



**Cymdeithas Cefnogi  
ME & CFS Cymru**

**Welsh Association of  
ME & CFS Support**

## **No one written off: reforming welfare to reward responsibility**

### **Consultation Response from WAMES (Welsh Association of ME & CFS Support)**

The UK Government's plan to help more people with long term conditions and people with disabilities into employment is admirable but flawed in many ways. Our concerns about the proposed changes to the Benefits system as outlined in *No one written off* were presented to the DWP as part of the consultation process which ended on October 22<sup>nd</sup> 2008.

#### **More pressure on ill people?**

We are concerned that the arbitrary target of reducing the number of people on Incapacity Benefit further by 1 million and the threat of sanctions for those who don't return to work will mean more pressure is put on a large number of the estimated 11,800 people in Wales who are ill with ME or CFS. The existing medical assessments fail to recognise the severity of ME and there is little understanding of fluctuating medical conditions and the very long slow recovery time some people with ME need. Many are forced to appeal the refusal of benefit and find their health is adversely affected by the stress.

Too many people with ME struggle to cope with everyday life and fear that they will be pressured to prepare to return to work before they are able and at a speed they are unable to sustain. We are also concerned that newly diagnosed people with ME & CFS will not receive the appropriate help and support they need to enable them to recover from their illness before being forced back into employment which may be unsuitable for them at that time. This could lead to ill people being made worse because of a lack of understanding.

#### **Individualised Support will be costly**

We are concerned that the cost of providing individualised support to all disabled people, those with long term illnesses and complex & multiple problems will be exorbitant. We are not convinced that it is possible to provide work training and employment that is part-time flexible and in a suitable location for all who would desire it. It would certainly not be possible to achieve this AND save the Treasury money.

#### **Would work training be 'suitable'?**

The new system would require more ill people to attend training to prepare for work but some will not be capable of 'attending' training outside the home. A more individual approach to ongoing education from home for those people who are house bound by their condition, may be more appropriate. Some may only be able to cope with a few hours' education spread over the week and part time on-line or correspondence courses should also be on offer. This should be a matter for individual choice and not a requirement. Entitlement to benefits should extend to those following part time courses from home

via e-learning and there should be no upper age limit (such as 21) for those who have long term health conditions.

### **Better options for volunteering needed**

People with a long term medical condition or illness where recovery or improvement can take years find the option of volunteering very useful. It can help them to gauge how well they can cope with various types of work, particularly if it is something they had no experience of prior to becoming ill. It is important, however, that they have the option to experiment and make changes if necessary e.g. to the number of hours, time of day worked or the types of jobs undertaken.

It might also be necessary for people to take breaks between volunteering opportunities to recover their health without losing benefit or having to reapply or fill in large forms. It might also be necessary to continue volunteering for much longer than a year as part of their long term plan to return to paid employment.

### **The needs of claimants with fluctuating conditions**

Recovery from an illness like ME or CFS can take a long time – setting a timescale to return to work may not be possible and could add undue stress which could have a detrimental effect on the recovery process. We do not believe there are enough “suitable jobs” for people with long term fluctuating health conditions. Employers require their workers to be dependable, which is difficult with a fluctuating condition. Even charities and voluntary agencies, who might be keen to employ people with disabilities, are often not in a position to cope with fluctuating conditions. Relapses are inevitable for many people with ME & CFS, although with careful management it might be possible to minimise them. Employers would need to be able to understand the need for patients to take time off work periodically to recover from a relapse.

Few employers can afford the extra admin and cost of offering part time work for just a few hours a week, which is all that some people can sustain long term.

In order for a job to be “suitable” there are many contributory factors e.g. if there are no suitable jobs in an area where an ill person lives, adequate account needs to be taken of i) the need for that person to be close to their support group (family and friends) which means they are therefore unable to move, and ii) the stressful effect that travelling further afield could have on their illness.

Cognitive problems, such as poor memory, information processing etc. can fluctuate just as easily as pain and energy levels, but are less obvious, even to patients themselves. Some people might need jobs where work can be checked by someone else.

The current system for assessing people’s ability to work is not effective. Our experience in Wales is that medical assessors are not always able to assess correctly the level of dysfunction in people with ME & CFS and especially whether a level of functioning is sustainable in a job situation. Because of the existing policy of getting people off benefits and back to work many ill people are being wrongly assessed as being capable of work, as is shown by the high rate of decisions being reversed at appeal. Our fear is that this renewed and harsher proposal to channel people off benefit and into work is likely to result in more appeals and distress to ill people, simply to achieve targets.

The current *Pathways to Work* scheme has limited success with people with fluctuating illnesses. There is a lack of funding, sometimes a shortage of suitable interview rooms for people with disabilities and little training for advisors about the challenges of living with a long term fluctuating medical condition and the need for a very long-term plan with respect to returning to work. This system would need to be vastly overhauled to make it more helpful.

### **The needs of claimants with multiple and complex problems**

We question whether it is economic to give personalised well informed support to *all* ill people with fluctuating conditions. This could be very expensive if it is done properly.

The threat of benefit sanctions aimed at very ill and vulnerable people is despicable. If an ill person is only able to sustain a job for a small number of hours a week (not possible under current regulations) what steps will be taken to help them avoid the poverty trap? What matters more, saving money by getting people off benefit, or enabling someone to develop skills and be useful to society for a few hours a week, even if they are never going to be well enough to be fully self-supporting?

The option of working from home with or without deadlines would be useful for many. Could employers be encouraged to return to a modern form of 'piece working'?

Working does not necessarily give independence and autonomy as it is a struggle for many to survive daily life. Working at jobs outside the home is only possible for some if they have a lot of support *at* home from family and friends. Extra money and help with care might be needed e.g. cleaning, dressing, child care and shopping. Even if a person is capable of working part-time or full-time, they may not be able to do so on top of their family responsibilities.

### **Carers and Job Seekers Allowance**

Informal carers are not currently adequately recognised by the government agencies and any move to put carers onto JSA would devalue even further the important part they play in society and the immense amount of money they already save the government. Not all carers are able to work but those that are should be able to, but they should not be forced.

October 2008

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