



South East London ME Support Group responds to *Improving Lives: The work, health and disability Green Paper*.

February 2017

The South East London ME Support Group is a small charity for the support of people living with Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome, in South East London. We refer to the condition as ME/CFS, and our response here relates solely to this condition. Our charity has offered information and support on disability benefits to our members since before ESA was introduced in 2008 and our submission is based upon the knowledge gained from supporting our members over these years.

Our response to *Improving Lives: The work, health and disability Green Paper* covers issues and questions raised in Chapters Two and Three only, relating to work coach capabilities and benefit assessments.

Introduction

ME/CFS and the rehabilitation debate

M.E. is a highly debilitating illness affecting around 250,000 people in the UK. The burden of this poorly understood disease on quality of life is exceptionally high: 9 in 10 are not able to work or study full time¹. 25% are confined to their home or bed by the severity of their condition and are unable to care for themselves.² As a patient

¹ Action for M.E. (2014). M.E. Time to deliver. Retrieved from <https://www.actionforme.org.uk/uploads/pdfs/me-time-to-deliver-survey-report.pdf>

² Pendergrast, T., Brown, A., et al. (2016). Housebound versus nonhousebound patients with myalgic encephalomyelitis and chronic fatigue syndrome. *Chronic Illness*, 12 (4), 292-307. DOI: 10.1177/1742395316644770

population, people with M.E. score consistently lower for physical function and health-related quality of life than any other chronic disease group.³

Common symptoms of ME/CFS include profound exhaustion; muscle pain and weakness (especially after even minor exercise); cognitive difficulties; hypersensitivity to sound, light and smell; severe headache; and digestive problems. ME/CFS is frequently a lifelong condition: many sufferers will not return to full health. Most will make some degree of recovery and experience fluctuating periods of relatively good and of poor health. The cause of the condition remains unknown and there is no cure.

Until recently, the belief was widespread that ME/CFS is a complex of maladaptive cognitions and behaviours that can be reversed through rehabilitation. However, large-scale trials of graded exercise therapy and cognitive behaviour therapy in the treatment of ME/CFS show only very modest improvements in self-reported wellbeing but no impact on employment status or benefit claimant status.⁴ The claim that rehabilitation through increased activity promotes recovery from ME/CFS is not supported by medical evidence. There is, however, evidence of reduced cardio-pulmonary output following exertion,⁵ which supports patients' accounts of how "pushing themselves" leads to relapse and deterioration.

The research evidence points firmly against using work or work-related activity as a rehabilitation tool in this disease. Indeed, systemic intolerance of exertion is now considered to be the hallmark of ME/CFS.⁶

³ Nacul, L. C., Lacerda, E. M. et al. (2011). The functional status and well being of people with myalgic/encephalomyelitis/chronic fatigue syndrome and their carers. *BMC Public Health*, 11 (1), 1–11. DOI: 10.1186/1471-2458-11-402

⁴ Vink, M. (2016). The PACE Trial invalidates the use of cognitive behavioral and graded exercise therapy in Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: A review. *Journal of Neurology and Neurobiology*, 2 (3). DOI:10.16966/2379-7150.124

⁵ Keller, B.A., Pryor, J.L., Giloteaux, L. (2014), [Inability of myalgic encephalomyelitis/chronic fatigue syndrome patients to reproduce VO₂peak indicates functional impairment](#). *J. Transl.Med.* 12, 104. DOI: 10.1186/1479-5876-12-104.

⁶ Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Board on the Health of Select Populations, Institute of Medicine (2015). *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an illness*. Washington: National Academies Press.

The Green Paper is based on the principle that the right work is good for health. We recognise the benefits that good work can bring to a person's social and emotional, as well as financial, wellbeing. However, in ME/CFS exertion can be detrimental to health, and this often the case for those who are moderately to severely affected.

Response to Chapter Two - Building work coach capability

We are extremely concerned that if work coaches are not trained to understand ME/CFS and the way in which activity/work impacts on health, attempts to support ESA claimants with ME/CFS into work, possibly with penalties for non-compliance, could severely impact on those claimants' health and wellbeing.

Why the need for work coach training in relation to ME/CFS?

The appearance of people with ME/CFS can be deceptive. Work coaches may, on first meeting a client with ME/CFS, find themselves facing someone who looks reasonably healthy and alert. However, in assessing what work the client is capable of undertaking (or indeed if s/he is capable of work at all) it is essential to bear in mind:

- In the course of a single day, many people with ME/CFS have brief periods (a couple of hours, perhaps), of relatively good functioning followed by a long period of physical and mental exhaustion. An appearance of normality at a given point in the day does not indicate ability to sustain good functioning throughout the day.

- People with ME/CFS whose condition has to some extent stabilised are sometimes able to establish a baseline of activity at which their symptoms remain more or less within control. However, exceeding this limit almost always leads to a severe exacerbation of both physical and mental symptoms which may last for days.

- As well as fluctuations through the day, most people with ME/CFS have often unexplained fluctuations over time, with periods of days or weeks when they feel more unwell than usual.

- In some people with ME/CFS, severe fatigue limits daily activity to self-care only (some even need help with self-care), meaning that no work-related activity in addition to self-care is possible. There are some for whom a single visit to a jobcentre would be impossible, and others for whom a monthly visit to a jobcentre would be burdensome and pointless as it might be the only outing they are able to undertake that week or even that month. On the other hand, at the milder end of the spectrum, some may manage part-time employment with appropriate adjustments. For the least severely affected, the work coach should be trained to offer information on:

- Measures which may enable people with ME/CFS to remain in or take up employment: e.g. reduced hours, flexible working and home working.
- Relevant legislative measures: e.g. the right to reasonable adjustments; the right to request flexible or home working after 26 weeks, whether or not as a reasonable adjustment.
- Assistive programmes such as Access to Work.
- The ways in which the work coach him/herself can intervene to ease communication between an employer or potential employer and an employee with CFS/ME, so as to support the employee's request for adjustments.

Much of this is explained further in the SEE M.E. Toolkit for Professionals

<https://www.actionforme.org.uk/uploads/pdfs/see-me-toolkit-for-professionals.pdf>

There is also the issue of self-employment. People with ME/CFS who feel able to do some work often prefer self-employment because of the control it gives over quantity and timing of work. However, people contemplating this are not necessarily aware of the administrative implications. It would be helpful if work coaches could also offer guidance on:

- Issues relating to self-employment and/or sources of information about this.

It is vital that the work coach be sufficiently informed about the condition to accurately determine the impact of activity on daily living before deciding whether, and to what extent, it is appropriate for a particular claimant to be kept in touch with the labour market.

It is also vital that work coaches understand that people with ME/CFS who are well enough to undertake some work will usually need to negotiate a claimant commitment which allows them to restrict their hours of work/work search to less (sometimes substantially less) than 35 hours per week.

Response to Chapter 3: Assessments for benefits for people with health conditions

We believe the Green Paper's proposal to break the link between cash entitlement and Jobcentre support is logically incoherent.

As we understand it, the purpose of introducing two categories of ESA entitlement (the support group and the work-related activity group (WRAG)) was to distinguish those claimants who are furthest from the labour market from those who are closer to it, albeit not fit for work, and who may benefit from work preparation activities.

The significantly higher level of benefit for the support group can only be justified if it reflects the greater distance from the labour market created by certain forms or degrees of impairment and the increased likelihood of poverty linked to long-term wagelessness. If, however, a work capability assessment (WCA) has no implications for the expected level of engagement with, or preparation for the labour market, which will be determined by a work coach, it is unclear what the justification can be for using the WCA as a means of deciding that some claimants warrant a higher level of benefit than others.

Mandatory engagement and conditionality

It is right to offer access to employment support opportunities to those in the support group who wish to engage with them. However, we do not endorse the proposal for mandatory engagement with Jobcentre Plus for people in the support group.

It is unclear from the Green Paper whether work coach "advice" to people in the support group will in fact be mandatory and whether there will be sanctions for failing to comply. Given the widely-voiced reservations about both the fairness and the usefulness (in terms of incentivisation) of sanctions for WRAG claimants; and given

that support group claimants are very likely to have a higher level of impairment than WRAG claimants, it would be a matter of great concern to us if these more vulnerable claimants are subject to a regime of sanctions similar to that which has prevailed for many WRAG claimants.

WCA descriptors

We find it disappointing that this opportunity has not been taken to review and revise the descriptors for the WCA, which have been widely criticised by MPs of all main political parties and which do not provide an adequate basis for assessment of a claimant's ability to find a place in the labour market.

Early engagement with Jobcentre Plus

Under ESA as it stands, an applicant is treated as having limited capability for work pending their WCA provided they have a fit note from their doctor. The Green Paper states that under universal credit people with health conditions or disabilities will be given the opportunity to engage with a work coach at an early stage prior to their WCA. While this could be useful in some cases, it could put damaging pressure on people who have recently become ill (notably our members with ME/CFS) whose best hope of recovery lies in an initial period of rest. We would further point out that the official assessment period is 13 weeks, and the fact that for some applicants it lasts much longer is an administrative failure that should be rectified.

Reasonable adjustments for housebound claimants

We recall that when ESA was first introduced, some of our members with ME/CFS who were housebound were assigned to the WRAG. Their requests for work-focused interviews by telephone, or for home visits for this purpose, were refused. This caused a great deal of distress and anxiety. If at least some claimants in the support group are now to be required to engage with a work coach, we would like reassurance that telephone interviews and home visits will be available where appropriate. We are encouraged to note that Caroline Nokes, Parliamentary Under-Secretary of State for Welfare Delivery, has stated that the DWP's home visiting service can be extended to all disabled claimants who ask for it when their circumstances make it difficult for them to go to a jobcentre.

Work coach discretion

The system envisaged in the Green Paper, whereby a work coach will determine the extent and nature of the obligations placed on a claimant, seems to rely too much on the judgement of a single work coach, who, however well trained, may be mistaken about an individual claimant's capacity for a certain amount of work preparation, or about the nature of the work preparation, suited to him/her. There should be a simple procedure whereby a claimant can request that the decision of a work coach as to what is realistic or appropriate for him/her be reviewed by a disability employment professional.

Data sharing across welfare systems

We are uneasy about the proposal to share information across WCA and PIP processes. While this might indeed ease the burden on claimants, there is a danger that a poor assessment for the purpose of one benefit could lead to a poor assessment for the other. The high rate of success at appeal for both ESA and PIP is evidence that assessments are not always satisfactory. Further, the descriptors for related activities for PIP and ESA are not always identical, so that information gained for the purpose of one benefit is not necessarily readily transferable to the other.

Finally, it seems to us that, given that new claimants found to have limited capability for work will in future receive nearly £30 per week less than current claimants, it is extremely unlikely that any current ESA claimant (other than those receiving credits only) who suspects that their health condition might worsen or recur in future would willingly sign off ESA and attempt a return to work. Many people found to have limited capability for work are severely affected by illness or disability, and we wish to register our dismay at the great hardship that this cut will cause.