Submission Email Body Content

The proposed 3 tier system in the Green Paper on Disability Reform has the potential to make me and tens of thousands like me significantly more ill and disabled. Please find my submission to the consultation process attached.

I have ME/CFS – a post viral long term chronic illness which severely restricts my life. There is little chance of improvement or recovery especially at my age and considering how long I have been ill. There is no education and almost no expertise on this illness in Ireland among medical professionals. Therefore, it is not possible for a medical professional to make a fair assessment of my abilities. I will be dumped into tier 3 in spite of the fact that I am mostly housebound and must be horizontal 20 hours of every day.

I am writing to describe my lived experience, to demonstrate that this proposal is a danger to my health and ask that it be scrapped immediately.

Attached Submission (via word doc)

Submission in response to the Green Paper on Disability Reform from a person living with severe, disabling, chronic ME/CFS.

(Myalgic Encephalomyelitis - 2024 ICD-11-CM Diagnosis Code 8E49). [ICD 10 G93.3]

As a person in receipt of Disability Allowance I am strongly opposed to the proposals in the Green Paper on Disability Reform. The 3-tier process proposed has the potential to make me – and tens of thousands like me – significantly more ill and disabled. I am writing to help you to understand my lived experience and asking for this proposal to be scrapped.

I have severe ME/CFS. This illness has reduced me to a ghostly fragment of myself. Weakened and vulnerable, yet I persist. The moment I read about the Green Paper the tiny

reservoir of energy I saved up to do the dishes drains away. My shoulders and neck stiffen, my stomach cramps, my heart is thumping, I can barely breathe. I don't understand how I can be drowning this way again, and yet I still do not die. I am condemned to life.
As I read through the Green Paper and realise the full horror of the implications I wonder if this new onslaught of stress will finish me at last?

I will be on trial again. Plunged back into the nightmare of the disability system assessment. I am not as lucky as a criminal – who is assumed to be innocent until proven guilty. Where the burden of proof is on the accuser.
I am a 'malingerer' until I can prove myself disabled. The onus is squarely on me to prove I cannot work - *as if the fact that I am not working is not proof enough*.

I face months or years of uncertainty and the ever-present fear that I will be abandoned by an impersonal system to starve. The appalling reality is that I do not have the energy to prove that I do not have the energy to work.

It would be of some comfort if the evidence I can provide for my inability to work would be sufficient. The word of a doctor and a consultant, which is accepted in a court of law, is not sufficient for the Disability Allowance. Certainly not in the case of ME/CFS and other post viral conditions such as Long Covid. In fact, finding a doctor or a consultant with any knowledge at all of this illness is very difficult and inaccessible to most. I don't see how we can be properly assessed when the medical knowledge of this illness is almost completely lacking in Ireland.

The current criteria for assessing disability are not appropriate to ME/CFS and so it is impossible to tick the boxes satisfactorily for them. We will all be dumped into tier 2 or 3 and have to fight again for our rights. Like everyone I know, I was refused Disability Allowance the first time I applied and was forced to appeal. This humiliating and highly stressful process took well over a year and caused a further decline in my condition which has proved to be permanent.

ME/CFS is a serious, complex, chronic illness which affects every system in my body, in particular my body's ability to produce energy. I have had it since a bout of Mononucleosis at age sixteen, I am now 58. Although I managed to work for many years by using my free time to sleep and recover, and I also achieved my dream of becoming a Life Coach. Sadly, I was not aware that being so highly motivated and driving through the exhaustion every day was damaging my body. My health declined suddenly and dramatically in 2016. Unfortunately, I was also unaware of how dangerous exercise is in this illness and at that point attempted to exercise my way back to health. This resulted in further damage and I was eventually forced to a complete stop. My 'new normal', which I have lived since 2016, is a life I would not wish on a dog.

I must spend 20 hours of every day lying down due to significant low blood volume/flow in my brain when upright. Could you live your life in four hours a day? Worried by the risk of further brain damage simply by being upright?

By the time I have managed the daily basics of living, I have no upright time left. I operate on about 15% normal energy; my memory is shot, and my cognitive abilities are impaired. With a long list of other debilitating symptoms caused by profound dysregulation of my nervous, immune, and cardiac systems, I never, ever, feel well.

Each day I wake up exhausted and in pain. My first task is to assess my energy levels and adjust my plans for the day accordingly. I must attempt to predict my condition on any given day – this is almost impossible – and I must try to do the most important task first so that if my energy gives out at least that will be done. That essential activity might be one of these: having a shower; doing the shopping; cleaning the dishes. All very energy hungry activities and only one of these is possible on a good day. Every day I must accept that I cannot do all of the things I would dearly love to. If I am very careful I might be able to scrape together the energy to write or craft for an hour - lying down - and while I am grateful to still have this, the sheer frustration is difficult to manage.

The spectre of this process and the potential cost to my permanent level of health is terrifying. My worst fear is of losing my independence, which ironically would make me even more of a burden on the state. I can't help wondering at what point does my already severely limited life become not worth the effort?

Please scrap this proposal. The money should be used to make work more accessible to those who can and want to work but face insurmountable barriers. It should not be used to coerce already vulnerable people into a process which will further disable us.

Name: (withheld)
Email: (withheld)