate his alliance with Wessely, encloses a copy of the letter by Dr Charles Shepherd published in the BMJ, along with the response from Aylward and Grahame, reiterating his "profound dismay and disappointment" on reading Shepherd's "inaccurate and unauthorized disclosure" of provisional components of the Handbook chapter.

Aylward then turns his attention to the ME Association's leaflet that Wessely enclosed in his letter, commenting: "That disturbing leaflet is a glowing expression of what the lobby would like to be the truth, rather than what is the truth." (Note Aylward's reiteration of Wessely's use of 'lobby', which would also later be used by psychiatrist Michael Sharpe in his [Unum writings](#) that I have discussed [here](#)). Aylward assures Wessely that the DLAAB has not yet reached a decision on the final content of the chapter, before inviting Wessely to a plenary session of the DLAAB on 2nd November. Aylward adds that Professor Thomas of the Royal Free Hospital will be giving a talk, and that this talk will "assist the DLAAB in its deliberations on the final text of the chapter concerned with ME".

This was likely an invitation Wessely could not afford to decline, and the plenary will be documented in the second part of the blogpost series. In the remainder of this post, attention is turned to Peter White's response to the DWP Disability Handbook debacle.

### **White's letter to Aylward, 10th November 1993 (White, 1993)**

As previously noted, White had clearly read the letter by Aylward and Grahame in the BMJ. White thus wrote to Aylward to express his concern, principally vis-à-vis the planned separation of ME from CFS in the Disability Handbook. He begins by emphasising that he has been studying post-infectious fatigue states for nine years

and that, following his work and his reading of "the world literature", there is no consensus that ME and CFS are separate entities. He then suggests that "separating the two conditions may enhance disability". White elaborates on this:

"The reason for this is that those who believe in the separate existence of "ME" believe this is a totally physical condition, probably related to immune dysfunction or persistent viral infection, for which no treatment is available. On the contrary, I think the present evidence suggests that the chronic fatigue syndrome is a genuine discrete syndrome and treatments and rehabilitation programmes are available which address both the physical and psychological factors that maintain this syndrome."

Here, the die appears to be cast for the future of ME. White plays down the case for persistent or post viral infection complications in ME, whilst merging ME into the psychosocial narrative of 'CFS'. In doing this, the neurological entity of ME, as recognised by the World Health Organisation, is erased. The 'treatments and rehabilitation programmes' are cognitive behavioural therapy and graded exercise therapy, which White has helped to develop.

### Concluding remarks

White's appeal to the application of cognitive behavioural approaches for 'CFS' is interesting in view of other data from The National Archives includes. In the minutes of a May 1992 'CFS' symposium, White's colleague and fellow psychiatrist Michael Sharpe reportedly admits that there is, at that time, no theoretical basis for cognitive behavioural therapy as applied to CFS (CIBA, 1992). Perhaps all had become clear in the intervening 18 months? Or maybe this is an early example of how eminent academics in the field of ME/CFS may construct theory – and data – to fit their personal biases and professional and political interests.

The above exchanges suggest that, if indeed a 'ME lobby' exists, it is not a lobby of patients but rather consists of psychiatrists keen to peddle their academic wares to the UK government for professional and financial gain. Other academics have been involved in persuading the government to buy into the psychosocial story of 'CFS'; the second part of this blogpost series will explore that a little further.

Click here for the second part of this blogpost series which focuses upon the DLAAB plenary session as mentioned above.

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**Figure C2***Self-authored blogpost on ME/CFS academic-state alliances*

Available at: <https://www.healthcarehubris.com/post/spotlight-on-me-cfs-who-is-lobbying-whom-part-two>

**Spotlight on ME/CFS: Who is lobbying whom? Part two**

4 October 2022

This post is the second of a two-part series looking at academic influence on the UK government's stance on ME/CFS, during the 1990s. It draws from The National Archives data which can be found on the excellent [blogsite](#) of UK barrister and person with ME, Valerie Eliot Smith. As previously noted, Valerie has discussed some of the data on her blog (for an example see [here](#)).

**A plenary presentation (or two)**

On 2 November 1993, a plenary session of the Disability Living Allowance Advisory Board (DLAAB) was held in Richmond House in London. Two academic-clinicians – the then Dr Wessely, and Professor Peter Thomas of the Royal Free Hospital in London – spoke on ME/CFS. The plenary was attended by the then Minister of State, DSS, and Minister for Disabled People Rt Hon Nicholas Scott.

What follows is an account of the minutes from these presentations, to be found in full in The National Archives data (see McGrath, 1993). Therefore, the verbatim extracts represent the wording of the minutes, not the exact words of the academics.

**Thomas: mass hysteria and 'subjective' fatigue**

The Royal Free was the location of a viral outbreak of ME in 1955 (also referred to as Royal Free disease, this outbreak led to the use of the term ME). However, in 1970s, two psychiatrists – McEvedy and Beard – [re-framed](#) this as mass hysteria, apparently on grounds that most of the sufferers were women, and reportedly without actually seeing the patients involved. (Colin McEvedy was a PhD student with a prior interest in hysteria who used the Royal Free outbreak as the subject of his thesis, Alfred Beard was his tutor, and the findings were published in the BMJ).

Although Peter Thomas was not working at The Royal Free during this time, he seemed to toe the line of the two male psychiatrists. Minutes of the presentations (written by Dr McGrath, DLAAB secretary) record Thomas' position on the Royal Free outbreak: "There can be no doubt that this epidemic represented mass conversion hysteria".

Thomas is clearly not a fan of the term 'ME', being recorded as stating that the "term means inflammation of the brain and spinal cord, for which there is no evidence whatsoever." It would also seem that Thomas is in favour of collapsing the entity of ME into the term CFS: "There is no difference between ME and CFS except in the patient's belief". He goes on to propose that the fatigue in CFS is "subjective", that is, it is has nothing to do with pathology of the muscles, the neuromuscular junction or of the central nervous system, but rather is related to issues with 'drive and motivation'. Additionally, he is recorded as saying that mental fatigue is associated with "emotional disorder".

Psychological factors are foregrounded in Thomas' presentation, with claims that "the high rates of psychological disorder in patients with CFS" largely comprise depression but also include some cases of hypochondriasis and "hysterical conversion syndromes". Accordingly, Thomas' idea of clinical management involves "identification of the underlying depression and persuasion of the patient to accept this explanation". This 'persuading the patient' continues today, with 'retribution training' for GPs becoming a subject of [research](#) (retribution involves clinicians trying to persuade patients that their illness is psychosocial, to be 'treated' with some CBT and exercise rather than requiring medical care).

Thomas also demonstrates the beginnings of the victim blaming narratives we are familiar with today when he suggests that CFS can typically be distinguished from depression via a “lack of self blame or self deprecation.” Here, there is an observable attempt to paint ‘CFS’ (and by extension ME/CFS) as some form of character flaw, an inability to take personal responsibility combined with a sense of self-importance\*. Thomas adds that that: “Patients with CFS are desperate to find some reason outside themselves which has caused their symptoms”. This (completely unevidenced) suggestion is highly consistent with Wessely’s early writings on ME/CFS (see [here](#) and [here](#)). Perhaps these similarities are unsurprising since Thomas and Wessely would go on to co-author academic work in this field.

*\*In this respect, it should be considered that when people with ME/CFS reject psychosocial framing, this does not represent mental health stigma or fear of such stigma, but rather a very understandable resistance to having their characters attacked.*

On the subject of the symptom of myalgia, Thomas suggests that this is “the same as the pain which is suffered by physically unfit people after exercise”, adding that people with ‘CFS’ are not active and therefore experience post-exertional myalgia after quite mild activity. This suggestion sets the stage for the deconditioning hypothesis; Thomas’ support for graded exercise is notably recorded in the minutes. This suggestion is also portentous of a narrative that would be repeatedly reinforced by the [academic-state-corporate nexus](#) of alliances: that of essentially healthy people who simply cannot cope with life, thus exaggerate or overly focus on their symptoms and believe themselves to be ill when they are not. Likening the experience of myalgia in ME/CFS to that of somebody who isn’t very athletic after a spot of exercise is evocative of the ‘common health problems’ construct dreamt up by Aylward and chums during their work for the Unum sponsored Cardiff research centre (see [here](#)). It is also similar to Wessely’s attempts to draw parallels between [neurasthenia and ME/CFS](#), neurasthenia describing a largely emotional ‘disorder’ that was thought to affect people (typically women) who could no longer cope with the exigencies of modern life.

Importantly, Thomas is recorded as stating: “CFS is NOT related to chronic viral infection, previous claims have been shown to be faulty” (though he does not explain this ‘faultiness’). He adds that that belief in viral persistence or pathology of other biological origin is associated with poor prognosis, thus foreshadowing the ‘dysfunctional illness beliefs’ trope we know today. Accordingly, Thomas carves out a role for and foregrounds what he calls “psychological and socio-cultural influences” in ‘CFS’, whilst downplaying any suggestion of biological influences – the beginnings of now dominant psychosocial discourse on ME/CFS.

Interestingly, Thomas is also recorded as stating that many cases of what was originally diagnosed as ME were discovered, on further investigation, to be – among other diagnoses - brain tumour, myasthenia gravis, hypothyroidism and metabolic neuropathies. Such findings surely underline the importance of comprehensive biomedical investigation before diagnosing ME, or CFS, and my reading of these minutes is that Thomas was actually in support of that. Unfortunately, Wessely and others would turn out to have other ideas: both the 1996 Royal Colleges joint working group [report](#) on ‘CFS’ and [papers](#) by the usual suspects recommend limiting investigations to little beyond basic bloodwork. The 2007 NICE guidelines on ME/CFS, and the revised 2021 guidelines, reflect this position.

### **Wessely: biology is out, illness beliefs are in**

Wessely’s contributions are notably shorter than Thomas’; in fact, it is not entirely clear whether Aylward actually invited Wessely to speak, or simply invited him to attend.

Wessely echoes much of Thomas’ views, although Wessely is recorded as stating that there is no evidence of hysterical symptoms (both Wessely and Thomas also rule out malingering and feigning respectively). Wessely reiterates Thomas’ claims of high rates of psychiatric co-morbidity, which according to Wessely are “well in excess of what might be explained as a reaction to physical illness”.

In a further echoing of Thomas, Wessely also downplays biological influences: Wessely rules out primary muscle dysfunction and CNS inflammation, adding: “There is little evidence that it is due to a persistent virus”. He concedes that Epstein Barr Virus may trigger the illness, but that post-viral fatigue should not last longer than 6 months. Dysfunctional illness beliefs are also once again implied: Wessely suggests that, according to

(admittedly limited) research, "poor prognosis, and failure to improve, is closely related to illness beliefs of a solely physical origin to symptoms."

The idea of medical collusion is introduced, with Wessely recorded as suggesting that doctors may perpetuate CFS. He is also recorded as saying that "the greater the disability the more likely is the disorder to be associated with either misdiagnosed psychiatric disorder or poor illness management". Here, a victim blaming dynamic is evident: patients who cannot recover may be blamed (possibly along with their doctors) for their inability to manage their illness. Moreover, whilst there should never be any blame or shame around mental health diagnoses, Thomas' contribution demonstrates how mental health is twisted into a character assassination by certain biopsychosocial proponents. Framing patients as having a 'disorder' of character is most certainly victim blaming.

Wessely also shows himself to be in favour of an exercise-based approach to 'treatment': "[...] the worst thing to do is to tell them to rest. Rehabilitation is essential, exercise is good for these patients, prolonged inactivity causes adverse physical and psychological consequences".

The suggestion from Wessely that: "Most cases can be expected to improve with time" has endured over the years. For example, the UK NHS Digital webpages on ME/CFS (the likely first stop for many people who want to source 'trusted' information on the condition) continued to claim that "Most people with CFS will improve over time, especially with treatment" until some time after the final NICE guidelines were published in October 2021.

Finally, Wessely takes a stance on benefits: "it is important to avoid anything that suggests that disability is permanent, progressive or unchanging. Benefits can often make patients worse". This suggestion, that has also endured over time and is now applied to any and every clinically and politically contestable illness, has been discussed elsewhere (see [here](#) and [here](#)).

### **The beginnings of a now dominant narrative**

What is clear from these minutes is that a new narrative on 'CFS' was beginning to take root in the UK, with the help of the UK government, by the early 1990s (academic psychosocial offerings exist before this timepoint). This narrative was likely facilitated by events on the other side of the Atlantic, notably the US CDC's downplaying of biological pathology in the Lake Tahoe outbreaks in the mid-1980s, followed by their 1988 working case definition [report](#) recommending the name 'CFS' (see [here](#), [here](#) and [here](#) for accounts of US politics pertaining to ME/CFS).

The interweaving of social power with unsubstantiated truth claims would become the psychosocial story that we all know today, one that eclipses ME as a neurological entity (as recognised by the World Health Organization in the 1960s), overlooks biological research on the condition, and instead insists that 'CFS' (and by extension, ME/CFS), can be 'treated' through challenging our 'dysfunctional' thoughts, and our 'maladaptive' behaviours.

As has been alluded to here and discussed elsewhere, this academic-state constructed story around ME/CFS would be further reinforced by alliances within the disability insurance industry (see [here](#), [here](#), [here](#), and [here](#)). Together, the 'academic-state-corporate' nexus of alliances have succeeded in hijacking a healthcare model (the biopsychosocial model) and re-writing medical history.

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## Appendix D: Further data on the political backdrop to MUS

### Figure D1

*Self-authored series of blogposts on the political underpinning of ME/CFS and MUS (Hunt, 2021a)*

Available at: <https://www.healthcarehubris.com/post/with-references-structural-dimensions-of-the-biopsychosocial-model-full-series-of-blogposts>

#### **Structural dimensions of the biopsychosocial model (full series of blogposts)**

5 June 2021

This extended blogpost simply brings all of the posts in the '[Structural dimensions](#)' series together, additionally referenced in academic style, rather than via hyperlinks. During the couple of years I spent researching for this series, I noted a repeated dynamic of going to retrieve a saved webpage – typically, demonstrating arguably compromising associations or irrefutable evidence of who said what and when – to find the 'error 404 page not found' message. So, for the sake of completeness, this post includes all the references along with URLs which were active at the time of posting.

(A summary blogpost can be found [here](#)).

#### **Blog one: Beginnings**

*Wherever power is at work, we should be ready to ask who or what is controlling whom, and why.*

Miranda Fricker (2007). 'Epistemic Injustice: Power and the ethics of knowing' (p.14)

Since the publication of the NICE draft on the diagnosis and conceptualisation of ME/CFS, the provisions of which have not been to the liking of a number of eminent researchers and clinicians, there appears to be fairly well orchestrated campaign of stigma and epistemic injustice against people with ME/CFS from certain quarters. I will write about this in more detail in another blogpost, but here I want to examine what arguably underpins and explains such stigmatisation, epistemic injustice and broader social injustice to which patients are subjected. Such injustices are not only committed by certain researchers and clinicians, but also by policy makers, governments, the media and mainstream society more broadly. I want to look at the structural dimensions of the biopsychosocial (BPS) model, that is to say, macro-level phenomena.

Peer-review published literature has demonstrated how the BPS model (in ME/CFS and to some extent other chronic illness) manifests and impacts on a micro level (for example, within healthcare encounters) and on a meso level (for example, in terms of healthcare policy) (see Blease et al., 2017; Geraghty and Blease, 2018; Anderson et al., 2012 for examples). However, discussion of macro level phenomena (structural factors such as economic policies, corporate interests, legislation and associated institutions) within the field of ME/CFS and so-called 'medically unexplained symptoms' are usually relegated to grey literature or personal blogs such as this one. When we consider the power complex that has constructed and reinforces such macro level phenomena, it's not very surprising that mainstream science and humanities journals have not historically wanted to rock the boat – though things may change with Long Covid.

In writing this, I focus on the situation in the UK, and draw principally from the work of a number of disability activists and scholars (for example, Jolly, 2012; Stewart, 2013, 2016, 2019; Berger 2014; Shakespeare et al. 2017).



Although I will focus on ME/CFS throughout, points raised in this blogpost apply to other chronic illness and disability, particularly those that can be shoehorned into the 'medically unexplained symptoms' umbrella or 'contested' illness category. This is very pertinent for those sub-groups of patients with Long Covid without detectable organ impairment, since biomedical conceptualisation and treatment is currently lacking. There are indications that Long Covid may be subjected to a similar process of politicisation as ME/CFS (Willis and Chalder, 2021; Sharpe, 2020) and I think it important that people with Long Covid are aware of the actors and structures underpinning this process.

### **Beginnings of a politicised healthcare model**

The BPS model in mainstream healthcare literature is typically associated with the thinking of George Engel (1977), a doctor in internal medicine and psychiatry with a psychoanalytical training who sought to address what he considered to be a reductionist, dualistic biomedical model. The BPS model purportedly encourages a more holistic form of healthcare, ostensibly acknowledging psychological and social factors in health and illness alongside biological considerations. However, Engel's BPS model has been critiqued on various grounds, notably an eclectic freedom and conceptual under-development which means that any pillar can be foregrounded as per the biases of whomever promotes the model (Ghaemi, 2009). This is a crucial point, because it has allowed the BPS model (as it is applied to disability and chronic illness) to be manipulated to serve political, economic and corporate interests without any empirical underpinning or theoretical coherency. As many disability scholars and disabled people have highlighted, these interests are associated with the work of certain academics within a broader context of government welfare reforms and health insurance industry profiteering. These reforms can in turn be located within a global context, that of ableist, neoliberal politics and the austerity management (structural adjustment) programmes of OECD countries, of which disabled and chronically ill people have borne the brunt (Stewart, 2019b). This application of the BPS model has been referred to as the 'Waddell-Aylward BPS model' (Shakespeare et al., 2017) after Professor Sir Mansel Aylward and the late Professor Gordon Waddell, both medics, academics and key architects of the BPS model as it is applied within health and social policy. I will use the term 'Waddell-Aylward BPS model' to differentiate from Engel's original papers, whilst also acknowledging that other academics have contributed to its development.

### **Foundations of the Waddell-Aylward BPS model**

The Waddell-Aylward BPS model appears to have its origins in Waddell's thinking on chronic back pain (Waddell, 1987, 1999); Waddell was an orthopaedic surgeon with a particular interest in back pain and related disability. Waddell suggested that back pain should not cause long term disability, that too much rest was harmful, and that a rehabilitative approach (notably with 'controlled exercises') was necessary and sufficient to facilitate recovery and return to work. Waddell also distinguished between what he considered an illness (a psychosocial entity) and a disease (a biomedical entity), considering back pain to be the former. Parallels to the BPS model of chronic illness and disability (including, notably, of ME/CFS), can already be observed. However, the model was largely developed through the work of the Centre for Psychosocial and Disability Research at Cardiff University, established in 2004, where both Waddell and Aylward were key academics: Aylward serving as director and Waddell as honorary professor. The papers produced by the Cardiff centre (Waddell & Burton, 2004; Waddell and Aylward, 2005; Waddell and Aylward, 2010) provided an academic framework, and therefore purported justification, for the UK government's welfare reforms and also helped reinforce a reform of health insurance policy towards disabled people (Rutherford, 2007a). By reform, I mean a policy of denying disabled and chronically ill people the financial support necessary to live maximally independent, dignified lives whilst those who drive said reform benefit politically, financially and professionally.

It is thus not coincidental that the Cardiff centre was sponsored for some years by US insurance company Unum (then, Unum Provident) and had associations with the UK government and other entities involved in welfare reform. For example, prior to taking up his post as director of the Cardiff centre in 2004 or 2005 (Aylward's account conflicts with Unum's on this point), Prof Sir Aylward had enjoyed a distinguished career in



the UK DWP (Department of Work and Pensions or DSS as it was for part of Aylward's office) as Chief Medical Advisor, Medical Director and Chief Scientist, whilst some of the centre's work (e.g. Burton & Waddell, 2004) was commissioned by the DWP. During Aylward's time in the DWP he had helped to develop various forms of disability assessment (Aylward & Sawney, 1999), notably with input from Unum presence, and was also involved in Atos, a French company whose healthcare division was contracted by the DWP to manage disability and fitness to work assessments (Berger, 2014). These assessments would essentially tighten the eligibility criteria for various disability-related benefits, significantly increasing the refusal rate of new claims and stopping of existing claims. Reform would also make applying for benefits far more stressful, and draconian sanctions now befall anybody who does not – or cannot – 'follow the rules'.

The Work Capability Assessment (WCA), introduced in 2008 to police eligibility for Employment and Support Allowance (ESA) that replaced Incapacity Benefit, has been associated with enormous psychological distress, destitution and increased suicides amongst chronically ill and disabled people (Barr et al., 2016; Stewart, 2018, 2022). Predictably, the DWP has repeatedly attempted to minimise such suffering and loss of life, not least through refusing to publish data around it, before being forced to do so under a number of Freedom of Information requests. In 2015, the media reported that more 80 people per month were dying after being told they were fit to work (Ryan, 2015; Butler, 2015). Mo Stewart has written at length about how the WCA is essentially a biopsychosocial model of disability assessment adopted by US insurance giant Unum for assessing insurance claims (Stewart, 2016, 2022). Further, Personal Independent Payment (PIP), which gradually replaced Disability Living Allowance (DLA) from 2013 was discussed as being underpinned by 'the' biopsychosocial model in the now infamous Lord Freud contribution during the 2012 Welfare Reform debates (Freud, 2012). The more rigid criteria of PIP have reduced benefits for many disabled people; in some cases, the right to accessible cars and other special equipment that offer disabled folk a degree of independent living has been revoked. Newspaper report and qualitative research has demonstrated the harrowing and often profound consequences for disabled people (Ryan, 2016; Saffer et al., 2018).

The UK government's associations with the private health insurance industry, notably Unum, date back to at least the 1990s and arise from common interests: both parties were concerned over the rising cost of supporting chronically ill and disabled people in the form of social security benefits and health insurance pay-outs (claims) respectively (Rutherford, 2007a). In the mid-1990s, Peter Lilley (then Secretary of State for Social Security) drafted in Dr John Lo Cascio (then second vice-president at Unum) to provide consultancy on how to reduce welfare spending through increasing restrictions on benefit claims. A healthcare or social policy model that appeared to provide a scientific basis for reducing welfare expenditure and maximising corporate profits was indubitably a politically and economically attractive prospect. Specifically, conditions that could be positioned as psychological or psychosocial in nature (lacking 'objective' biomarkers), and thus amenable to psychosocial interventions, could be exempted from welfare provision and disability insurance pay-outs, effecting a retrenchment of the welfare state whilst boosting profits in the private sector. To do this whilst maintaining a façade of ethics, the interventions would have to be demonstrated as being evidence-based (see: Faulkner, 2016). An added bonus for Unum was that, if access to social security was further limited by the UK government, those potential claimants who could had the means might be persuaded to take out private income protection insurance, which Unum was keen to sell - and equally keen to renege on, when disabled and chronically ill policy holders tried to claim for the financial support they were paying for. In fact, Unum has a well-established history of being a financially and morally corrupt, disability denying - I might say disability hating - corporation (Williams & Hooper, 2010; Hansard, 1999). The BPS model was thus chosen as a political tool to justify the reduction of welfare expenditure whilst opening up new markets for corporate profiteering.

The Cardiff centre embodies various rather questionable associations that I have previously termed the academia-government-health insurance complex. Jonathan Rutherford, professor of cultural studies at Middlesex University, has referred to this as the academic-state-corporate nexus (Rutherford, 2007b), and since Prof Rutherford's term is less clunky than my description, I'll use his term throughout. We'll come back to this nexus in more detail later. In the next blog, I'll consider some key constructs of the BPS model, constructs that are largely created for political purposes with a distinct lack of empirical underpinning.

## Blog two: Constructs and propaganda

*"People go to war for ideas, not for evidence."*

Prof Gordon Waddell, in: White, P. (ed) (2005). Biopsychosocial medicine: An integrated approach to understanding illness. p.218

In this blog I will cast an eye on some key constructs within the biopsychosocial (BPS) model of chronic illness and disability. These constructs have quite literally been constructed by the academic-state-corporate nexus (a term used in Rutherford, 2007b) for political purposes, with a subsequent attempt to construct (invent) an evidence-base to fit the policy.

### 'Common health problems'

The Waddell-Aylward BPS model targets what architects of the model refer to as 'common health problems'. These are constructed as mental health, musculoskeletal and cardio-respiratory conditions that are "characterised more by symptoms and distress than by consistently demonstrable tissue abnormality" and are thus considered "subjective health complaints" (Waddell & Burton, 2004; Waddell & Aylward, 2010). The referenced papers, produced by the Cardiff centre, clarify that 'common health problems' are another term for 'medically unexplained symptoms' (MUS) or 'functional somatic syndromes', notably citing work by Sir Prof Wessely who has led the way in extending psychiatric reach over anything that can be possibly framed as such. Prof Peter White is also cited within the same context, apparently to provide empirical substantiation to the claim that 'MUS' are subjective and without objective disease or impairment. In practice, labels such as MUS persist even where patients are not biomedically investigated in the first place, making MUS a clinically meaningless yet politically very useful concept. It is noteworthy that 'chronic fatigue syndrome' (the BPS term for ME/CFS, which is frequently further reduced to 'chronic fatigue') is mentioned in the Cardiff centre's work within the context of these common health problems, under the rubric of mental health (Waddell & Burton, 2004).

Waddell and Aylward argue that workers' compensation and social security benefits were originally designed for people with "severe medical conditions and permanent impairment" (2010), conditions associated with detectable pathology, whilst common health problems are considered to be "similar in nature and sometimes even in degree to the bodily and mental symptoms experienced at times by most adults of working age" (Waddell & Aylward, 2010, p.6). Let's just stop and reflect on this. This means that conditions such as ME/CFS, a condition that has been associated with a lower health-related quality of life and/or greater functional impairment than (for example) various cancers, multiple sclerosis, chronic renal failure and stroke (see Hvidberg et al., 2005; Kingdon et al., 2018), that can leave people bedbound and tube-fed, a condition that has killed people, are framed by Waddell and Aylward as similar in nature and degree to symptoms that most working age adults might experience. It could well be argued that this is somewhat akin to comparing HIV/AIDS to a common cold.

### Deserving and undeserving sick

According to the Waddell-Aylward BPS model, illness is a behaviour and sociocultural phenomenon, whilst disability as it pertains to common health problems is largely conceptualised within a framework of "conscious choice" (Waddell & Aylward, 2010, p.21), where psychological factors (notably dysfunctional beliefs and attitudes and fear-avoidance) are posited to influence disability (Waddell & Burton, 2004). Effort and motivation are expected to lead to recovery, notably through compliance with cognitive-behavioural rehabilitation strategies such as graded exercise and cognitive behavioural therapy (Waddell & Burton, 2004). Receipt of benefits and 'decisions' around being unable to work are equally conceptualised as 'free choices' (Waddell & Aylward, 2010, p.22). Social factors are acknowledged largely as they fit the individualist and neoliberal narrative of agency and free will. That is to say, reinforcement of illness behaviour through 'colluding' clinicians and/or family within a culture of entitlement is one of the dominant narratives, yet critically-informed social factors such as social disadvantage and discriminatory attitudinal contexts are,

conveniently, markedly downplayed. The parallels to the BPS model of ME/CFS as it appears in mainstream literature are clear: the models are one and the same.

According to BPS thinking on ME/CFS, effort and motivation are key in improving health outcomes (Picariello et al., 2017) whilst patients' cognitions and behaviours are framed within the same 'dysfunctional' discourse with attendant recommendations of cognitive-behaviourally inspired interventions (White & Wessely, 1996; Knoop et al., 2010). ME/CFS is framed as an illness where, once again, 'illness' is considered as a sociocultural phenomenon largely without biological underpinning (Stanley et al., 2002; Sharpe & Greco, 2018). As per the Waddell-Aylward creation, the BPS model of ME/CFS only acknowledges social factors as far they fit an individualist narrative of psychologisation. Receipt of benefits, membership of support groups and 'over-solicitous' significant others have at various points been argued to be associated with poorer health outcomes in ME/CFS (Bentall et al., 2002; Band et al., 2015), thus limiting social influences to purported social reinforcement of 'aberrant' psychology. Once again, critically-informed social factors are not mentioned. Again, this is very convenient and serves to shift the spotlight of scrutiny from the model itself, and motivations of its creators, onto patients.

It is important to note that the form of psychologisation promoted by this model goes beyond suggesting that patients have a psychological or mental health condition. Rather, in suggesting that patients are motivated by 'secondary gains' (attention, financial benefits, avoidance of work and other obligations etc.) and that conscious choice and free will play a significant role in recovery, the model crosses the line from clinical judgements to moralistic and stigmatising ones. Such judgements also appear to be lacking in rationality: why anybody would choose a quality of life lower than cancer, would gain anything from being forced to bear witness to their slow and painful decline into oblivion, all whilst being treated like a social pariah, is never really explained. Secondary gains (along with much thinking in psychiatry) has its theoretical roots in unfalsifiable Freudian theory and has been adopted by eminence-based medicine to serve the financial, professional, political gains of those who perpetuate it.

The BPS model also creates divisions between 'serious medical conditions' (worthy of welfare support and biomedical healthcare) and 'common health problems' (unworthy of such), divisions which have been argued by disability scholars to be evocative of the deserving and undeserving poor narrative (Stone, 1984; Shakespeare et al., 2017). According to such divisions, it could well be argued that people with ME/CFS are unjustly framed as the undeserving sick – by the very people who claim to want to help them. The UK press has historically done very little to counter such narratives, towards chronically ill and disabled people more broadly (Briant et al., 2013) and towards ME/CFS more specifically (Liddle, 2019). In-group out-group dynamics (worthy – unworthy) are also a key ingredient in stigma, discrimination and oppression. Stigma in particular proves a very handy political tool when socially powerful people desire, for their own ends, to commit the most egregious abuses against less socially powerful people – and get away with it.

### **Eminence-based propaganda**

One of the most shocking aspects of the state-sponsored is the lack of evidence-base and lack of theoretical coherency of the BPS model. Independent Disability Studies Researcher Mo Stewart has suggested that UK welfare reforms (in particular the Work Capability Assessment) can be considered a form of democide (Stewart, 2019b), pushing thousands of disabled and chronically ill people into early death through neglect (starvation, untreated disease, destitution) or suicide. As Stewart (2014) also notes, many more have been plunged into constant fear of having no means to survive and into utter despair, living in conditions which surely must represent a violation of their human rights. In order to guarantee mainstream society's complicity with such abuses, the UK government needed to present their policies as evidence-based. Eminent academics have played a key role here, abusing their epistemic and social power in presenting what is little more than state-sponsored disability denial as a mix of science and expert opinion.

Much has been written on the limitations of the BPS model, both looking at Waddell & Aylward's work (Shakespeare et al., 2017) and the vast literature produced by proponents of a BPS understanding of ME/CFS (Geraghty et al., 2019). A strong theme is that of conflating correlation and causation, with such conflation being employed to make exaggerated claims. The Cardiff academics, (for example Waddell & Burton, 2004)

pick out reported associations between unemployment and poor physical and mental health, with the conclusion that the former causes the latter (hence justifying all manner of unethical measures to get people back into work, whether they are capable of work or not). It does not seem to occur to these academics that poor physical and mental health might contribute to unemployment, particularly in a society that does not accommodate chronically ill and disabled people in education, healthcare and employment. In the field of ME/CFS, BPS proponents have repeatedly drawn upon observed associations between variables (e.g. 'catastrophic' beliefs and fatigue) such as to infer that one causes the other (Stahl et al., 2014); predictably, in the direction that fits their theoretical model and supports their favoured interventions. As Shakespeare et al. (2017) point out, this has fundamentally changed the BPS model from Engel's largely descriptive framework to one of alleged causal explanations.

Self-referencing, mis-referencing and selective referencing to aid weak arguments is not uncommon amongst BPS proponents. For example, Waddell and Aylward (2010) refer to "extensive evidence" that financial levels of benefits influence number and duration of claims, supporting this with one reference co-authored by Waddell and Aylward that appears to be specific to back pain. In the same paper (Waddell & Aylward, 2010), they claim to have the knowledge to significantly reduce sickness absence and long-term incapacity by citing self-authored work (Waddell & Burton, 2004), when as Shakespeare et al., (2017) point out, the cited work fails to provide an empirical base, conceding that the evidence is in fact lacking in many respects (Waddell & Burton, 2005, p.50). How the BPS model was extrapolated from low back pain to almost every other health condition conceivable is not entirely clear; it would appear to be largely achieved by Waddell repeatedly citing himself and like-minded colleagues.

In the field of ME/CFS, internationally debunked BPS research is repeatedly referenced by its authors to purportedly demonstrate robust findings of effectiveness of favoured interventions. This continues even in the face of NICE concluding that such research is of low and very low quality, and that these favoured interventions (CBT and GET) should not be offered as clinically proven treatments (GET having been repudiated, CBT to be offered only as a supportive therapy for patients who choose it). Historically, reports which could be expected to have significant impact on healthcare and social policy have been carefully crafted by selective authoring and selective referencing. One example is the 1996 Joint Report of the Royal Colleges of Physicians, Psychiatrists and General Practitioners on 'CFS' (RCP, 1996) where it would appear at least half of the authors and over half of the references were strongly biased towards a psychological understanding of ME/CFS. The report, predictably, played down biological underpinnings of ME/CFS, advising against all biomedical investigations but the most basic of blood and urine tests and suggesting that GET and CBT were the most 'hopeful' approaches. In 'Medical Medicine: How to make an illness disappear', Prof Malcom Hooper and Margaret Williams provides instances of how the authors of this report mis-reference papers to ostensibly strengthen their unsubstantiated position (Hooper & Williams, 2010). The above-mentioned examples of eminence-based propaganda are the tip of the iceberg but hopefully serve to make the point.

Finally, strategic use of language (including theoretical constructs) is apparent both in the writings of the Cardiff academics and usual suspects in the psychologisation of ME/CFS. 'Disability' takes on a whole new meaning, essentially to mean something that a disabled person chooses or creates with social and financial reinforcement. However, when key actors in this game want to defend their positions or deflect from criticism, they will profess to believe that patients are genuinely disabled. Given that many people do not equate disability with individualist, victim-blaming, psychosocial phenomena as per the BPS model, it is easy to see how such assertions might be mis-construed as coming from a place of benevolence. Likewise, 'illness', which is typically used in social sciences to describe the personal lived experience and broader socially situated experience of ill-health - without moralising connotations - is variously redefined as the 'subjective feeling of being unwell' or something akin to medically unexplained symptoms, as in 'illness without disease'. The emphasis on patient subjectivity and alleged lack of disease is juxtaposed with the assumed objectivity of expert opinion and so-called evidence base, whereby patient narrative becomes the lowest form of evidence and moralising 'clinical' judgements creep in. This mix of self-created, misappropriated, vague and fluid terminology is intentionally obfuscating and may raise issues with validity and replicability in research. An example of this in the field of ME/CFS is the BPS hijacking of the diagnostic entity ME through the creation of 'CFS', conflating the two terms through 'ME/CFS' (cue numerous conflicting case definitions), then dropping

ME (when it suits) to leave CFS or just plain 'chronic fatigue'. Creating such ambiguity helps to deflect from an underpinning lack of evidence-base. As Waddell suggested, who needs evidence when you have ideas?

In the next blog, I will look more closely at the tangled web of professional associations that underpin the state-sanctioned abuse of chronically ill and disabled people. With the emergence of Long Covid, and a strong possibility of a tidal wave of post-viral chronic illness and disability, the motives and actions of the academic-state-corporate nexus should be of great importance to everybody.

### **Blog three: Academic-state-corporate nexus**

*"O, what a tangled web we weave when first we practise to deceive!"*

*Sir Walter Scott, Marmion: A Tale of Flodden Field*

As has been established, the Waddell-Aylward biopsychosocial (BPS) model and the BPS model of myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) - and any illness that can be shoehorned into a box of 'medically unexplained symptoms' (MUS) - are one and the same. This is largely because ME/CFS (under the preferred name 'chronic fatigue syndrome') was used as a blueprint for welfare reform and to serve the interests of the academic-state-corporate nexus. An exceedingly tangled web of connections exists between the Cardiff academics and key proponents of the BPS conceptualisation of ME/CFS, along with their government and health insurance industry associations. This power complex is arguably strengthened through biases within the media, research funding bodies and academic publishing - all areas where certain BPS proponents of ME/CFS have influence. Criticism of the BPS model on theoretical and empirical grounds has been covered in various peer-reviewed published papers (Shakespeare et al., 2017; Geraghty et al., 2019; Geraghty & Blease, 2019) and also through patient narrative, though the latter has historically been subject to epistemic injustice. However, the associations and conflicts of interest that exist within this academic-state-corporate nexus rarely seem to make it through peer-review - I suspect rarely get past initial editorial nod. These connections can arguably be encapsulated through the oft-named Woodstock conference.

### **The Woodstock nexus**

In 2001, a conference was held in Woodstock on the subject of "malinger and illness deception" (see: Rutherford, 2007a; Hooper & Williams, 2010). Significant attendees included Prof Gordon Waddell and Prof Sir Mansel Aylward (Aylward was then medical advisor to the DWP), Prof Peter Halligan (who went on to become associate director at the Unum Psychosocial Research Centre), Prof Derick Wade (formerly of the Oxford centre for Enablement and author of various papers on the BPS model, notably with Halligan). Prof Sir Simon Wessely, Profs Michael Sharpe and Peter White - all with a special interest in 'chronic fatigue syndrome' as they like to call it - were also present. Malcolm Wicks (then, Parliamentary Under Secretary of State for Work) and Dr John LoCascio (then, Unum's second vice-president and medical director at Unum) also attended, along with 'Wessely School' psychiatrists Profs Christopher Bass and Anthony David. The meeting was funded by the DWP and its purpose has been summed up by Jonathan Rutherford as none other than "the transformation of the welfare system" (Rutherford, 2007a, p.38). Essentially, the nexus needed to work out how to frame chronically ill and disabled people as morally void scroungers and malingerers with no insight into their own health conditions, so that benefits and insurance pay-outs could be denied, all whilst claiming to be working in best interests of these communities and following the science.

Woodstock isn't the only meeting of minds that encapsulates the academic-state-corporate nexus, and it's important to note that associations existed between many of the attendees long before 2001. Other joint works and offerings can be found (see: White, 2005; Halligan & Aylward, 2006). Perhaps Woodstock is often referred to so frequently within the context of this nexus because the associations - and motivations - are so damn obvious. You'd think there would be some attempt to cover up such iniquity, but a typical feature of eminence-based healthcare and social policy is that key actors believe themselves to be beyond criticism because they are, well, eminent. The Woodstock conference also spawned a book, entitled 'Illness Deception and Malingering' after the conference itself, co-edited by Prof Peter Halligan with chapters authored by, amongst others, Prof Sharpe, Prof Sir Wessely, Prof Sir Aylward and Dr John LoCascio (Halligan et al., 2003). The publication - which is essentially a collection of narratives about deceitful patients who take advantage of

the system and feign disability for secondary gains that represent obstacles to their recovery - also acknowledges the contributions of other Woodstock attendees including Profs Derick Wade, Peter White and Gordon Waddell. The Woodstock connection can also be observed in DWP commissioned and Unum sponsored monographs that issued out of the Cardiff centre, notably 'The Scientific and Conceptual Basis of Incapacity Benefits' which essentially laid down the protocol for the 2007 welfare reform act. This work draws on the work of a number of the usual suspects, with a foreword of special acknowledgement for Halligan, Wade, Wessely and White.

### **ME/CFS as prime trifecta target**

It is fair to suggest that ME/CFS would have been high on the agenda during the Woodstock conference. Prior to Woodstock, a narrative around ME/CFS as a psychosocial entity amenable to CBT and GET was being constructed by psychiatrists with an interest in ME/CFS, in some cases in collaboration with actors within the DWP. Aylward in particular seemed very impressed with Wessely's position on ME/CFS and had given a talk on 'CFS' (Aylward, 1998) which seemed to draw directly from Wessely's work on the subject matter – notably on purported parallels between CFS and neurasthenia (Wessely, 1990; 1997). Also prior to Woodstock, Unum had singled out ME/CFS as a target for aggressive claims policy management. Unum documentation from 1995 shows CFS was referred to as "new banner for neurosis" and states:

"UNUM stands to lose millions if we do not move quickly to address this increasing problem. The subjective nature of CFS leaves us highly exposed to the self-diagnosis of claimants, some of whom take advantage of doctors and the entire insurance industry". (Jackson, 1995).

In the same Unum policy document, Unum conceptualises ME/CFS as a response to social and economic stressors, combined with 'failure of coping mechanisms' and 'entitlement philosophy', noting that people with ME/CFS tend to understand their illness as a medical condition as opposed to a psychiatric disorder (with the inference that people with ME/CFS lack insight into their health condition). Once again, we see the propaganda of the academia-state-corporate nexus in full swing: Unum's narrative here is strongly reflective of the UK government's stance within the context of welfare reform, of the Cardiff centre's reform monographs that informed this stance, and of eminent academics who expound the BPS model of ME/CFS.

We also see from Unum's documentation that money lies at the root of the institutionalised abuses committed against chronically ill and disabled people. Cutting welfare and healthcare expenditure and/or boosting the profits of the insurance industry is a barely concealed theme in BPS-inspired literature (Waddell & Burton, 2004; Chew-Graham et al., 2017; Sharpe, 2002) and some literature has overinflated costs of MUS to the NHS (Tuller, 2019). As Waddell once said: "It is all about money. The main thing was to persuade the treasury that there was an opportunity for keeping costs down, particularly over the longer term" (Waddell cited in White, 2005, p.219). Not just keeping costs down of course, but also making a tidy profit for those involved in keeping costs down. And if keeping costs down means subjecting chronically ill and disabled people to medical neglect, psychological trauma, destitution and early death, then so be it. As previously suggested, a large-scale breach of human rights required mainstream complicity, and such complicity was partly achieved through presenting propaganda as science. Complicity was also achieved through scapegoating of disabled people, and ME/CFS appears to have been considered a prime target.

In the remainder of the blogpost, I will look at a few further examples of the associations that exist within the academic-state-corporate nexus. This is really the tip of the iceberg, but hopefully will serve to demonstrate the inextricably tangled nature of this web of corruption.

### **State - corporate associations**

We've already touched the surface of the links between the UK government and Unum (see Stewart, 2015, 2019; Rutherford, 2007a). Professor Sir Mansel Aylward might be considered a prime example of these associations. Aylward is also, in my opinion, a prime example of lack of reflexivity vis-à-vis potential conflicts of interest, or lack of moral compass – or both – that appear to be the prerequisite of entry into the state-

corporate-academic inner circle. Aylward moved straight from his role as Medical Director at the DWP to directorship of the Unum funded Cardiff research centre. In fact, according to some sources there may have been an overlap with the appointment of directorship in 2004, before leaving the DWP in 2005 (Select Committee on Work and Pensions, 2006; Black Triangle Campaign, 2012). In any case, it might well be asked why Aylward, having been heavily involved in the UK welfare reform during his time at the DWP, would think it acceptable practice to work for a research centre sponsored by a health insurance giant, and a profoundly fraudulent one at that. Serious issues with Unum's conduct were common knowledge (Hansard, 1999; Stewart, 2015) before Aylward's move to the Cardiff centre, and Aylward acknowledged that Unum were sponsoring the centre before his taking up office as director. In fact, Aylward seems to have had his fingers in the profitable pies of the health insurance industry (or associated entities) for quite some time prior to taking the helm at Cardiff.

Aylward was a member of the DSS 'medical evaluation group' (established to develop more stringent benefits assessing) from the mid-1990s. LoCascio (then both Unum executive and welfare reform consultant to the UK government) was also a member. The two men certainly seemed to sing from the same song sheets. A paper by Aylward and LoCascio (Aylward & LoCascio, 1995) has all the ingredients of the BPS model we know today. The authors bemoan the increased claims for benefits on grounds of 'subjective impairments' ('chronic fatigue syndrome' is mentioned and appears to be framed as a psychiatric disorder), suggesting that such impairment is related to secondary gains and somatisation. Predictably, they conclude that psychiatrists and psychologists can play an important role in assessing purported contributing factors to long-term disability. At the same time, both Aylward and LoCascio support a reduced role for NHS physicians in determining long-term disability, a role that is to be taken on by disability medical analysts - to be trained and examined through a diploma created with DWP and Unum influence (See: Dewis, P., 2002). Aylward's involvement in Mediprobe (Rowe, 1998) - a company set up in the mid-1990s apparently whilst Aylward was on the board of the DSS Benefits Agency Medical Service, with Aylward's wife listed as director - was likely aimed at finding the 'right' medical doctors for such a system. Essentially, the company existed to facilitate civil servant doctors in processing disability claims for insurance companies. In the state social security system, benefits assessors typically are not even medically trained.

### **State– academia associations**

Certain academics are known to have taken up roles as advisors to the UK government – officially and unofficially. Both Sir Prof Simon Wessely and Prof Peter White are known to have had communication in the 1990s with various facets of the DWP or DSS as it was then - specifically the Disability Living Allowance advisory board and Benefits Agency Medical Services in which Aylward was involved (see: The National Archives, uploaded by Smith, 2015). In letters to and from the DWP, both psychiatrists appear to be quite anxious that ME/CFS might be considered a permanent disability in the then upcoming DWP Disability Handbook (Disability Handbook" is a guide for non-medical decision-makers with advent of DLA in 1992 – moving control away from GPs). In one letter to Aylward, Wessely states that the "main difference between CFS and the major psychiatric disorders is neither aetiological, nor symptomatic, but the existence of a powerful lobby group that dislikes any association with psychiatry" (Wessely, 1993). This 'anti-psychiatry' narrative pervades much BPS discourse around ME/CFS. Wessely adds that the DSS is sending out a "most unfortunate message" that colludes with patients' erroneous beliefs that they have a severe neurological condition and reminds Aylward of the costs involved in considering ME a severe permanent disability. This cost is presumably one to be borne by the government in supporting disabled people, but such a move would indubitably also cost Wessely's career dearly. (For clarity, the communication I am referring to here is October 1993. Wessely addresses some of his communications with the UK government on his website, including a letter to Aylward in January 1992; to my knowledge he does not refer to the communication I mention here).

Prof White's documented communications with Aylward involve White's suggestion that the separation of ME and CFS would "enhance disability" and that CFS, his preferred term, has "rehabilitative treatments" available (White, 1993). These 'treatments' are of course CBT and GET, which Prof White has helped to develop. This conveniently amounts to the erasing of ME as a discrete diagnostic entity, contrary to the WHO's recognition

of ME as a neurological disease back in 1969. It is a matter of public record (Select Committee on Health, 2007) that Prof White has provided consultancy for the UK government (DWP and Department of Health and Social Care) on ME/CFS, having been involved in developing national guidelines on ME/CFS for the Department of Health (NHS Plus, 2006) alongside influencing DWP guidance on ME/CFS for decision-makers. White was also involved in the Chief Medical Officer's Working Group discussions on ME/CFS from 1998 to 2002 (CFS/ME Working Group (2002), but walked out part way through the process (along with Trudie Chalder and other BPS advocates), apparently because the report looked set to stray too far from the BPS line (see: Hooper & Williams, 2010). The CMO Working Group was part-funded by the Linbury trust, well-known for supporting research by Wessely et al and with established links to the UK government.

### **Academia – corporate associations**

Certain BPS academics, notably in the field of ME/CFS, are known for providing consultancy across a vast array of health insurance companies on the alleged nature of ME/CFS and how it is purportedly amenable to psychosocial interventions developed by said psychiatrists (Select Committee on Health, 2007; Hooper & Williams, 2010). Prime examples, beyond Aylward's connections which have been touched upon, include Prof White's long-standing association with Swiss Re (reinsurance) and Prof Sharpe's association with Unum and Allied Dunbar. It is increasingly difficult to source first-hand documentation on such associations, not least because many URLs which once navigated to first-hand information now navigate to 'page not found'. It might be asked why webpages would be removed if such associations were not deeply compromising for those involved. However, some remaining sources have been preserved by patients through freeze pages or uploading copies of original documentation online. One particularly interesting source is a Unum Provident brochure (Unum, 2002), to which both Sharpe and Aylward contribute. It has been highlighted elsewhere, but is worth touching upon.

Prof Sharpe (Sharpe, 2002) refers to people with ME/CFS as 'policy holders' and reiterates his view on ME/CFS (or CFS as he calls it) as a psychosocial entity to be 'treated' with his favoured interventions of CBT and GET. Sharpe also highlights the 'problem' that ME/CFS poses to the health insurance industry and health services and rhetorically asks whether they can afford not to address this issue. (Note the parallels with Wessely's suggestion to Aylward that ME/CFS as a disability risks costing the government a lot of money). Sharpe demonstrates the typical BPS crossover from clinical to moralistic (and empirically unsubstantiated) judgements when he suggests that (some) patients are "driven by anger and the need to explain continuing disability", proposing the benefits system and potential litigation (inferred secondary gains) as another obstacle to 'recovery'. Why this dual and conflicting relationship as insurance consultant and scientist-clinician is not considered problematical by Sharpe is unclear. It is somewhat akin to somebody with stakes in the sugar industry being involved in research on nutritional interventions for diabetes, yet there seems to be an almost universal lack of reflexivity within the BPS cabal, and an apparent assumption that conflicts of interest are not a concern for eminent academics.

Insurance industry-academia links within this nexus were spectacularly played down when Prof White led a research team on the PACE trial (White, et al., 2011) part funded by the DWP with Aylward's assistance, with Wessely and Aylward on the Trial Management Group and Trial Steering Committee respectively. Sharpe was a principal investigator along with Prof Trudie Chalder, who has also done consultancy work for insurance companies. The now infamous trial sought to prove the effectiveness of White et al.'s favoured 'treatments' of CBT and GET in the management of ME/CFS. Despite the PACE trial being debunked a large portion of the patient and scientific communities as methodologically and ethically flawed, and despite NICE (2020) assessing the quality of evidence for GET and CBT in managing ME/CFS as low and very low, the BPS ideological brigade (to steal Dr David Tuller's term) are acting like nothing ever happened. This is facilitated by comrades in high places in academic publishing (see ME Association, 2011) and not infrequently biased peer review processes. BPS hegemony persists, now with a threat of Long Covid being annexed.

In the next blogpost, I will look at the downstream effects of upstream policies and structural corruption.

### **Blog four: Downstream effects of upstream corruption**



*"The privileged are simply less likely to believe claims about oppression when they come from those who actually experience it".* Nora Berenstain (2016). 'Epistemic Exploitation'. *Ergo: An Open Access Journal of Philosophy*, 3 (22) 569-590

Macro, meso and micro level phenomena are never fully separable and pathways of influence may be both top-down and bottom-up. In this blogpost I will cast an eye on how macro social and economic policies such as welfare reform, and structural phenomena such as entrenched biopsychosocial discourse, can influence downstream healthcare and social policy and practice – alongside broader social opinion - through various channels. Again, I will focus on myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) as an analogue of broader chronic illness and disability matters.

### **Academic reach**

ME/CFS academics within the academic-state-corporate nexus have worked at macro, meso and micro level within the healthcare system. Beyond their work for the government and health insurance companies, such academics have served as clinicians and clinical researchers as well as NHS advisors, contributors to clinical guidelines and clinical handbooks (see Geraghty, 2020). Some of the academics also developed a case definition of ME/CFS (or CFS as they like to call it) – Oxford Criteria (Sharpe et al., 1991) - that is so broad it risks selecting otherwise healthy individuals who present with the symptom of chronic fatigue or people with primary psychological conditions. Despite a good portion of the scientific community suggesting that Oxford should be permanently retired, it lives on and is typically used in BPS research which then informs practice guidelines. As previously touched upon, these academics have been the driving force in re-framing ME (a WHO-recognised neurological disease) into a psychiatric disorder, albeit one with moralising overtones about patient character. Many of these academics and associates are prolific publishers in well-respected scientific and professional journals (journals whose editorial boards not infrequently include BPS proponents), including the British Medical Journal (BMJ), which arguably informs as well as represents medical opinion. The BMJ has historically appeared content to publish highly stigmatising pieces about people with ME/CFS (Godlee, 2011; Hawkes, 2011) and, it would appear, any illness that is poorly understood, poorly delineated and/or poorly treated (Smith, 2002). Finally, BPS proponents have developed a RCGP training package on ME/CFS for healthcare professionals (METRIC) which teaches clinicians to understand ME/CFS as a psychosocial entity (RCGP, 2012/2018). It would seem very reasonable to suggest that the ideology and interests of academics within the nexus have exerted an influence at every level throughout the healthcare system.

### **The Unum way**

The health insurance industry's influence (notably that of Unum) can also be understood as pervading all levels of the health system. Unum stated that it promotes a "non-medical, enabling model of rehabilitation" (Select Committee on Work and Pensions, 2006), where 'non-medical' appears to equate to an empirically unsubstantiated psychosocial emphasis and 'enabling' approximates coercing. Some of the Psychosocial Research Centre's work during its Unum sponsorship was in the field of GP education and revision of sick certification (Waddell & Aylward, 2005); Select Committee on Work and Pensions, 2006; UnumProvident, 2006). Part of the idea was to encourage GPs to get chronically ill and disabled patients back into work with a scheme of GP incentives and/or sanctions. GPs were to be schooled not to collude with patients to reinforce illness behaviour, to emphasise the importance of work and to acknowledge conditionality - that receipt of benefits would only be a possibility once the patient underwent 'rehabilitative' interventions. At one point, Job Centre staff were stationed in GP surgeries as part of the Pathways to Work scheme that Mansel Aylward helped to develop. In the field of ME/CFS, some of the usual suspects have suggested that patients should try rehabilitative interventions (interventions that are not empirically supported) before they are considered disabled for benefits or insurance purposes (Sharpe et al., 1997). Patient survey data (Oxcatts, 2019) shows that some ME/CFS patients have felt coerced into undertaking CBT and GET, in some cases resulting in harm, and apparently in some cases associated with such conditionality. This raises questions around freely given informed consent and broader clinical ethics. Nevertheless, Unum and the Cardiff academics were hopeful that the Unum way would produce a significant shift in healthcare practice (UnumProvident, 2005; Rutherford,

2007a), with CMO at UnumProvident Michael O'Donnell stating "It will not be many years before the rest of medicine follows our lead" (O'Donnell cited in UnumProvident, 2005, p.9).

The influence of Unum's philosophy of 'enablement' – which can also be observed in government discourse (see: Faulkner, 2016) and some of the Cardiff academics' work (Waddell & Burton, 2004) – shows itself within healthcare in the transition from sick note to fit note and the ascendancy of psychosocial interventions (typically CBT and some form of graded exercise) as primary 'treatments' for any chronic illness or disability that can be shoehorned into so-called 'medically unexplained symptoms'. The 2007 NICE guidelines for the diagnosis and management of ME/CFS (recommending CBT and GET) were underpinned by an implicit narrative of enablement and, perhaps unsurprisingly, were influenced to some degree by the Unum-sponsored Cardiff research centre's work: one of the centre's publications was referenced in the RCGP-published version of the 2007 NICE guidelines in the context of the importance of work for health (Turnbull et al., 2007). A similar narrative is being extended to Long Covid; for example, Prof Derick Wade (PACE apologist, Woodstock attendee, author of BPS literature and formerly of the Oxford Centre for Enablement) has authored papers and presentations looking at rehabilitation following Covid-19, advocating a BPS formulation of the patient's case and involving use of graduated exercise and psychosocial therapies (Wade, 2020a, 2020b). However, as George Faulkner (2016) has pointed out, a narrative of enablement which promulgates an unduly positive conceptualisation of ill-health and associated purported path to recovery can actually have the very opposite effect to enablement, disempowering chronically ill and disabled people.

#### **The fourth estate**

As noted in a previous blogpost, depriving chronically ill and disabled people of financial support necessary to survive (through refusal of benefits) requires mainstream complicity, and the same could be said for depriving chronically ill and disabled people of adequate medical care. In the case of ME/CFS, mainstream complicity with the institutionalised abuse of patients has been achieved in part through the UK press, which has historically represented people with ME/CFS very poorly, albeit with a few exceptions (Ryan, 2019). Notably, more positive coverage (O'Neill, 2020) of ME/CFS in a few instances has appeared since the emergence of Long Covid. However, the dominant media narrative of ME/CFS appears to be one of a psychosocial entity with not infrequent suggestion of malingering (Liddle, 2019), with ME/CFS advocacy framed as anti-psychiatry (Pemberton, 2011) and extremist (McKie, 2011). Some of the academics in the academic-state-corporate nexus have associations with the Science Media Centre, which exists to provide the UK media with science and health-related news briefings and interviews. In Prof Malcolm Hooper's work "Magical Medicine: How to make an illness disappear", he says: "Editors of broadsheet newspapers have confirmed that editorial policy will permit them only to publish items about ME/CFS that come from the SMC" (Hooper and Williams, 2010, p.73). If this is true, then it would certainly explain much of the (mis)representation of people with ME/CFS in the UK press, the highly biased interviews with BPS proponents who are framed as heroic victims of patient abuse (McKie, 2011), and the backlash against journalist George Monbiot's impactful and sympathetic piece in the Guardian earlier this year (Monbiot, 2021). Given that some research suggests that clinicians may glean some of their 'information' about ME/CFS from the media (Chew-Graham et al., 2009) - presumably in the absence of adequate medical education - it might be asked to what extent clinical practice is influenced by a largely biased and misinformed UK press as opposed to sound clinical judgement.

More broadly, media coverage of chronically ill and disabled people has shifted in a stigmatising and scapegoating direction since the global financial crisis of 2007/2008 and the UK government's austerity measures (Briant et al., 2013), with some indications that this has shifted public perception; such scapegoating might go some way to explaining rising rates in disability hate crime. These are important considerations given the economic costs of the pandemic and the possibility of a new wave of austerity – how will these costs be recuperated, who will bear the brunt, and how will this be justified? I rather suspect that disabled and chronically ill people will again be primary targets. Whilst the media has done little to represent disabled people in a respectful and accurate manner, it has also done little to expose some of the drivers behind the stigmatisation of disabled people. Mo Stewart, Independent Disability Studies Researcher, has pointed out that the UK press have been largely silent on Unum's involvement in welfare reform (which has also impacted on

healthcare) since Jonathan Rutherford's piece for *The Guardian* in March 2008 (Rutherford, 2008). It may well be asked whether a similar blanket ban exists for national media discussion of the academic-state-corporate nexus as appears to exist for the accurate and sympathetic coverage of people with ME/CFS – in particular given that these subjects are inextricably linked.

### Human costs

The impact of an unaccommodating, if not downright hostile, health and social system on chronically ill and disabled people can be observed in patient survey data and qualitative research. In the case of ME/CFS, patients have suggested that fights with the benefits system adds to of living with ME/CFS and the stress of the benefits process can cause relapses (Drachler et al., 2009). Broader disability research indicates that disabled and chronically ill people feel dehumanised through the benefit system and that stresses of navigating this system impacts negatively on their physical, psychological and social functioning (Saffer et al., 2018). Healthcare experiences of people with ME/CFS (both from the perspective of patients and clinicians) have been well-documented (see: Anderson et al., 2012): clear cases of negative stereotyping and stigma on the part of clinicians have been demonstrated (Raine et al., 2004; Chew Graham et al., 2009), with concordant felt stigma and associated distress on the side of patients (Dickson et al., 2007).

Most disturbing are cases of suicide amongst chronically ill and disabled people, which may well be related to the inadequacy and hostility of the health and social security system. As previously noted, welfare reform has been associated with rising rates of suicide amongst disabled people, whilst various studies have suggested an increased suicide rate amongst people with ME/CFS compared to the general population (Jason et al., 2006). My experience of working with people with contested and unsupported illness is that suicidal ideation often arises not from the illness itself, or from underlying depression, but from the distress associated with stigma, marginalisation, unacknowledged losses and dehumanisation – a recent study by Devendorf et al. (2020) appears broadly consistent with these observations. It is as yet unclear how the medical profession and broader scientific and political structures will frame Long Covid; however, some sub-groups which lack specific and detectable organ impairment are clearly susceptible to psychologization and politicization, and there are signs that this is already happening (Willis & Chalder, 2021; Miller et al., 2021; Sharpe, 2021). My own experience, as a marginalised woman who has for decades been point-blank refused investigations past routine bloods (despite my symptoms clearly indicating need for further investigation), suggests that some patients are literally left to rot by the healthcare system, and treated like a social pariah by the benefits system. Now mainly confined to bed, I lose consciousness on a daily basis, experience daily episodes of paralysis, go days without sleep, stop breathing in my sleep on the occasions I manage some sleep, and am losing my eyesight - amongst a plethora of other disabling symptoms. The NHS is still trying to convince me (or perhaps trying to convince itself) that this is a form of somatisation that can be cured with some psychoeducation. Having worked in the NHS, I am sadly aware that my case is not exceptional. Whilst this may seem literally incredible to those who do not have first-hand experience of the abuses occurring within our health and social systems, I think it can be explained through understanding the structural dimensions of the BPS model, and the incredibly powerful complex of interests that can be defined as the academic-state-corporate nexus.

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[End of appendices]