

Wednesday, 29 December 2010

As a carer I wish to comment on the consultation re **Disability Living Allowance reform**. I am happy for you to use the contents of this letter. I am not giving any further personal details to protect the identity of my caree – it also does not seem relevant to disclose my own personal details as I am not expecting a personal response but am offering suggestions from our personal experience that may help in formulating the overall reform.

I would suggest we represent a small minority of people within the spectrum of mental illness, as so far we have found 2 other people with the same severity of condition in the past 20 years- but in terms of chronicity we are important as the condition – **Bipolar affective disorder**- can be made worse by the stresses of bureaucratic processes and when severe can remove you from employment in early adulthood, often unable to return.

I am aware that for those with a fluctuating condition DLA is often awarded inconsistently across the county. Some people with Bipolar are awarded open ended awards- whilst we have always had time limited award. I would appreciate a system that was fair to all or more consistent.

Having the most severe form of Bipolar (requiring police to escort to hospital , secure units and lots of medication every 18-24 months) , the requirement to apply can in itself cause the very stress which we are advised to avoid. I welcome a simplified process which is clear and takes account of the nature of such conditions and does not unfairly discriminate against those who try to manage this condition.

Professionals can be deluded by my caree as a result of how his illness presents. So I am not confident that a random **face to face interview** will make any difference to applying for the award unless you are a professional who knows him well- our previous experience of our award being reassessed, and having to attend when my caree was 'manic' and appeared happy and fully functioning (my opinion was not taken into account by those assessing the functioning that my caree appeared to have at the time or the effect it was having on them) meant the award was stopped – followed by a involuntary section and admission to secure hospital.

My caree did not become unwell over night & the process of having to go to appeal contributed to them becoming unwell- so the actual process caused harm, cost the NHS money and affected me- all round not good!

I would suggest for those who are affected by stress related conditions that have prevented them from working or engaging in activities others may simply find a bit difficult- should not be harmed by this new system and it should be adapted as in terminally ill cases so that the system does **NOT worsen the disability**. Each hospital admission causes disintegration from family, friends and society so it's very important that consideration is made of this.

Having recently reapplied for DLA award reminded us how it was a truly depressing experience – with us listing all the horrible effects the illness has –

there were no good bits- but this severe illness can not only fluctuate but change in nature.

We have recently had a bad period of illness caused by the illness changing to rapid cycling so that from morning to evening the possibilities of what we can do or not do change dramatically.

How would the new system capture this? I don't know but suggest it should be part of your consideration.

I would strongly suggest that severe and enduring mental illness are rated perhaps by quality of life- in some form measured/triaged by number of involuntary admissions, medications, network of contacts/friends, socialisation ability etc.- and treated as needing fast track response to reduce problems with causing ill health .

Bipolar when severe is truly disabling- however we are aware of others who manage to work with it – and have a much fuller less affected life- so its not the case that you can not work with Bipolar or socialise.

For us it ranges^{es} from being unable to do any thing other than sit and look out of a window- needing help to eat, drink , dress, or to feeling socially inept and challenged by simple things like queuing or going to superstore which are always there –to being able to do every thing and more but possibly a danger to others with physical overactivity and belief in God like powers- how would you capture this- without reassessing every 6 mths with all the pressures associated with this ?? This needs to be part of the understanding of this condition and able to be captured or considered as part of strategy.

Also if every health professional you have had contact with strongly advises against working but the state system pushes you towards it – it leaves you in a quandary. For some working – in its traditional form is not possible- working in an adapted form for many is much more possible but over a much longer period of time.(I would suggest 10-15 years is a good time scale with the current support and medications to get someone well enough to attempt work with severe illness in a way that does not make them ill, is meaningful and productive and contributes financially)

For us its not possible as we can not work voluntary or gain experience because of the long time out of employment means no personal references and we have no way of knowing when illness will strike next.

Some way of contributing which does not penalise you but you can offer 4 hours slots when able would be useful – but often my caree can not tell when he is well or not and potentially this could be dangerous to others and himself. How far should we go to attempt to stop disability preventing us from engaging in the workplace- its not going to be possible for all would be our reply- but at times it might be possible for nearly all .

I have highlighted some personal issues we have experienced which apply to others also – which we feel would help you ensure that the **new reform does**

no harm , where possible , and captures in an effective way the most relevant information.

I would suggest that you can not use an algorithm for all conditions and need to fast track by professional in consultation with existing professionals in contact with that person to get best & most appropriate assessment for severe chronic illnesses. I would also suggest that carers responses are taken into consideration too when completing assessments.