MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Department of Infrastructure and Regional Development Consultation on *The Whole Journey Guide*

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About Multiple Sclerosis Australia

MS Australia (MSA) is the national peak body for people living with multiple sclerosis (MS) in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Research
- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- International collaboration

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with MS, their carers and the broader MS community.

Our Vision

Is consistent with the vision of the Multiple Sclerosis International Federation – **'A world without MS'**

Our Mission

MSA will support our members and work towards meeting the needs of people with MS, their families and carers. We will facilitate a national comprehensive representation of the Member organisations through advocacy and communication.

Our Purpose

On behalf of our members and people with MS, our purpose is to develop:

- **Research:**
  Supporting ongoing research to pursue further knowledge in targeting prevention, improving treatment, enhancing quality of life and ultimately, to find a cure.
- **Advocacy and Awareness:**
  Although MS impacts people differently, there are common, fundamental issues for people affected by the disease. We are steadfastly committed to giving these people a voice and remain willing and able to work with government and the Australian society to champion issues in a dynamic policy environment to bring about change to the lives of people living with MS.
- **Communication and Information:**
  Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member organisations and our key stakeholders.
- **Support for our member organisations:**
  As MS specialists providing and facilitating high quality services that span the life-time needs of people affected by MS and other degenerative neurological conditions, their families and carers – from the point of early symptoms and pre-diagnosis, that addresses their changing needs.
- **International Collaboration:**
  Representing the MS cause and promoting collaboration with our domestic and international partners.

Introduction

MS Australia (MSA) is pleased to provide a submission to the Department of Infrastructure and Regional Development consultation on The Whole Journey Guide.

The focus of the comments provided in this submission are on key areas that will impact on people affected by MS.

Overall, MSA is supportive of the comprehensive approach to public transport taken in The Whole Journey Guide and the key to its success will be in effective and timely implementation. In previous submissions regarding accessible public transport standards, MSA has expressed frustration at the pace of change for the implementation of recommendations from previous reviews.

Connectivity of public transport journeys is very important to people with MS who sometimes have to travel long distances for medical appointments – they need to be confident of a safe, accessible and reliable service. This is especially true for people with MS living in regional, rural or remote settings where services are much less frequent or completely non-existent though there is little if any details about arrangements for people living and travelling in these settings in the Guide. To address this, an example of a service held in high regard by people with MS in rural and remote settings, Community Transport Services Tasmania (CTST), is described on page 7 of this submission.

Another concern for people with MS is to ensure the staff of all transport providers are well trained and briefed. MSA has received complaints in the past from people with MS who were making a journey in accordance with a journey planner, but were left at the tram stop or bus stop because the drivers did not understand what their obligations were.

A serious issue for people with MS is their invisible symptoms. MS symptoms that are hard to see include fatigue, pain, cognitive problems like memory loss or trouble solving problems, weakness, blurred vision, numbness, prickly or tingling sensations, heat sensitivity, dizziness, balance/coordination problems, and bladder or bowel problems. Sometimes these symptoms result in mobility issues and a person having to use a wheelchair, a motorised scooter or some sort of walking aid, sometimes they do not. It is important for all levels of staff in public transport service organisations to understand that not all disabilities are clearly visible and sometimes people may need special assistance if required.

MS Australia consulted widely amongst the MS community and is able to provide the following case studies which best illustrate the issues and difficulties people with MS have with the current public transport system.

Overall, the feedback from people with MS is positive and we hope that these positive stories reinforce good practices such as:

- The “Tram Tracker” app in Melbourne
- The Public Transport Victoria Journey Planner
- Low floor trams in Melbourne
- CTST in Tasmania

In response to our Facebook posts regarding this consultation, the most common issue raised was the lack of lifts at:

- Parliament Station, Melbourne
- Edgecliff Railway and Bus Station, Sydney
- Unanderra Station, Sydney

and the gap between train and platform at stations such as Strathfield and Newtown in Sydney.

Case Study – Karen (Melbourne)

The good:

When public transport runs on time, it's great, and in theory, the tram tracker app is useful. The tram drops me out front of my work, so it's convenient.

The bad:

When the trams are running late, I'm stressed. The tram tracker doesn't reliably provide current information. In the morning, I'll make my way to catch a tram as it says that it will be there in 5 mins, then when I get to the tram stop, I see the tram shunt down the line and miss the lower stops. The tram tracker app will then update, telling me that the next tram is in 15 mins. This is extremely frustrating when I am required to wait in the cold morning unnecessarily (around 7am).

Today was particularly frustrating. I boarded a tram, only to find out that my concession card didn't work – it had expired. There was no indication that this would happen. There was no expiry date. Not wanting to get fined, I got off the tram at the next stop and walked to the shop where I had originally purchased the concession card. The attendant had a lot of difficulty dealing with the fact that I had a concession card. I was told to go to the train station to get it fixed up. There are no manned train stations in my area – especially ones that I could get to without getting on public transport. Then I was told that I could not get the funds in my expired card unless I went to a manned train station. This all happened just before 7am this morning. I was stressed and emotional. My feet haven't stopped tingling from this morning (and they usually don't tingle that much). The shop attendant finally worked out how to supply me with a new card (which I was told that I had to pay for!). I had to call the complaints line (who told me that I didn't have to pay for a new card – but I did anyway as I needed to get to work) and I'm still trying to sort it out – I need to call them at the end of the day to try and resolve everything. It was a very unsatisfactory experience. The result is:

- I was late for work,
- I'm out of pocket with another Myki fee,
- I had to top up my new Myki,
- I haven't been reimbursed for the funds on my old Myki as yet, and lastly
- The stress triggered my MS symptoms.

The ugly:

Some passengers – asking me to stand up for an elderly person (I've just entered my 5th decade) while there are children (ages 4-5 sitting on seats). This is when I've finished work and I'm feeling very fatigued and I have to concentrate on my balance while standing up in the tram.

No one gives up a seat for you as I don't have a walking aid.

You do the right thing by swiping on and off, yet there are many who evade fares and take up valuable seats. They need to look at the system on the trams.

In summary, on average my experience with the tram network (ie. how it's run) has not been good.

I should add to the Myki experience – it took me at least an hour after work on Friday, talking to one of the Myki supervisors, to sort out the initial stages of my Myki card. I'm still awaiting reimbursement for the card (I don't have much hope in getting it back) as well as the transferral of my balance from my old card to the existing one. Their network of outlets to help people with concession cards is almost non-existent – well at least in my area.

Case study – Ron (Melbourne)

I am a long term person with MS who has been riding the Public Transport Victoria system three days a week for the past three and a half years on a Pryde Jet 2 Electric Wheelchair.

Overall my experience is very positive.

My wheelchair is an appropriate size for buses and trains. Larger chairs and scooters are generally too large for the bus services.

The PTV journey planner is one of the best interactive websites I have ever seen and works well for me.

The bus and train drivers are courteous and helpful...I suspect there has been some training involved...it has improved over time on the buses.

My only concerns on the buses are the ramps. The (tilt of the) final slope is important and was far too steep on a few occasions. The busses should tilt but a few times it didn't tilt enough. Too steep risks flipping the chair backwards or forward leaving me unnerved. This happened due to mechanical bus faults or flawed driver training. Not very often and not for a while.

The other problem is the metal edging around the ramp housing recess. The later bus designs have a chamfered grit embedded surround. Chair Drive wheels don't grip the edge especially on rainy days. Fortunately the later designs of bus don't have this problem.

I haven't tested the tram network yet...not enough stops or low floor trams going where I want to go yet.

Case Study – Matt (Melbourne)

Having newly lost my ability to walk and drive in the last few months, I do not yet have much experience of using public transport as a disabled person. However, my experiences so far of using Melbourne's trams and Sydney's trains have been wholly positive.

The low floor trams in Melbourne in particular, which I now once or twice per week, are amazingly accessible, and make it incredibly easy to get around the city at all but the very busiest times. As a result, I find I can rely on the tram when I need it, and that has a big impact on my access to work and community.

My main limitation on using the tram more is the number of accessible lines and stop. I currently use the tram only once or twice per week, but would use it much more frequently if in the future the number of lines and stops that are accessible increases. For example, my nearest tram stop is only 2 or 3 minutes away, but my nearest accessible stop is 15 minutes away.

Case Study – Nigel (Melbourne)

In January last year I tried to visit a friend in Royal Melbourne Hospital who was recovering from a major operation. However, I was unable to do so because it seems there is no way to get to the hospital by train and tram in a wheel chair!

I planned to go by public transport, going by train from Bentleigh to Flinders street and tram from there to the hospital. I checked that there are accessible tram stops in the hospital precinct and rang Transport Victoria who confirmed that I could get from Flinders St to the hospital in my wheel-chair on route 59. Unfortunately when I arrived in the city I found this was not the case and there is no accessible tram service to the hospital precinct!!

The situation was that there are two tram services running between Flinders St station and the hospital; route 59 goes up Elizabeth St and along Flemington Rd, and route 19 goes up Elizabeth St and then up Royal Parade, with the hospital being between the two routes. There are several accessible tram stops on the common section of the two routes and on route 59 at the Royal Children's Hospital and close to Royal Melbourne hospital. There are no accessible tram stops on route 19 beyond the common section. However, the reverse is true of the trams there are accessible/low-floor trams on route 19 but not on route 59!

Thus there are two tram routes serving Royal Melbourne Hospital route 59 and route 19 and one has accessible tram-stops but no accessible trams and the other has accessible trams but no accessible tram stops!! I queried this at the Flinders St information desk and they confirmed it. I gave up and went home without getting to visit my friend.

This is laughably ridiculous as well as totally unacceptable. One would have thought that if there was a destination would have priority for accessible public transport it would be the Melbourne Hospital precinct.

I wrote to the (state) minister asking her to ensure that accessible trams are introduced to route 59 without delay, if necessary by shifting them from route 19. The reply I received is attached. You will see that the only date actually mentioned is 2032!!!

Case study – Simone (Melbourne)

Thank you for the opportunity to provide some feedback in relation to my experiences with the public transport system.

I have relapsing-remitting MS, I do not have mobility aids.

I live in Glenhuntly and work in Melbourne CBD. I board the train at Glenhuntly train station and disembark at Parliament train station.

Common experiences for me:

- Not being able to get a seat as the trains are so overcrowded, at least twice a week there have been cancellations and/or delays and we are squashed in like sardines which causes me to overheat. Standing on the train is often impossible for me as I have shocking nerve pain in my legs. I have often had to get off the train at another station or letting multiple trains go as they are so full. I have often given up in tears and just gone home.
- The city loop train being redirected to Flinders street by-passing the city loop, this happens at least twice a week. This requires me to get off at Richmond and walk down and up steep ramps which I am simply often unable to do.
- The disability seats on the train have signs saying to give up the seats for people with mobility aids, asking for those seats is very difficult as I do not have a mobility aids and my symptoms are invisible.

Although these challenges may seem minor they impact me in a major way. I do my best to live a normal life, go to work etc. our shocking public transport system makes this really difficult. If it impacts me so much I can't imagine how difficult it must be for the many people with far worse symptoms and mobility restrictions than me, I feel so sorry for them and hope the Government considers their needs. Bad experiences on public transport for these people including myself who is far less vulnerable than many has a ripple effect including, isolation, depression and anxiety just to name a few.

An example of best practice - Community Transport Services Tasmania (CTST)

At a recent focus group of people with MS held in northern Tasmania, the CTST service was held up as an excellent service, particularly to connect people in rural and remote settings.

The service is described on the CTST web-site as follows:

> CTST is a state-wide Home and Community Care funded (HACC) Incorporated Association, funded jointly by the Commonwealth and Tasmanian governments to delivery community transport services.
>
> The Client group serviced by CTST covers:
> - Frail aged over 65's – funded by the Commonwealth government
> - Under 65's and younger people with disabilities – funding by the Tasmanian government.
>
> The services are delivered to clients by some three hundred and eighty active Volunteer Drivers across Tasmania covering major centres and isolated rural areas. Their business or service delivery model is based across Tasmania comprising twelve separate districts, each staffed with a Transport Coordinator meeting the client transport needs of that area.
>
> Each district has an allocated number of vehicles and a local supply of volunteers. Clients make a contribution through a fee which is a distance based fee and is consistently applied across the state.
>
> The CTST vehicle fleet comprises some seventy vehicles and ranges from sedans to large commuters.

Given the services' popularity amongst people with MS in northern Tasmania, the CTST could be worthy of further evaluation and consideration of roll out in other appropriate parts of Australia.

KEY FACTS:
- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 23,000 people throughout Australia
- It is the most common chronic neurological condition diagnosed in young adults.
- MS is most commonly diagnosed between the ages of 20 and 40
- 75% of people diagnosed are women.
- MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it means a progressive decline over time. For all, it is life changing.
- Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems.
- There is no known cause or cure.