

# Just Invisible: Quotes

Note: These quotes are taken from the report "Just Invisible: Medical Access Issues for Homebound/Bedridden People". Many more are available in the full report.

Aside from my name - Ricky Buchanan - all contributors were asked whether they preferred to use their own name, or a pseudonym or whether they would prefer to be anonymous, so these names may be changed. Many contributors have a well founded fear of a backlash from the medical system if they speak out with their own names.

*"I feel like we're just invisible. Like this problem isn't even on anybody's radar because nobody knows we exist. We are, by the nature of our disabilities, inside all the time so nobody sees what happens to us."* - Ricky Buchanan

## Problems with access to GPs

*"With regard to GP home visits I've found 2 Catch 22s: I have been refused GP a home visit on the grounds that you must visit a GP in their surgery before they will come out. I have also been told that phone consults can only be done if I see the doctor at least once a year in their surgery. In both cases the visits cannot be done due to my being housebound. Therefore I get no home visit and no phone consult. And no prescriptions. The rules need to start from the point of view of the patient's need and not require the impossible from the patient."* - Anon4, who is homebound with ME/CFS

*"When I lived in a nursing home for the aged (I was aged 39) my GP would do visits and all charged at bulk bill rate. My scripts would be collected by the local pharmacy and the medicated delivered back to the nursing home. As soon as I left the nursing home, the GP would not visit me, unless I paid heaps of money for a home visit. I had to collect my own scripts from the chemist. I did not leave the nursing home because I was "better".* - Hunter, who is restricted in his ability to travel anywhere in an upright or sitting posture due to Dysautonomia

*"My only option was the National Home Doctor Service (who do not do routine care), and because they did not have diagnostic tools available to them, they just kept throwing antibiotics at me based on guesswork. I now have severe excoriations [...] because of the antibiotics that have been thrown at me for the last six months. It is now severely infected."* - Anon2, who is quadriplegic

*"I get frequent urinary tract infections. I need to have a pathology test to determine what type of infection, but meanwhile I need to start antibiotics because UTIs make me very unwell and result in other complications. I can't get the pathology test done, or get a script for antibiotics if I don't attend the GPs office, but the simple fact of having the UTI means I am even less able to do that. I have ended up in hospital with a severe kidney infection on a number of occasions, despite the fact that my GP is 100m from my house*

*and could have prevented the infection getting this bad if I could have had these routine measures in place from home." - Julia*

## **Problems with access to telephone consultations**

*"I've been fortunate to find a GP who will do phone consultations. Unfortunately, Medicare won't cover these appointments, so I have to cover the whole cost myself. I'm being forced to pay more because I can't get to a clinic." - Simone, who is bedbound with ME/CFS*

*"I have been on the same medications for years. The problem is not going away. But I can't call the GP and ask for a new script because they tell me they don't get paid if I don't come in. I can't come in. So how do I access the prescription?" - Julia*

*"As a home bound/bedbound rural & remote patient i am unable to access any locum services and also have to pay full GP fees for my fortnightly phone GP consult, despite being in receipt of a Centrelink Disability Pension Health Care card" - Allie, who is bedridden with ME/CFS, Mast Cell Disorder, Dysautonomia, and Fibromyalgia*

*"For me, even things as simple as being able to phone to discuss a new prescription instead of visiting the GP clinic would make a big difference." - Penelope McMillan, who is intermittently homebound with ME/CFS*

## **Problems with access to scripts and medications**

*"I've been looking into [how to get repeat scripts while homebound] and it's been horrendous. I can get a prescription for one month from them, but after that, have to go back to my docs. I'm too ill to go to docs, so have been trying to find out what to do to get meds repeats (including antideps) and it's been awful. Apparently there is no solution." - Anon1, who is homebound with ME/CFS*

*"I had rung the locum my doctor recommended, only to be told they don't do prescriptions, and when I asked what housebound people with chronic illness did then, they said that's "when I would be admitted to a care facility", though they did offer a single script to tide me over. My doc's surgery said only "don't know" and "try google". - Anon1, who is homebound with ME/CFS*

## **Problems with access to medical specialists**

*"Sometimes... depending on funding.. we have Parkinson's or neurological specialist nurses we can contact to discuss things in between specialist visits that GPs may not have much knowledge about. But funding is inconsistent in Qld and it can be difficult to keep one for anything more than 6 to 12 months." - Anon3*

*"I have tried to access private specialists when I am desperate. I have tried everything I can to access the public ones, and failed, and I need help now before things get much worse. But even when I do that (which involves another GP appointment I cant get*

*to, another referral, another specialist deciding if they will see me only after they have received the referral, and if they reject me – which many have – then I have to start over) I can only afford to do that every now and again because I have no income outside of Centrelink. And I can only afford it because I don't actually do anything else, like leave the house, have a social life, get an education. Even when I make that decision, I can turn up and their offices are inaccessible. It is just so soul destroying." - Julia*

## **Problems with access to hospital outpatient services**

*"Getting to hospital and back means a patient transport ambulance and even for a single 5-minute appointment it means spending most of a whole day in the transit lounge in the hospital waiting for things to happen. The effects on me from going through this are at LEAST 1 week of severely exacerbated symptoms, at worst it could make me permanently more disabled. Knowing that there's a potential alternative but I'm just not allowed to access it is very frustrating." - Ricky Buchanan*

*"I only live 5km from the hospital, but the stretcher transport must pick me up 1-2 hours ahead of my appointment, and I have to wait 1-6 hours after my appointment for another stretcher transport to take me home. A single 5-minute appointment ends up being this agonising marathon of lying on trolleys that hurt, not having proper access to the bathroom, and having to stay in this cavernous transit lounge where people yell and everything echoes ... and then once I get home I have a week with all my usual symptoms flared up to the point where I can't enjoy anything. It's hellish." - Ricky Buchanan*

*"I have asked if I can have the first or last appointment. If they can call me and tell me when to come, because I live close by. Sometimes they will do it, after HARP intervenes, and that makes the world of difference. But that only lasts for that appointment, and the next time I have to start all over again." - Julia*