

Executive Summary



Medical Access Issues for Homebound/Bedridden Persons

“I feel like we're just invisible. Like this problem isn't even on anybody's radar because nobody knows we exist.” - Ricky Buchanan

The entire medical system has been designed and based around physical attendance - if you don't turn up you are assumed not to need or want the service. If you are homebound/bedridden and you live in the community, then the healthcare system treats you as if you do 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.

What does homebound/bedridden mean?

None of these words have standard definitions in either the medical or disability realms, but for the purposes of this document:

Homebound / Housebound: 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.

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.

Being homebound/bedridden means that attending medical appointments is difficult or even impossible. Some homebound/bedridden people can attend appointments if sufficient supports are provided (appropriate transport, somewhere to lie down while waiting, etc), but for other people there is no chance to attend appointments under almost any circumstances.

What problems do homebound/bedridden people have?

Not being able to attend appointments reliably, or at all, means you have trouble with accessing all of the aspects of the medical system including GPs, specialists, hospitals, and allied health services.

There are also knock-on effects from being locked out of this care, for example extensive medical reports are required before people can access Centrelink and NDIS services, so people unable to access medical services are effectively unable to access these other services too.

Why does it matter?

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.

What needs to be done about it?

No epidemiological research exists on homebound/bedridden people, so as a first step research is needed to find out the size of the homebound/bedridden population and its composition.

As access to a general practitioner is the bedrock of our medical system, the most important thing that would immediately assist homebound/bedridden people is to make sure that they have access to home visits by their regular GP when necessary, and to Medicare-rebated telephone visits where these could reasonably substitute for home visits.

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. 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.

To assist homebound/bedridden people in accessing medical professionals, we need to consider extending the existing Telehealth systems for rural and remote patients to also cover homebound/bedridden patients, and consider allowing extended-time referrals as well.

When accessing hospital as an outpatient, long wait times and other inefficiencies are a big problem for homebound/bedridden patients. Amongst other things, access to patient transport needs to be streamlined, and there needs to be a way to coordinate care for complex outpatients who need to be treated by more than one specialty, need to be treated by senior clinicians, and who are made sicker by the need to repeatedly travel to and from the hospital.

For homebound/bedridden people who are inpatient in hospital, not being able to be looked after by their own support workers is a big problem, as is being discharged into the "care" of community services which are not accessible to them.

For allied health, including psychology services, homebound/bedridden people need access to properly funded home visits, and where Telehealth initiatives exist for rural and remote patients these should also be expanded to cover all homebound/bedridden people.

Centrelink, NDIS, and other government services also need to be sensitive to the difficulties that homebound/bedridden people have getting medical reports and paperwork together, and consider providing more time or accepting GP reports rather than specialist paperwork only.

Conclusion

Nearly a third of the people quoted in the full version of this document stated they had requested anonymity because they were afraid of medical retribution for speaking out. The effects of being blamed and punished for not being able to properly fit within "the system" due to one's disabilities can not be emphasised too strongly.

The good news here is that because there has not been any advocacy around this area before, there are several "low-hanging fruit" in the recommendations - things that governments, hospitals, doctors, and RACGP could quickly implement at fairly low cost to them. These things, such as basic education around homebound/bedridden issues for all medical professionals, and extending existing Telehealth systems to cover homebound/bedridden patients, could have a big impact on the wellbeing of homebound/bedridden patients.

We *need* to do this.

Now you've read this summary, the full issues document and other supporting information can be downloaded from:

<http://notdoneliving.net/justinvisible/>