

“Just Invisible”



**Medical Access Issues
For
Homebound/Bedridden
Persons**

Acknowledgements

I'd like to especially thank all of the homebound/bedridden people, and carers of homebound/bedridden people, who generously agreed to use their very limited energy to review this document and offer suggestions and quotes. I couldn't have done it without your encouragement and feedback. Thank you.

The Author

This document has primarily been written by me, Ricky Buchanan, with assistance from friends and acquaintances who are bedridden and/or homebound people. There is more information about me personally in Appendix A.

This document has taken a great deal of time and energy to write. As I am myself bedridden from a combination of disabilities, I have much less energy than I would like to spend on this project but I have done the best I can. Hopefully I've done it justice.

Obtaining Copies

This document can be downloaded from <http://notdoneliving.net/justinvisible>

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I am very happy to be contacted by anybody about this document.

Medical Access Issues For Homebound/Bedridden Persons

1. Introduction	5
1.1. Definitions	5
1.2. How big is this problem?	6
1.2.1.What we need to fix this	7
1.3. Why is this an issue?	7
1.4. Won't the NDIS fix this?	8
2. Relevant human rights and policy	9
3. Problems accessing General Practitioners	10
3.1. No right to GP home visits	10
3.1.1.Quotes	11
3.1.2.What we need to fix this	12
3.2. No right to GP telephone consultations	12
3.2.1.Quotes	13
3.2.2.What we need to fix this	13
3.3. Problems accessing preventative care	13
3.3.1.Quotes	13
3.3.2.What we need to fix this	14
3.4. Problems accessing scripts and medications	14
3.4.1.Quotes	14
3.4.2.What we need to fix this	15
4. Problems accessing medical specialist doctors	16
4.1. Quotes	16
4.2. Problems with referrals to specialists	17
4.2.1.What we need to fix this	17
4.3. No right to Telehealth medical rebates	17
4.3.1.Quotes	17
4.3.2.What we need to fix this	18
5. Problems accessing hospital as an outpatient	19
5.1. Problems with getting to and from hospital	19
5.1.1.Quotes	19
5.1.2.What we need to fix this	19
5.2. Problems with public hospital inefficiency	20
5.2.1.Quotes	20
5.2.2.What we need to fix this	20
5.3. Outpatient appointments can't be consolidated for patient benefit	21
5.3.1.Quotes	21
5.3.2.What we need to fix this	21
5.4. Problems with Hospital Admission Risk Program (HARP)	21
5.4.1.Quotes	22
5.4.2.What we need to fix this	22
6. Problems accessing hospital as an inpatient	23

6.1. Problems being looked after while in hospital	23
6.1.1.Quotes	23
6.1.2.What we need to fix this	24
6.2. Problems occurring during discharge	24
6.2.1.Quotes	24
6.2.2.What we need to fix this	24
7. Problems caused by medical gatekeepers	26
7.1. Quotes	26
7.2. What we need to fix this	26
8. Problems accessing allied health and associated services	27
8.1. Home visits for allied health	27
8.1.1.Quotes	27
8.1.2.What we need to fix this	27
8.2. Accessing optometry and audiology services	28
8.2.1.What we need to fix this	28
8.3. Accessing psychology services	28
8.3.1.Quotes	28
8.3.2.What we need to fix this	29
9. Problems accessing Centrelink/NDIS	30
9.1. What we need to fix this	30
10. Limitations	31
11. Conclusion	32
Appendix A: About the author	33
Appendix B: Method	34

1. Introduction

"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

The problem that homebound and bedridden people have with access to healthcare is a systemic one.

This is not like access to public transport, where we have excellent anti-discrimination laws but the government keeps awarding exceptions to the rules.

This is not like access to websites, where there are excellent guidelines about how to be accessible but people just don't follow them.

This problem is that the entire medical system has been designed and based around physical attendance, and that it treats non-attendance almost exclusively as a problem of patient noncompliance. There are a few small tweaks to make exceptions for people in rural and remote areas, and some even smaller tweaks for people who live in aged care, but in the main if you are homebound/bedridden and you live in the community, then the healthcare system treats you as if you do not exist and should not exist.

In the cases where a homebound/bedridden person is well accommodated, it is not because the healthcare system is working well. It is almost exclusively because someone has gone deliberately out of their way to help, and they will probably not be adequately compensated by Medicare or any other government system for doing so.

1.1. Definitions

Please note that none of these words have standard definitions in either the medical or disability realms. These are the definitions we're using for the purposes of this document:

Homebound / Housebound¹: Someone is homebound or housebound if leaving the house is either impossible, or causes such major medical or psychological problems that the person can only go out less than once a week on average.

¹ Every time I use these words I get disability advocates double-checking if these are appropriate words and even trying to stop me from putting them in publications. Yes, I understand why "wheelchair bound" is not an acceptable phrase, but there are two important differences here - firstly there are literally no alternative words to discuss people who cannot usually leave their bed or house. We can say "wheelchair user" but clearly "house user" or "bed user" does not convey the equivalent meaning. Secondly, being confined to one's bed/house is in no way an enabling experience in the way that using a wheelchair is enabling. If anybody wants to work with me to develop new language around this I'd love to participate, but for now this is what we have.

Bedridden / Bedbound: Someone is bedridden or bedbound if they must spend all, or nearly all their time lying in bed. This may include being able to leave bed for toileting, bathing, and some other minor activities.

Other phrases such as "Chairfast" are used in aged care to describe someone able to sit in a recliner but with little or no ability to leave their chair.

Throughout this document we use the phrase "homebound/bedridden" to denote someone who is homebound and may also be bedridden.

People who are homebound/bedridden may live in the community, or in any of the available types of group care including rooming houses or nursing homes.

Some homebound/bedridden patients will have no ability to leave their homes at all under any circumstances short of a life-threatening medical emergency (if even then). If these people are not provided with home-based medical care they will simply miss out on any care at all, until the problem becomes life-threatening, or will simply die at home.

Other homebound/bedridden patients are able to attend medical appointments occasionally, given stretcher transport or wheelchair transport, but this can come at the cost of weeks and months of exacerbated symptoms so appointments will be attended sparingly, with the patient "triaging" their own need for medical care until they judge the problem at hand is worse than the exacerbated symptoms that medical care will cause.

1.2. How Big Is This Problem?

Literally nobody knows the number of homebound/bedridden people in Australia - there's zero research into how prevalent homebound or bedridden people are, especially those living in the community (ie: outside of nursing homes). Shockingly, I have not been able to find any relevant epidemiological research from anywhere in the world at any time period, so there is no way to even estimate the size of the problem.

There is no specific organisation or peak body which represents people who are homebound/bedridden either in Australia or internationally, so there is no group whose membership could usefully be mined for information either.

Clearly this is a huge problem for government policy - it's very difficult to solve a problem when nobody can even estimate the number of people that may be affected.

Again, because there is no epidemiological research we don't know exactly which disabilities are likely to cause somebody to become homebound/bedridden or how often this occurs.

Disabilities which may cause people to become homebound/bedridden include Multiple Sclerosis, Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME), Dysautonomia, complex or high-level spinal cord injury, the end stage of many progressive conditions, severe chronic illness, and severe mental illness, amongst others. Many elderly people will become homebound or bedridden for some years at the end of their life. People who are severely debilitated because of undergoing chemotherapy and similar medical treatments, or because of inadequate disability supports, may become homebound/bedridden for a time.

On the level of the individual medical practice, we doubt whether most GPs or specialists have any idea of which of their patients are homebound/bedridden (or nearly so) because this is not a problem that doctors consider. Intake paperwork does not ask if you are homebound or bedridden. People who phone the surgery to request a home visit or telephone consult are often rebuffed by a receptionist or practice nurse saying that home visits are not possible, and are never even able to make the request to a doctor. If a

chronically ill or disabled patient stops attending the surgery, there is no followup to check whether that person needs home visits or telephone consultations. There is no Medicare incentive for tracking this knowledge. To the system, the homebound/bedridden patient remains simply invisible.

1.2.1. What We Need To Fix This

- High quality epidemiological research into the number of Australians who are partially or completely bedridden or homebound is needed. This must include both young people and elderly people, and must include those living in the community and those living in all types of congregate facilities (group homes, nursing homes, rooming houses, etc). Care must be taken to include those who have communication difficulties, mental illness, and other marginalisations, as many people who are homebound/bedridden also fall into other groups which are commonly undercounted by statistics.
- At an individual practice or individual doctor level, enormous systemic change and education is required so that doctors perceive that being a homebound/bedridden person in the community is a possibility and something they should ask about and keep track of.

1.3. Why Is This an Issue?

When the healthcare needs of any population are not met there are impacts to the individuals involved as well as impacts on society in general.

Some impacts to homebound/bedridden people whose healthcare needs are not met include:

- Reduction in overall health - an increase in morbidity and mortality.
- Inability to recover from minor setbacks - injuries or illnesses which are untreated or under-treated may become a new contributing disability rather than a temporary event.
- Capacity to do things at home is diminished – when all energy is spent accessing healthcare, there is a significant loss in capacity to reach out to people, to work, to study, to participate in family life.
- Social isolation becomes more severe as a result of increasing isolation - all of life becomes "smaller". This also causes mental health to decline even if there is no underlying mental illness.
- Those with episodic conditions find that they become constant because there is no access to the healthcare needed to reach the upswing of the cycle.

At the economic level, in the long term these things will inevitably cause increased medical costs, increased mental healthcare costs, and increased disability support costs. Having a family member who is homebound/bedridden also often means that at least one other family member is excluded from the paid workforce as they need to take a caring role.

1.4. Won't the NDIS Fix This?

It is important to note at this point that the NDIS will not be a panacea for these problems even after its rollout is complete.

Firstly, not all homebound/bedridden people are eligible for NDIS. NDIS only covers those people whose disability is permanent or likely to be permanent. People can be homebound/bedridden for many years with a disability which is not permanent, or not provably permanent to the threshold required for NDIS acceptance.

Secondly, for reasons discussed later in this document, even homebound/bedridden people who are eligible for NDIS may have great difficulty amassing the required medical evidence to prove their eligibility, or may not be able to do this at all. As things stand now, these people will be stuck in the catch-22 where they are excluded from NDIS because the severity of their disability prevents them from proving their eligibility.

Finally, even for those homebound/bedridden people who become NDIS participants, the COAG agreement covering NDIS² specifically states that NDIS is not responsible for meeting supports which are part of another system's universal service obligation (USO) and the accessibility of the health system is part of the health system's USO.

The COAG agreement also states that the health system is responsible for "Inclusion of people with disability in preventative health and primary health care delivered through General Practice and community health services".

This is a problem which is primarily of the health system's inaccessibility to homebound/bedridden people, and it is the health system which needs to fix it.

² See <https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf>

2. Relevant Human Rights and Policy

The Convention on the Rights of Persons with Disabilities (CRPD) was formally agreed to by Australia in 2008. The CRPD requires governments to treat people with disability as equal citizens, who have human rights and who are as deserving of their place in the community, society and the law as other citizens.

In particular, the first part of article 25 of CRPD states the following³:

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall

a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;

Australia's National Disability Strategy 2010-2020⁴ acknowledges in part 6 that "people with a long-term disability are among the most disadvantaged and invisible groups in our community, with comparatively poor health status and a health system that often fails to meet their needs. This includes people with an intellectual disability, as well as people with other long-term physical and mental conditions, whether present at birth or acquired later in life."

The first directive in part 6 of the National Disability Strategy, which covers health and wellbeing, states the policy that:

All health service providers (including hospitals, general practices, specialist services, allied health, dental health, mental health, population health programs and ambulance services) have the capabilities to meet the needs of people with disability.

Clearly this would include people who are homebound and bedridden.

³ See <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-25-health.html>

⁴ See https://www.dss.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf

3. Problems Accessing General Practitioners

Access to general practitioners is the bedrock of our medical system in Australia. Without a GP there is no way for a patient to have ongoing prescriptions written, no way to access referrals to specialists, and no way to get medical testing done.

Ideally for bedridden and homebound patients, who almost always have complex medical needs, an ongoing relationship with a general practitioner who can come to understand their situation must be our goal.

The quality of life impacts on being housebound/bedridden are significant and are often overlooked by the medical system. When a patient says they are “bedridden” many people in the community assume this is the same as being in bed with a bad case of the flu. It is not. The extent to which this limits quality of life is profound, and trying to explain this to multiple GPs is inefficient, unworkable and exhausting.

3.1. No Right to GP Home Visits

Being able to access a GP is the most basic need in terms of medical services. The underlying conditions that affect people who are homebound/bedridden are often those that are not well understood by the medical profession. Establishing a relationship with a GP is critical in order for there to be one individual in the medical world who understands how this condition impacts the person – the more complex or unusual the condition the more important it is to have a GP who has known the individual over time.

In the 4th edition of the RACGP guidelines, GP practices are required to provide home visits to practice patients who are homebound⁵.

This is already inadequate - it doesn't help anybody who doesn't already have an established doctor/patient relationship with a GP as there's no requirement that a practice accept new bedridden patients and therefore almost none of them will (it's not cost effective). This also means that anyone who's bedridden is trapped with the GP they have and if that person leaves or retires or that relationship terminates for other reasons, there is no way to find a new GP.

In addition, many GP services "provide" this home visiting service by telling homebound patients to wait until their office has closed and call the after hours GP service. This means every call the patient will see a random doctor, they have no ongoing relationship with anybody, the doctor they see has no access to their file, no knowledge of their condition or their special needs, and after-hours services are unable or unwilling to prescribe many of the tests or medications needed by patients with chronic conditions. At worst, many patients report that GPs simply state that home visits are not available and patients must come to them - there is no way for a patient to enforce a RACGP requirement for home visits, and patients do not understand it is their right.

⁵ See the last heading on this page: <https://www.racgp.org.au/your-practice/standards/standards4thedition/physical-factors/5-1/physical-access/>

Unfortunately it gets much worse - the 5th edition of the RACGP guidelines makes even this inadequate access optional. The provision of home visits by a GP is now listed under "could" not "should"⁶ in the guidelines.

I've also heard several stories of patients being told they can't have home visits until they go into the clinic to establish it, or that they can't have ongoing telephone consultations without periodically visiting the doctor in person (this problem may also be caused or worsened by medical gatekeepers - see later section). This can be an impossible request for a homebound/bedridden patient and shouldn't be required of someone who can't manage it.

All these problems, of course, are compounded for patients in regional and rural areas where there are ongoing shortages of GPs and little or no choice of practitioner. If you are homebound and the only GP in town refuses you home visits, there is no recourse.

Providing GP services to homebound/bedridden patients, a vulnerable and needy population, should not be seen as just an aspirational goal, it should be absolutely guaranteed.

3.1.1.Quotes

"My doctor always says I need to go in to sort things out. She's eased up a bit and gives things to my Mum for me when Mum goes in. But it just doesn't cater to people severely disabled or homebound" - Sarah, who is homebound with ME/CFS

"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 excoriation around both my vagina and anus because of the antibiotics that have been thrown at me for the last six months. It is now severely infected." - Anon2, who is quadriplegic

"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

"A couple of years ago I asked the GP I had then about home visits. I was trying to shift to a clinic that was closer, but they had a waiting list for new patients. I knew the GP lived around the corner from me, because he told me. I figured he could just drop by on the way to work or the way back. He said Medicare wouldn't cover that, so he wouldn't do it." - Julia

"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

⁶ See here <https://www.racgp.org.au/download/Documents/Standards/RACGP-Standards-for-general-practices-5th-edition.pdf>, on page 32 at the bottom.

"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

3.1.2. What We Need To Fix This

- Homebound people MUST have access to GPs who will provide home visits whenever necessary, and must have access in a way that means they have an ongoing relationship with a GP and are not using after-hours services or random locum doctors as their primary care providers.
- If the doctor who is currently providing you with home visits retires, moves practices, or otherwise becomes unavailable then the onus should be on them to find you a reasonable replacement doctor who will also provide in-person home visits.
- For people who become homebound/bedridden while they don't have a GP, I recognise that GPs need to be able to protect themselves and can't be required to take on a specific new patient for safety reasons, but this needs to be balanced with the homebound/bedridden patient's right to medical care. I don't know what the answer is, but until RACGP at least recognises this is a problem we can't move towards fixing it.
- Medicare needs to consider increasing home visiting fees. Currently, doctors are paid more for visiting a single nursing home patient than they are for visiting a single home visit client.
- General education is needed for all medical professionals about homebound/bedridden clients and their needs. Too many medical professionals seem to be under the misimpression that it is impossible to be at this level of illness while living in the community.

3.2. No Right to GP Telephone Consultations

Medicare does not cover telephone consultations with GPs under any circumstances. This leaves homebound/bedridden patients no choice but to request a home visit which, as documented above, is not an easy thing to get.

Medicare-rebated telephone consultations could usefully be used by homebound/bedridden patients for simple consultations such as requests for repeat scripts and other routine matters that did not require the GP to be physically present. If this avoided a need for the much more expensive rebated home visits, it could easily save Medicare money overall as well as allowing GPs to more easily provide appropriate and responsive services to homebound/bedridden clients.

3.2.1.Quotes

"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

3.2.2.What We Need To Fix This

- Medicare needs to look into the economic feasibility of providing rebates for telephone consultations with homebound/bedridden patients.

3.3. Problems Accessing Preventative Care

Someone who, due to being homebound/bedridden, is struggling and failing to get even basic access to primary healthcare is probably not going to have energy left over to also fight for access to screening tests such as mammograms, pap smears, vaccinations, and other standard preventative measures.

Preventative care is important - many people who are homebound/bedridden have impaired immune systems and are therefore at greater need for vaccinations including an annual flu vaccination, shingles vaccinations, and may also be at increased risk for cancers that may be caught with early screening.

A basic requirement for accessing preventative care is an ongoing relationship with a general practitioner, but that isn't sufficient - screening tests such as mammograms require travelling to a facility with the required equipment, and depending on one's disability other tests such as pap smears may require specialist doctors too.

A partial solution would be for hospitals to provide this preventative care when patients are admitted for acute reasons - but as with consolidation of outpatient appointments (addressed later in this document) - this is something that hospitals just don't do at the moment.

3.3.1.Quotes

"I'm lucky to have a caring GP who provides in-person home visits to me, so I can access vaccinations, but mammograms require travelling to a facility (which I can't

do) and the GP is unable to do my pap smear for reasons related to my severe disability, so that too requires travelling I simply cannot do." - Ricky Buchanan

3.3.2.What We Need To Fix This

- Again, an ongoing in-person relationship with a GP is needed to give access to basic preventative care such as vaccinations which can easily be provided in-home.
- Hospitals need to be willing to provide preventative care for patients who are unable to travel to access that care, but who are at the hospital (either as an inpatient or outpatient) for other reasons.

3.4. Problems Accessing Scripts and Medications

Being able to access a GP is important, but being able to fill scripts that GP writes is also important, as is being able to access appropriate repeat scripts for ongoing medications.

Many homebound/bedridden patients are on complex regimes of medications, so getting repeat scripts written in a timely fashion can be an ongoing nightmare.

Again, this is a problem that requires in-person visits with a GP with which the patient has an ongoing relationship. After hours doctor services often can't or won't write repeat prescriptions, especially if they are for narcotic medications or other medications that may also be accessed by addicts.

The local pharmacy also comes into play here. A pharmacy who is willing and able to pack Webster packs, and who can deliver medications when required is a godsend to those who are homebound/bedridden.

Ideally the pharmacy can keep scripts on their premises and directly contact the GP when routine repeat scripts are needed for long-term medications, the GP can then either write the script and provide it directly to the pharmacy, or can contact the patient if the medication needs changing or reviewing. This does occasionally happen - my own GP and pharmacy thankfully do this for me - but it seems to be an extremely rare arrangement.

3.4.1.Quotes

"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

"I am forced to travel 110km return, employing a PCA for a minimum 3 hours every alternating week when I'm required to attend my GP's office due to prescribing rules for my pain management medication. The three-hour journey and GP visit

impacts my health significantly; currently requiring at least a fortnight's recovery of total (23.5 hours/day) bed rest. Obviously the routine of fortnightly visits due to the prescribing rules denies me any chance of stabilising my complex and disabling conditions, and has resulted in significant and continuing loss of health and functional capacity." - Allie, who is bedridden with ME/CFS, Mast Cell Disorder, Dysautonomia, and Fibromyalgia

"I take medications that require authority from the health department. There are limits on the number of these meds that can be prescribed and the time between prescriptions, which leaves a small window during which I need to get back to the doctor to refill the prescription. If I can't see the GP (or other doctor) during that time, the medication runs out, and my ability to go anywhere or do anything is reduced even further. Then I start cancelling things I have been waiting months for, and saving my energy for, because I don't have the medications to be able to cope with them." - Julia

3.4.2.What We Need To Fix This

- Again, an ongoing in-person relationship with a GP is needed to give access to someone who will write basic scripts for medications.
- A pharmacy who is willing to make home deliveries, and ideally to contact the GP directly, will make sure the homebound/bedridden patient can get scripts filled and actually access the medications prescribed.

4. Problems Accessing Medical Specialist Doctors

Being able to access appropriate specialist care is vital to enable homebound/bedridden persons to be properly diagnosed and treated when a GP thinks specialist assistance is appropriate. Once again, GPs are the route to get to specialists, so an appropriate long-term relationship with a GP is vital for the process.

Unlike GPs, specialist doctors will basically never do home visits under any conditions, so for a homebound/bedridden person getting to see one is much harder.

Specialists also have an unfortunate tendency to tunnel vision - to see only the specific problem in front of them and to ignore the broader context of the patient's whole disability. For a homebound/bedridden patient, a very small loss of function which might be acceptable to an average person might mean the difference between being able to transfer safely and not, or the difference between getting out of the house once a week versus never getting out of the house. There needs to be an acknowledgement of the patient's wider context and their goals and needs.

4.1. Quotes

"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 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

"My rural and remote location means a minimum 8 hour return trip to a metropolitan hospital, and 14 hours return to a capital city. The cost of a PCA for either trip is simply inconceivable; nor would I be able to sustain either journey sitting upright for longer than an hour. These circumstances have rendered access to medical specialists, various testing equipment and other services unavailable to me - further exacerbating the speed and severity of my health decline." - Allie, who is bedridden with ME/CFS, Mast Cell Disorder, Dysautonomia, and Fibromyalgia

"I have a complex spinal condition that has in the past required input from specialists worldwide. I don't currently have anybody providing medical care for this condition because I aged out of paediatric orthopaedic care and can't access the adult ones to find the right specialist. Meanwhile I became bedbound, due to other issues not being managed, and that lead to a reduction in mobility. That caused osteoporosis and I started breaking bones. I have broken 9 bones in just under 3 years. Each break has been viewed through the lens of an otherwise healthy young person breaking a bone, and conservative treatment decisions being made. They lead to a terrible outcomes like my shorter leg, which was the stronger one before, becoming shorter and also crooked. So now I am more unstable than ever which increases my risks of more breaks." - Julia

"I need to have botox every six months to reduce my bladder pressure. There are risks of prolapse and other irreversible consequences if I don't, and I become very unwell when this doesn't happen. I experience severe kidney pain, have blood pressure swings, am nauseous, get more infections and very unwell. To access the botox I need to have a urodynamics test. That was fine when I lived in Melbourne, the public hospital did that test and I didn't have to wait very long to have it done. But when I moved to a regional city, to be closer to people who could support me more, there was only one person who did this testing. She went on maternity leave. I could not access the testing, so there was no point using all the energy I had to see the urologist, because they couldn't do anything unless I had the test done. I waited 18 months, and was extremely unwell and kept getting sick, the entire time, to have this test done. There were many reasons – the person who does the test being unavailable, the waiting list to be seen when she came back, the referral I had expiring, my inability to see the GP (and the ever increasing list of things I needed to see her for as things kept unravelling, and my limited ability to discuss these issues before my blood pressure started circling the drain) and the person going on leave again before I was seen. I had no way to access the test anywhere else." - Julia

4.2. Problems With Referrals to Specialists

GP referrals are required for a specialist appointment to be Medicare rebatable. Referrals are also time limited - if a homebound/bedridden patient can't access a specialist in the timeframe of the referral, they have to go back to the GP and start over. Some specialists allow an updated referral to be provided after the appointment has occurred, but many will not. For a homebound/bedridden patient who needs to make an extraordinary effort to attend both GP and specialist appointments, while also dealing with specialist's waiting lists, the entire process can become an impossible juggling act of trying to get the timing right.

4.2.1.What We Need To Fix This

- Medicare needs to consider allowing extended timing on referrals which are used by a homebound/bedridden patient.

4.3. No Right to Telehealth Medical Rebates

There is a system set up to give Medicare rebates for video consults with specialists. It's not perfect - many specialists don't participate in it to start with - but it's something. The problem for homebound/bedridden patients is that only those living in rural and remote areas are eligible for it.

4.3.1.Quotes

"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

4.3.2.What We Need To Fix This

- Make the Telehealth system available to anybody whose GP confirms that the patient is homebound/bedridden.

5. Problems Accessing Hospital as an Outpatient

5.1. Problems With Getting to and From Hospital

Patient transport, including stretcher transport, is supposedly available for outpatient appointments but the means for accessing this is often unclear and at the discretion of the hospital. In many cases a form must be filled out by the GP and faxed to the hospital - not just to set up access to the patient transport system, but repeated GP forms for every single trip. For homebound/bedridden patients who, as described in this document, have little or no access to a GP, this immediately makes patient transport difficult or impossible to access.

Patients I spoke to also reported being told that patient transport can't be arranged for a specific time, which prevents the person from being present at the time of their appointment. Other homebound/bedridden patients suffer from severe sensitivities to loud sounds, or severe chronic pain which is exacerbated by insufficiently padded hospital trollies - all of which makes waiting for hours in a transit lounge filled with many other patients either extremely painful or simply impossible.

Many patients believe, with significant justification, that the entire patient transport system is set up specifically to discourage its use.

5.1.1.Quotes

"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

5.1.2.What We Need To Fix This

- Access to patient transport needs to be streamlined, especially for patients who will always need to access this system for reasons of permanent disability.
- Patients need to be cared for appropriately while waiting in transit lounges, including - where necessary - finding people a quiet place to rest and the possibility of arranging for patients to transfer from a trolley to a hospital bed while waiting.

5.2. Problems With Public Hospital Inefficiency

Public hospitals are the places where specialists with sufficient knowledge of the conditions causing people to be homebound/bedridden are available, and also the health services people who are welfare dependant can afford.

Public hospitals are also teaching hospitals, so even when the homebound/bedridden person has been able to negotiate a way to be seen, they are then seen by a junior doctor who is often ill-equipped to deal with the complex issues the homebound/bedridden patient presents with. At best they tell the homebound/bedridden patient to wait while they summon the more senior doctor (who may also need to do the same, repeated over until the specialist the homebound/bedridden patient actually needs to see is called), at worst they are uncomfortable doing so and they send the person away without their healthcare needs being met.

Public hospital clinics also routinely schedule everybody to arrive within certain time blocks. There is very limited flexibility to deal with the person who can not adhere to these scheduling arrangements. An appointment to see a specialist generally means an appointment with the outpatient clinic, and a long wait to see anybody. People who are homebound/bedridden are often unable to tolerate the conditions required for this long wait. Even those who have been able to access patient transport (which is inaccessible for many - see previous section) and avoid the multiple transfers and other capacity reducing incidents that make the entire event more difficult, being required to sit in a waiting room for hours is simply impossible for many homebound/bedridden people.

5.2.1.Quotes

"I finally had the appointment to see the ortho doctor. I turned up on time, and went to the waiting room. After 30 minutes I explained I couldn't sit any longer, could I lay down to wait. They said they didn't have anywhere available. I explained that even more than otherwise, my sitting capacity is limited, because my wheelchair back is broken and I am waiting on a new one. They told me the wait was at least an hour. I knew it was more than that because the room they use for this doctor was empty – he wasn't even there yet. I live five minutes away (for a reason!) and said I would go home and wait where I can lie down, but needed to know when to come back. They said an hour. I called back in an hour and they said they can't tell me, I need to come in. I couldn't do that all over again. They said they would send me a new appointment, I asked if they could tell me when it is so I don't make other appointments at the same time – that happens a lot, no appointments for months and then they are all on the same day at the same time - they said they couldn't do that. They sent me an appointment for two months later. At which time I will do the same thing over again, having transferred on a broken leg for another two months, and repeat. This doesn't work." - Julia

5.2.2.What We Need To Fix This

- Public hospitals need some way to coordinate care for complex outpatients who consistently need to be treated by senior clinicians.
- Public hospitals need to have some accessible pathway for homebound/bedridden patients who are unable to tolerate the long waits caused by block scheduling for outpatient clinics.

5.3. Outpatient Appointments Can't Be Consolidated for Patient Benefit

Public hospitals provide patient transport for those unable to use standard methods of transport (though this is inaccessible for many - see previous section), but for homebound/bedridden patients the very act of travelling can cause weeks or longer of significantly worsened symptoms.

Most outpatient treatment at public hospitals is organised around the "clinic" system, where doctors are only available for outpatient appointments at certain times corresponding to their specialties. This is very efficient for hospitals and doctors, but for patients who have complex medical conditions requiring them to be seen by multiple specialties it means additional travel and additional time spent waiting. For a homebound/bedridden patient whose condition is worsened by each trip, this can be a nightmare.

Hospitals clearly have the ability to do these things on an expedited basis - this is exactly how the emergency department works - but there is no recognition that this is an important thing to do for homebound/bedridden patients to streamline appointments to minimise the number of times they must travel to hospital.

5.3.1.Quotes

"At the moment I'm waiting for both a colonoscopy and a liver ultrasound. Even though the colonoscopy will include an overnight admission (and possibly more days), the hospital setup means this will take two trips, no matter what. There's ZERO ability/willingness for them to ultrasound my liver while I'm there for a colonoscopy, or vice versa. It means I skip a lot of medical things that really should be done, because I just can't face the after-trip illness unless there's no option. It's infuriating that I have to get sicker just so the hospital's bureaucracy can be catered to." - Ricky Buchanan

"Outpatients appointments do not take into account that its a two hour shift of personal care prior to setting out to the hospital. One appointment the room is only available from 7am to 8.30am, meaning to get there, two Disability workers have to start prior to 6am. Hospital personnel are not trained in providing appropriate care for people with disabilities with high support needs." - Anonymous primary carer

5.3.2.What We Need To Fix This

- Public hospitals need some way to coordinate care for complex outpatients who need to be treated by more than one specialty and who are made sicker by the need to repeatedly travel to and from the hospital.

5.4. Problems With Hospital Admission Risk Program (HARP)

The Hospital Admission Risk Program (HARP) is intended to reduce avoidable hospital admissions by a case management approach. In theory this would help overcome the barriers for some homebound/bedridden individuals seeking access to healthcare, but the nature of the program prevents this from occurring. Firstly, it is time limited - when one critical incident has been resolved, the case is closed. But because the underlying problem has not been resolved, the problems will recur over and over.

Secondly, there is a wait time, and an intake procedure. So the person experiencing the exact same issues a week after the case has been closed will be forced to undergo a further wait time to be allocated a resource, tell the story all over again (and it may have moved on by then) and then have the same time limited response available. This simply doesn't address the fact that the healthcare system is not set up to adequately deal with people who are homebound/bedridden.

Secondly, HARP intersession is only available for those homebound/bedridden patients who end up with repeated avoidable hospital admissions. For those homebound/bedridden patients for whom inaccessible medical care means they end up languishing at home and slowly getting sicker, but not being repeatedly admitted to hospital, HARP offers no services at all.

Whilst it may provide an intervention to a cycle of exclusion on occasion, it does not address the underlying issues and at worst just adds one more service the homebound/bedridden individual needs to fight to be able to access.

5.4.1.Quotes

"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

"One of my public hospital specialists said that I clearly needed HARP because I was getting sicker and sicker because I couldn't travel to the hospital ... but because I'm chronic-illness type sick and not acute-illness type sick I wasn't being admitted to hospital for it, so HARP wouldn't accept me." - Ricky Buchanan

5.4.2.What We Need To Fix This

- HARP services need to be available on a long-term basis for those who have a long-term need for the services.
- HARP, or a similar program, needs to be made available to homebound/bedridden patients who otherwise simply do not receive outpatient or inpatient hospital care because hospital is inaccessible.

6. Problems Accessing Hospital as an Inpatient

The experience of the homebound/bedridden people who contributed to this paper is that hospitals have a poor record of taking note of pre-existing conditions and understanding the limitations of the underlying disability. They focus on the issue they are treating, and don't adjust the way they provide support to people with disabilities.

This is not a problem specific to homebound/bedridden patients, but since homebound/bedridden people almost always have disabilities which are complex and severe it is a larger problem for this group than many others.

6.1. Problems Being Looked After While in Hospital

Nurses and existing PCAs at hospitals don't have the additional time to look after patients with disabilities. Even if they did, training a new person about how we need to be looked after can be impossible, or prohibitively exhausting for homebound/bedridden patients.

One anonymous person told me that NDIS had advised them they would expect support workers to train hospital staff to do their jobs while the disabled person was in hospital ... but that NDIS had acknowledged to them there were no clear sensible consistent guidelines. Several other people have reported that hospitals won't let privately hired support workers function within the hospital for "insurance reasons".

Having private support workers train hospital staff, or expecting hospital staff to provide personal care to severely disabled patients is completely inappropriate and just doesn't work. Support workers need to learn how best to support a client and it's not something you can tell the next person in a few minutes during handover. Depending on the needs of the client, support workers may need a week or more of training to do their jobs adequately. Especially for clients who have impaired thinking, memory, or communication skills, the expectation that they can be adequately cared for by people who have not been trained is so bad as to be farcical.

6.1.1.Quotes

"I raised the need that there needs to be a special page set out to be put into clinical notes...they have one for dementia but not special needs." - Anonymous primary carer

"I had a significant spinal surgery and was in the stage of recovery where I could be assisted to do transfers. I had asked on many occasions to have a catheter bag. The doctors and nurses kept asking me why I wanted this, there is a risk of infection and so on. They said I could be assisted to transfer to the toilet. I ALWAYS use a catheter, and the brace on my back prevented me leaning forward without toppling off the toilet. Because they didn't understand my need to use a catheter prior to the surgery, they could not comprehend what I was asking for. It didn't help that all the doctors were males, and would not have the same problem!" - Julia

Readers are also directed to this article about Rachel Croucher, a quadriplegic whose needs were sorely neglected while she was a hospital inpatient: <http://>

www.dailymail.co.uk/news/article-5556261/Quadriplegic-woman-claims-left-lie-faeces-Austin-Health-hospital-Melbourne.html

6.1.2.What We Need To Fix This

- Homebound/bedridden people need permission to be cared for by their own experienced support workers while in hospital.
- In general care for people with disabilities who are in hospital is a bigger problem than I can solve in a single document. I hope other groups are working on this.

6.2. Problems Occurring During Discharge

The process of being discharged from hospital can be very slow and challenging. For a person who is homebound/bedridden, often they are better off at home where their environment is set up for them an appropriate assistive technology is available.

The objective of the hospital system is to provide the care needed in the acute setting, and then discharge the person as soon as it is safe to do so, with a view to ongoing rehabilitation or nursing occurring in the community. The problem is that homebound/bedridden people often can not access those services in the community.

There are sometimes services that will come to the house, but only if that is included in the initial referral. Even for the most experienced self-advocate, who knows how to project-manage the discharge process from their bed, a referral to community supports can turn out to be inappropriate after the fact. Once the patient leaves the hospital, there is usually no follow up at all. The patient is required to sit at home and wait for things to happen. If referrals were not made with the necessary detail, including requesting a home visit, the community service will simply post out an appointment to the patient. When the patient calls to say they can't attend, the case is often closed and that is the end of that. Unless the service is told there is a need for home visit from the outset, they won't make that change later, and there is nobody available at the hospital end to amend the request.

6.2.1.Quotes

"If a hospital tells a homebound patient that they are being discharged because the doctor feels their care would be "better managed in the community," that doctor must then provide the precise reasons that lead them to making the conclusion the care would be better managed in the community. Because let's face it, that's just a way of getting us out. So if that's the phrase they are going to use, let's hold them to it. It's a duty of care issue to discharge someone into a safe setting." - Anon2

6.2.2.What We Need To Fix This

- General education is needed for all medical professionals, including allied health professionals, about homebound/bedridden clients and their needs. If people running outpatient services understood this problem, perhaps they would be further motivated to do something about it.

Medical Access Issues For Homebound/Bedridden Persons

- Hospital personnel need to be educated to ensure that homebound/bedridden patients are only referred to services which are actually accessible to them.
- There needs to be an accessible point of contact at the hospital so that if homebound/bedridden patients are discharged with inappropriate referrals, this can be fixed.

7. Problems Caused by Medical Gatekeepers

A medical gatekeeper is a person who controls the patient's entry into part of the health system. This is commonly a receptionist or practice nurse who controls access to a GP, medical specialist, or appointments for medical tests. Done well, medical gatekeeping streamlines access to resources and helps make sure patients needs are met - but when it is done badly, medical gatekeeping effectively keeps homebound/bedridden from accessing services at all.

If you telephone a practice, it is these people who will commonly control a patient's access to home visits, to speaking on the telephone to the doctor, and to other things such as obtaining repeat scripts without physically attending an appointment. Medical gatekeepers who work in a place that offers medical testing often control which patients' special access requests are granted. Because these requests are often filtered before a patient ever has a chance to speak to a doctor, the doctors working at that practice may have no concept of how many patients in their practice need these services.

If a homebound/bedridden person discusses their concerns with a doctor, there is at least a chance they will try to make arrangements. But most often they are trying to negotiate an arrangement with a receptionist or a busy outpatient department, and these gatekeepers simply have no understanding of the issue, and no authority to vary the way things are done. Education of the health sector as a whole (including gatekeepers) would be expected to improve this so that homebound/bedridden people are not trying to explain a problem that the sector doesn't even know exists.

An additional problem is that some doctors and testing locations require that referrals are delivered in person before the appointment can be made or specialists that require that referrals are faxed, when almost no patient have access to a fax machine. GPs may be happy to fax things, but again may require that the patient bring the referral back to be faxed if they didn't originally realise faxing was needed. All of these things may be relatively small barriers for non-disabled patients, but for a homebound/bedridden patient they become insurmountable obstacles.

7.1. Quotes

"I rang up to book in a series of cardiac tests at my local rural hospital and they wouldn't give me any appointments unless I brought in my referrals in person (not possible as I'm in the middle of a shocker of a flare and my husband would have to get time off work) or I fax them in, because we all have faxes at home." - Michelle, who is partially homebound with dysautonomia

7.2. What We Need To Fix This

- Doctors and all other medical gatekeepers need to be educated about the problems of homebound/bedridden patients, and how requiring in-person attendance when not absolutely necessary can be an insurmountable barrier to homebound/bedridden people accessing medical care.

8. Problems Accessing Allied Health and Associated Services

8.1. Home Visits for Allied Health

Even for allied health professionals who will nominally do home visits, most will charge extra for this service and the extra amount will almost never be covered by funding services.

Medicare does offer some fairly minor coverage of allied health services under programs like the Chronic Disease Management Plan⁷, but does not provide additional funding for patients who require home visits.

NDIS should in theory provide sufficient funding for home visits where NDIS funds allied health services and home visits are required, but whether this works out in practice is still to be seen. See later section about problems accessing Centrelink/NDIS.

Even allied health services which do nominally provide home visits for some services will often fail to provide home visits for anything which could be done more easily or cheaply in clinic, failing to understand that homebound/bedridden patients are not able to visit them in clinic.

8.1.1.Quotes

"I am currently arguing with my local orthotist about providing a home visit to cast my legs so my new leg braces can be made. They are quite correctly pointing out that this will be awkward and messy to do at home, and I agree, but that does not magically make me become able to travel to their clinic. They seem to believe that if they can just explain to me well enough, or make the whole process sufficiently difficult on my end, that I will either give up and go away or agree to travel to the clinic. This is not an isolated occurrence, it is basically repeated every single time I require a new service." - Ricky Buchanan

8.1.2.What We Need To Fix This

- Funding schemes, including Medicare and NDIS, must properly fund home visits by allied health professionals where these home visits are medically required.
- General education is needed for all medical professionals, including allied health professionals, about homebound/bedridden clients and their needs.

⁷ See <https://www.humanservices.gov.au/organisations/health-professionals/enablers/education-guide-chronic-disease-individual-allied-health-services-medicare-items-10950-10970>

8.2. Accessing Optometry and Audiology Services

Some services advertise this - for example the web page for "Healthcare2You Eyecare" advertises amongst other things "domiciliary eye care"⁸ - but in fact only provides services to aged care facilities and not private homes.

There are occasional private practitioners who are willing to provide these services, but it is very difficult for homebound/bedridden patients to find these practitioners because there is no central body who has a record of the relevant practitioners.

8.2.1. What We Need To Fix This

- Some type of discovery mechanism is needed so that people who are homebound/bedridden are able to find those rare services which provide home visits. This would probably best be coordinated by an organisation representing homebound/bedridden people, if one existed.

8.3. Accessing Psychology Services

Being homebound/bedridden is difficult. Even if the person does not suffer an underlying mental illness, the ongoing stress caused by being socially isolated and being unable to do most things society considers "normal" is significant. On top of this, being shut out of proper medical care and government services adds enormously to people's stress.

Access to proper psychological and psychiatric services is not a panacea here, but it is one vital ingredient in care for homebound/bedridden people.

The Better Access Initiative is a Medicare-funded program which provides up to 10 individual and 10 group therapy sessions a year available to patients with an assessed mental disorder who would benefit from a structured approach to the management of their treatment needs. In November 2017 changes were introduced to this plan to allow up to 7 of the 10 sessions to be delivered via telehealth to patients living in rural and remote areas⁹ - but again, homebound/bedridden patients who could have benefited from this system have been forgotten.

8.3.1. Quotes

"Wanted to see a psychologist but barely any do home visits and i tried to organise one who did.. She said she didn't have the machine to process medicare card. So told me to go in. Then got annoyed and told me she refused to see me because i had to cancel due to not being well enough to go. But i had told her everything i dealt with when we discussed home visits." - Sarah, who is homebound with ME/CFS

⁸ See <https://healthcare2you.com.au/services/eyecare-and-optometry.html>

⁹ See <http://www.health.gov.au/internet/main/publishing.nsf/content/mental-ba-fact-pat> about the scheme in general, with documentation of telehealth addition at the bottom under the heading "Changes to the Better Access Initiative".

"If I wanted to have a psychologist over the phone, which I did, I had to pay completely out of pocket with it, there were no options." - Emma, who is homebound with ME/CFS

8.3.2.What We Need To Fix This

- Medicare-funded psychological services such as the Better Access Initiative should be expanded to fund Telehealth services for homebound/bedridden persons, regardless of where they live.
- General education is needed for all medical professionals, including allied health professionals, about homebound/bedridden clients and their needs.

9. Problems Accessing Centrelink/NDIS

Being locked out of the medical system as this document has described has very serious knock-on effects. Not being able to reliably access GPs and specialist doctors means not getting paperwork filled out for Centrelink or NDIS. For many homebound/bedridden people, this means not being able to access those programs.

After-hours GP services won't do paperwork, and most regular GPs won't do paperwork unless you physically turn up for the appointment.

Public hospital clinic doctors also won't do paperwork, and because you get a random doctor every time you attend a public hospital clinic they usually don't know you well enough to do the paperwork even if they were willing.

There are also numerous reports of NDIS discriminating against homebound/bedridden people with disabilities such as Chronic Fatigue Syndrome (ME/CFS) which have a history of not being covered by disability funding programs¹⁰. This is an enormous problem for people with these conditions, but beyond the scope of this document.

9.1. What We Need To Fix This

- Again, an ongoing in-person relationship with a GP is needed, and a way to access specialists who are willing and able to fill in paperwork for homebound/bedridden patients.
- Centrelink and NDIS (and similar programs) need to be sensitive to the fact that homebound/bedridden people will have enormous problems getting paperwork together, and may need much more time or even permission to use GP reports rather than specialist reports for paperwork.
- Programs such as NDIS need to accept patients based on their level of functioning and disability needs, not their diagnostic labels. This is written into the NDIS legislation but unfortunately does not seem to be happening in practice.

¹⁰ See <https://www.sbs.com.au/news/the-feed/fighting-disbelief-chronic-fatigue-syndrome>

10. Limitations

The biggest limitation of this document is that there is no research into this population, so we don't know who is homebound/bedridden, why they are homebound/bedridden, how many people are homebound/bedridden, what ages they are, what disabilities they have, or anything else.

It is worth noting that fully 30% of the homebound/bedridden people I spoke to specifically told me that they had requested anonymity because they were afraid of medical retribution for speaking out. I can't tell you how many people refused to speak to me at all for the same reason, but I have reason to strongly suspect it is a non-zero number. When you have only a minuscule piece of access to the medical system at all, and significant experience of being blamed and punished for not being able to properly fit within "the system", speaking out can be terrifying. I think this underlines how desperately we need to reform the entire way that homebound/bedridden people access the medical and disability system.

This document has been put together with information from my own life, having been homebound/bedridden to varying degrees for 20+ years, and with information from my friends and acquaintances who are bedridden, and from people I came across on Facebook support groups for conditions such as ME/CFS and Dysautonomia which can cause people to be bedridden. Further details of the method can be found in Appendix B.

This means this document is clearly slanted towards the problems I have had myself, and that the people around me have had. Most of us are young and most of us are homebound/bedridden because of chronic conditions and disabilities, and all of us are able to get online through smart phones/computers because this is how we network. We represent a fairly narrow spectrum of disabilities, because most of us met through condition-specific support groups and/or as friends of friends. None of us are elderly, illiterate, unable to speak English, significantly intellectually disabled, or communication impaired to a point where we can't manage Facebook.

Unfortunately, until there is funding available for research into the homebound/bedridden population, this is the best we have.

11. Conclusion

This document has shown that the bedrock of access to medical care - an ongoing relationship with a GP - is something that many homebound/bedridden people are excluded from. Homebound/bedridden people need access to a GP who is willing to make regular home visits, help with paperwork, write scripts and referrals to others where appropriate, and above all a GP who will fight to make sure that the homebound/bedridden person has access to appropriate care and services.

Firstly, the RACGP must update its guidelines so that GP services are required to provide appropriate care, including in-person home visits and telephone consultations where appropriate, to homebound/bedridden patients of theirs.

In addition, governments and RACGP needs to work with stakeholders towards developing appropriate guidelines to ensure that homebound/bedridden patients who do not have a current GP are able to obtain one. Governments may have to provide Medicare incentives towards this end, as homebound/bedridden patients currently are unwanted by GPs generally.

General education is needed for all medical professionals, including allied health professionals and medical gatekeepers such as receptionists, about homebound/bedridden clients and their needs. There seems to be a general assumption amongst many in the medical profession that people who need this level of support are, or should be, institutionalised - this is incorrect.

Governments must urgently fund epidemiological research about the prevalence of homebound and bedridden people in the community, including research on why people become homebound/bedridden, who is most likely to be in this category, and how services can best be delivered to this population.

Government programs including Centrelink and NDIS must acknowledge that people who are homebound/bedridden will have substantial difficulty obtaining medical specialist reports and completing paperwork and provide appropriate support to these people.

We have an opportunity to make people's lives meaningfully better - we must do this.

Appendix A: About the Author

My name is Ricky Buchanan. I'm a 43 year old Melbourne woman who's been disabled since my teenaged years and bedridden since my early twenties.

I have a bunch of somewhat rare conditions - Ehlers-Danlos Syndrome (this makes me floppy and super prone to joint injury), Dysautonomia (automatic nervous system is broken, so my blood pressure, pulse, and digestion are unpredictable and I faint when I stand up for more than a minute or two), Mast Cell Activation Disorder (causes lots of allergy symptoms all the time without any actual allergies), and Chronic Fatigue Syndrome (fatigue so severe that even sitting up or moving my arms and legs is hard).

The end result of these conditions is that I'm bedridden. I can walk just barely enough to get to the toilet and back, but I can't sit up or walk apart from that - not even enough to use my reclining wheelchair.

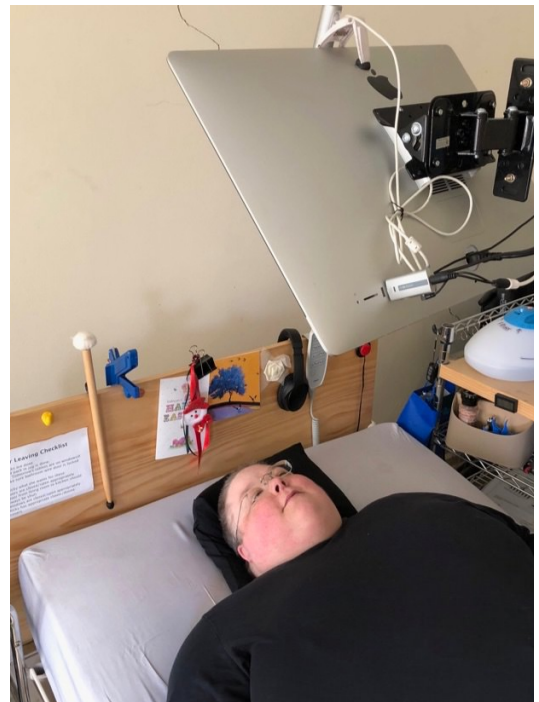
I lie flat on my back all day - there's a hospital bed in my living room with a computer system set up so I can use it lying flat, and a waterbed in my bedroom for sleeping. I can listen to audiobooks and podcasts and the radio, watch small amounts of TV or videos on the computer, use my computer to read and draw and stay connected via Facebook and Twitter, and write articles and blog posts if I'm careful to "save up" the typing until I have a patch of the day with some energy.

I have been meaning to construct a document like this for many years. Unlike many people who are homebound/bedridden, I do not have a condition which seriously impairs my thinking or communication, and I have been bedridden for decades now, so I am excellently placed to document these failures of the medical system.

When I am not trying to change the world, I design new bits of assistive technology for myself, use my computer to draw, listen to endless hours of audiobooks, create websites¹¹, and take photos of my cat.

I can be contacted at:

Email: ricky@notdoneliving.net



This is my computer system, set up over the hospital bed in my living room.

I am happy to be contacted by journalists, policy makers, and anybody else about this document.

¹¹ Readers are welcome to peruse my website at <http://notdoneliving.net/>

Appendix B: Method

On March 13 2018, I had trouble accessing an orthotics clinic due to being homebound/bedridden, and posted much of what later became section 8.1 ("Home visits for allied health") to my Facebook account as a "friends-only" post. The post received a total of 20 comments, including many from other friends of mine telling their own stories of failing to access care because they were homebound/bedridden (I have 433 Facebook "friends" but Facebook does not provide statistics for personal accounts so I can't tell you how many people viewed any of the posts I made).

On March 16 I read a post in a local Facebook-based ME/CFS support group¹² by someone who was unable to access prescription medications because her GP had refused to do home visits and referred her to a locum service, who refused to write scripts. I had knowledge that the RACGP version 4 guidelines required home visits to be provided when needed, so I looked them up and was appalled to discover that the RACGP version 5 guidelines had no such requirement.

I posted the information about the RACGP version 5 guidelines (which was later expanded to become section 3.1 "No Right to GP Home Visits") on my personal Facebook profile on March 16 2018, as a public post¹³. It obtained far more "likes", shares, and comments than my posts usually do, including several reactions from other homebound/bedridden people.

It became clear to me that I had a lot to say on this topic, and also that it was something that also affected many of my friends. Over 20+ years of being homebound/bedridden I have struggled to access healthcare of all types and clearly this is an advocacy issue that nobody seems to be working on. I had felt that the issue was just too enormous for me to tackle, but once I started writing everything came pouring out as if I had been composing this document in the back of my brain for years.

I publicly posted an initial 13 page draft of this document (less than half the final size) to my personal Facebook profile on 14 April¹⁴, specifically asking for quotes from Australian homebound/bedridden people that I could use in the final document. I also shared the same post to an international group I run for bedridden people¹⁵, noting that I was looking specifically for comments by Australians.

Quotes were provided as comments on the Facebook document, as private Facebook messages, and also via email. In two cases, I saw relevant posts or comments made on Facebook by someone I knew was homebound/bedridden, and asked via private Facebook message whether I could quote them in this document. In total, 12 homebound/bedridden people (plus me) and 1 carer for a homebound/bedridden person provided direct quotes used in the final document.

Additional valuable feedback on the document was provided by another person who cares for a homebound/bedridden person but did not wish to be quoted, and an occupational therapist who has worked with homebound/bedridden clients.

¹² See <https://www.facebook.com/groups/MECFSAustralia/> - the group is closed for privacy so I am unable to refer to the specific post.

¹³ See <https://www.facebook.com/rickybuchanan/posts/10155989311955792>

¹⁴ See <https://www.facebook.com/rickybuchanan/posts/10156068592280792>

¹⁵ See <https://www.facebook.com/groups/livingfrombed/>

Medical Access Issues For Homebound/Bedridden Persons

Everybody who has been quoted in the document was asked if they preferred that I use their name, a pseudonym, or referred to them as anonymous, and also given a chance to provide a description to go with their name (some people opted not to provide any description).

Several of the sections in this document were also added after comments were submitted that covered that particular area.