

attention an email to

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Option 3 would provoke excessive hardship, especially for those outside city areas.

I am a patient with a non-life threatening chronic pain condition. I suffer from Fibromyalgia and was initially diagnosed by a GP and then a Specialist at the age of 14 after classic onset caused by the Epstein Barr Virus (aka Glandular Fever) when I was 11 years old.

I had a few years of remission aged 19 to 21 and then came down with the Chicken Pox. I had a very serious case of the chicken pox, and was *re-diagnosed* by GP and Specialist aged 21. That's four separate medical opinions. That Specialist told me and I quote "You have Fibromyalgia. It's very painful. The condition will wax and wane all your life. There is nothing I can do you for you, go home and learn to live with it with the help of your GP."

For the first 15 years of my diagnosis I was continually told I was "too young and therefore irresponsible" to be given any type of pain killer that was not Over the Counter. At the age of 34, after multiple ER visits for acute, unmanageable pain (a drain on tax payers) in a 3 month period, I was finally granted access to opioid medications; I take Targin 5 mg each morning and each night – the lowest possible dose. This medication is all that keeps me from being bed bound. I am not permitted to take an extra tablet and it is given to me on a 28 day basis, enough for each day and not a tablet to spare.

This week, the scheduling of codeine medication has been changed. As I already take an anti-inflammatory medication that is script only, my only options for OTC pain relief now is Panadol. Clearly if this was enough to treat my pain I would use it – but sadly it is not.

I suffer Chronic Migraines as part of my medical condition, and am hospitalised approximately every 3 months because I cannot always keep the medications that prevent this acute attack in my stomach; I vomit profusely and have to be admitted to hospital for an anti-nausea injection and an anti-inflammatory injection while being closely monitored by symptoms of a stroke.

I suffer a serious migraine *on average every 3 days*, as well acute muscle cramps, joint pain, nerve pain, stomach pain and much more. Although I am on many medications to prevent and block my pain (more than 8 medications a day including Cymbalta, Oruvail, Epilim), these are only so effective (30% effective in fact according to the drugs own literature) and I suffer a lot of break through pain. For this breakthrough pain, I have been allowed Endone 5 mg or Mersyndol. I am given a 5mg packet of Endone a month for break through pain; the packet contains 20 tablets. Over a month, that breaks down to 4 tablets per week with only 4 hours of pain relief per tablet to use each week. Consider the 20 hours of break through pain relief a week that offers me against the hours in a week; 168 hours in a week. 20 hours of relief. Due to codeine no longer being available, I will now have up to 148 hours each week with nothing I can take for my pain. *I am always in pain; it's the nature of my condition. The only variable is whether the pain is tolerable or not.* Medication is only used as a last resort. I do not expect to be pain free, I do however, believe that I deserve a quality of life that involves more than writhing on the floor in tears of pain every other day. So would you if it was your loved one suffering. As it is, the removal of codeine means I will need to see my Dr for more pain relief. I live in a rural area, 70 km away from the nearest GP who is prepared to treat my condition. I have a 12 year history with this medical practice. It already costs me \$35 a month in petrol, and \$80 a month in prescription medications and I am very fortunate that my GP bulk bills – most do not.

Now I will need to see my doctor weekly for pain relief instead of every 28 days. That will push my petrol bill up to \$140 per month. My Targin script is very strict of course, I am allowed 1 tablet in the morning and 1 tablet at night. I must see my Dr every 28 days to have my script renewed, and in turn, my GP has to ring and have the script authorised by the Government. I am not allowed to see a different GP for this medication, so if for e.g. I was to travel away for 2 weeks, I cannot get my script while away, but would have to plan my travel around these 28 daily Dr appointments. Clearly, receiving an opioid for long term pain is not as easy as “popping in to see any GP and leaving with a script” – they are not handed out willy-nilly and the strict regulations prevent Dr shopping – something I applaud but it comes with its own set of difficulties for those in genuine need. The only other alternative my GP has is to up my opioid prescription strength; by removing codeine as a possibility, you're looking at forcing me to up my opioid dependency. More than a bit of irony there.

Why don't I just see my GP for a codeine script? My GP is booked out 4 days in advance, so unless I know I will be having a migraine on Friday, booking ahead is not really an option. Acute pain is, for the most part, unexpected. That means my other option is to clog up the ER waiting room because it's the only way I can see a Doctor on the day of my pain.

Because my chronic pain is not caused by cancer, nor is it considered life threatening, I am disadvantaged. *My condition is life-long and incurable.* There is an 18 month plus wait to see a pain clinic in my area. I don't believe we even HAVE a pain specialising Doctor in our area. Should I have to travel to Brisbane, 3 hours away, to see a pain specialist every 28 days?

In the 23 years I have struggled daily with this condition I have been blessed to find many ways to reduce my pain; these include the use of medications, hydrotherapy, physical therapy, I own a TENS machine, use of heat packs, hot baths, Epsom salts, massage, mindfulness training, meditation, yoga, relaxation music, daily graded exercise, counselling, Cognitive Behavioural Therapy, natural therapies, and alternative supplements such as Magnesium, herbal immune support boosters and topical products such as Voltaren Gel, Deep Heat and above all pacing myself. I *am* on a waiting list to see a pain specialist, but even my GP feels there is little to nothing they can teach me in way of pain reducing techniques that I do not already utilise. During my last migraine attack, the paramedic mentioned he suffers migraines and yet had never thought to use meditation music while having an attack. *Again, medication is my last resort, not my first.*

I would like to take a moment to show what would happen to me if opioid medication was only available from a specialist.

I live in the Northern Rivers in NSW a rural area, but NOT a remote area. As already stated, I travel 70 km each way to see my GP, a return trip of 140 km that takes an hour each way and is utterly exhausting to someone who suffers ongoing, un-remitting fatigue exacerbated by normal day activities; this trip alone causes hardship to me physically and financially.

My Specialist is located over 200 km away from me. He has a 3 month waiting list for each appointment. Seeing him every 28 days IS NOT POSSIBLE. To see him costs me \$350 upfront. Each time I visit my Specialist, I have to hold back my fortnightly rent(\$230 p/f) and my food money \$75 (per fortnight) AND borrow the remaining money off my partner. This upsets my real estate agent very much and always

results in me being given a written warning – making me a bad tenant just because I have to pay for medical appointments. Centrelink is pushing for all rent to be direct debited – this would make me unable to afford to see a specialist **at all**. If for e.g., the specialist appointment were booked towards the end of that fortnight, I would have to *put off buying food until I had been to the Specialist*. It may be the out of pocket expense is only \$75 per visit, but finding the cash up front to be reimbursed is near to impossible. My partner would have to take the day off work to drive me, as a 4 hour return trip is well outside my driving capabilities. That would include loss of his wages into the cost of a visit so approx. \$140 loss there as well.

I am on New Start Allowance. Despite my GP and my Specialist both sending documentation to Centrelink stating I am CLEARLY unfit for work, because my illness cannot be seen on a scan like a broken bone, or “proved” with a blood test (diagnosis is by a process of elimination - which is very thorough) they refuse to acknowledge my illness OR MY DOCTERS REPORTS and make me look for work, despite being sacked last year for “incompetence due to illness”, an acute relapse was brought on by Centrelink insisting I was fit to work. The Centrelink person that decided if my medical claim for disability was valid was not even a Dr, but an occupational therapist. *At the time of our phone call, she had never heard of my condition*. Nonetheless, I was refused a Disability Pension. Six months at part time work and I had a complete relapse and am now bedridden, instead of only housebound. A small distinction to some, but it is my whole world. I now need to see my Specialist just to try and be excused from work duties.

Let me be clear; I do not expect to be pain free. Ever. I do however, believe that I deserve a quality of life that involves more than writhing on the floor in tears of pain every other day. My income is \$535 a fortnight or \$262 per week. The Specialist appointment cost *is more than my weekly income*. I would have to find an extra \$55 a month in petrol to visit the Specialist and still have to see my GP for all my other non-restricted scripts. The part I find most alarming about needing to see a specialist for pain relief is this: my current Rheumatologist explained sadly to me during my last visit “That he really doesn’t know how to help me, I’m trained in arthritis diseases, and while Fibromyalgia technically falls under this umbrella, I feel it should be managed by your GP. I’m actually thinking about stopping seeing all my Fibromyalgia patients, as there is little I can do to help them.” My GP feels my acute care should be handled by the Specialist. Where am I supposed to turn?

In short, there is an 18 month wait to see a pain clinic/pain doctor in my area. The Specialist is prohibitively expensive at one visit every three years, let alone every 28 days, even if appointments were available this often – and they are not – I could not afford them if they were.

Were this to go ahead, I can see many chronic pain patients in similar predicaments to myself simply giving up and committing suicide. Chronic pain is not an easy thing to live with, and while some people abuse the system, most of us are trying everything in our power to help ourselves.

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