



**Meniere's
Australia**

*Working to improve the diagnosis,
treatment and management of Meniere's disease*

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Review of WA's Current and Future Hospital and Community Health Care Services”

‘Identifying any outstanding needs and gaps in health care services’

ConnectGroups the association for Support Groups in WA, would like to submit to this inquiry, with particular reference to Item 2,

‘identifying any outstanding needs and gaps in health care services’. In order to do so we urgently need your feedback on a number of questions.

Support groups play a vital role in the community, by offering people with health (and mental health) issues an affordable and sustainable way to access information, help and understanding. In the current economic climate, with the rise in the occurrence of mental illness, and with an ageing population, the need for support groups is likely to increase.

However, to our knowledge there has been limited recognition of the value of support groups by the way of government financial assistance or the provision of resources to support groups and we would like to bring this to the attention of the current government. In order to do this we would greatly appreciate you answering as many of the following questions as you can (dot points are fine) and returning your responses to us as soon as possible so that we can prepare a strong submission.

Meniere's Australia WA response

The issue of emotional wellbeing is felt to be closely linked to the building up of resilience, self-esteem and mental health. The acceptance of individuals and groups within the community is seen as vital to building emotional wellbeing and a sense of self worth. United Way 2008 Community Needs Analysis

Social Isolation

The issues of social isolation are compounded because people are perceived as disconnected from their community due to poverty, health and lack of public transport.

Emotional Wellbeing

The issue of emotional wellbeing is felt to be closely linked to the building up of resilience, self-esteem and mental health. The acceptance of individuals and groups within the community is seen as vital to building emotional wellbeing and a sense of self worth.

Providing support for those experiencing the symptoms of Meniere's; which includes hearing loss – communication breakdown, vestibular (balance) disability – mobility

issues, Tinnitus and feeling of fullness in the ears/head. Secondary symptoms include anxiety, depression and a range of other disability impacts. This leads to social isolation and a sense of disconnectedness from others which have been identified as a major issue for people living with Meniere's disease - an invisible, debilitating condition which is often misunderstood by health professionals and Government bodies. The issues are magnified for people living in remote communities with little access to health services.

People with Ménière's experience vertigo, hearing loss and tinnitus. Some of the key issues that arise for people with Ménière's include the secondary symptoms of social isolation, anxiety, depression and inability to maintain employment – thus a low income...

The key focus of Meniere's Australia WA(MAWA) is to ensure that a vulnerable section of the community stays connected and kept up to date with current details of the services and organisations that are available. MAWA works in conjunction with other organisations but the major difference is this program is run by people who live with the daily issues of Meniere's disease.

MAWA aims to:

- Address and reduce the social isolation of people who contact the MAWA.
- Provide bi-monthly contact in the form of written communication.
- Provide telephone contact and counselling as requested/needed.
- Encourage people to 'reconnect' with the community in a safe environment.
- Encourage people to explore options available in the local community.
- Provide role models who successfully manage their condition.
- Improve the emotional wellbeing of the individual and their family.

Information and Suggestions on behalf of Meniere's Australia Inc. Western Australia (MAWA)

On average, how much does it cost you to run your support group each year (consider venue hire, beverages etc, administration costs, insurance etc)?

Projected Expenditure Amount

Professional fees and salaries (100 hours at \$15.00 hour)	\$ 1,500.00
Postage and stationary	\$ 900.00
Internet and website	\$ 1,000.00
Advertising and promotion	\$ 1,000.00
Venue Hire estimate Quarterly Meetings	\$ 600.00
Equipment Hire – FM system for hearing impaired	\$ 2,000.00
Advertising and promotion	\$ 1,500.00
Materials/consumables/	\$ 500.00
Other: Launch Seminar	\$ 5,000.00
Insurances Public Liability etc	\$ 500.00

Total Expenditure

\$14500.00

Does your support group receive any ongoing operational funding from the state or federal government?

No – Meniere's Australia Western Australia (MAWA) has just become established under the umbrella of Meniere's Australia (MA). Financial assistance for start up and organisational development has been provided with seed funding from MA. A priority is

identifying funding sources to implement an awareness campaign and organisational development

Does your support group receive any practical assistance/resources (e.g. a facilitator, use of meeting venue, administrative support) from a government funded organisation other than ConnectGroups or a government department?

No – MAWA does not receive any assistance of resources as detailed above.

How many volunteers does your support group engage and in what capacity?

Local Volunteers in WA

Currently recruiting volunteers from membership base but will be looking for additional support from the community

1 x State Regional Co-ordinator plus contact person

1 x Contact person Perth and recruiting regional contacts, especially in country locations where isolation and lack of access to health services is a major issue.

2 x Management committee representatives on MA national committee.

3 x regular assistant local volunteers

Access to 10 Meniere's Information and Resource Centre volunteers based in Victoria for administration tasks (mailouts etc)

How many people attend your support group on a regular basis? (If you don't have exact numbers please estimate)

Currently (July 2009) and with little to no publicity as yet, MAWA Membership numbers have jumped to 57. MAWA only held its inaugural planning meeting on 30th May 2009. Our membership previously belonged to the Victorian and NSW Meniere's Support Groups. In May 2009 MAWA membership was 45.

*Based on the Australian Bureau of Statistics 2005 Population Health Survey estimate that Meniere's disease affects one in 600 Australians then, with recording a population of 2,204,000 people in WA in December 2008 and an increase of 66,000pa, indications are that at an estimated **3,700 Western Australians are currently suffering with Meniere's** or other vestibular disorders and the symptoms of vertigo hearing loss and tinnitus.*

*It is anticipated that membership and requests for information and services will increase dramatically as the WA community and health services become aware of MAWA. We expect membership numbers will increase representing a reasonable percentage of the estimated **3,7000** West Australian's with Meniere's and other vestibular disorders.*

Meeting Attendance at the Inaugural Meeting of the Meniere's Australia WA was 16 of the 45 members, (35%) plus a further 12 apologies from members who couldn't attend due either to (4) distance (9%) or (3) prior engagements (7%) or (5) Meniere's related incapacity on the actual day (11%).

62% of members either attended or expressed interest in attending the meeting.

If you could access low or no cost venues at public hospitals to run your group would you do so?

Yes including Regional and Country hospital and/or community health care facilities to:
a) Provide regular local and affordable venues for country and regional members or local support groups to hold meetings

- b) *Provide affordable venues for Support Groups to arrange some country or regional based seminars and workshops for the benefit and convenience of country or outer region members.*

What other resources would benefit your support group?

1. *Provision of accessible premises (eg for hearing impaired) in public venues. (Requirement of the Disability Discrimination Act)
If public venues not accessible then availability of equipment such as hearing loops or portable FM system for use at meetings, workshops, seminars etc as many sufferers of Meniere's Disease have hearing loss.*
2. *Funding or provision of a laptop with power point presentation facilities for use at meetings, workshops, seminars etc*
3. *A resource pool of the above mentioned resources at Administrative Regional Healthcare Hospitals and Centres Country and outer suburban) for use by regional groups of all Connect Group's registered support groups at minimal cost when holding regular meetings or participating in local workshops and seminars.*
4. *Provision of compulsory Accredited Training and a recognised accredited certificate for volunteer members of support groups who are willing to undertake training to either act as guest speakers to increase public awareness or participate in Hospital and Community Health Care staff, and Professional Health Care staff & personnel training and workshops providing the patient's perspective in relation to the condition that volunteer lives with.*

*****NB Such training and certification is essential to up grade and ensure the integrity of Support Groups in the eyes of health care workers and professionals and to secure acknowledgement of support groups as a bona fide and essential member of the community health care team.***

6. *That the Health Department of WA acknowledge, support and enhance the role and benefits of health related support groups that are registered with Connect Groups by:*
 - i. *Including each of these support groups in the alphabetic listing facility on the WA Health Department Web site so that each group is listed alphabetically under the Disease or Condition it supports and also, under up to four major symptoms indicative of that condition.*
 - ii. *Health workers referring searchers to Connect Group's website for current contact details of listed support groups. e.g. (Under "M" on the Health Department website), Meniere's Disease - Meniere's Australia – WA Branch contact.*
 - iii. *Legislation for the invitation and opportunity for inclusion of relevant support group representatives at all community and hospital health care staff training courses. Seminars and workshops as well as the representation of relevant support groups in all healthcare and professional health care education and training curriculum.*

Suggested sample Details: www.connectgroups.org.au (Meniere's Australia WA Branch, would also be listed under (T) Tinnitus; (E) Ears ringing or noise in, (V) Vertigo Vestibular; (D) Dizziness and also possibly (H)Hearing Loss.)

What 'gap' in service provision does your support group fill?

Support Groups, most of which receive recognition and expert information and guidance from Specialists and Researchers associated with their disease or condition, play an increasingly important, supportive, community based role by:

- *Providing information and support to people with long term illness or conditions*
- *Arranging forums for Health care professionals and other relevant healthcare agencies to provide education, information and advice to groups of members and families, on to how to live more comfortably and positively with their condition and to provide updated information about research or possible treatments.*
- *Increasing public and health services awareness of the condition and the needs of its members to retain; maintain or improve their quality of life*
- *Encouraging and assisting medical research and professional knowledge by organising workshops or functions to raise funds and increase public awareness of research programs*
- *Provide volunteer helpers and appropriate volunteer populations for research participation.*

The above statement and list relating to the benefits of support groups in general, has been demonstrated and substantiated specifically by the history, goals and current achievements of the nation wide support group Meniere's Australia Inc.

- *The growth of both the Victorian and NSW Meniere's Support Groups due to the demonstrated needs and demands of the increasing numbers of people experiencing Meniere's and Vestibular disorders throughout Australia resulted in the development of a National organisation in recognition that all Australians will receive and have equal access to support services, information and personal support irrespective of geographic location.*
- *Due to demand and obvious need, it was realised that to efficiently and economically meet the Australian wide demands for resources and services the Victorian and NSW organisations established a National administrative body, (Meniere's Australia Inc) to support, guide and share information and resources with all.*
- *Using volunteer State and Regional Coordinators and also (where demand is identified), in larger rural cities or regions ensures the development of services according to population and demand throughout Australia.*
- *Comparison of public and health care awareness and improved services for people with Meniere's in Victoria and NSW with the current situation in Western Australia substantiates the need for funding and support to ensure people in WA have equal access to the benefits provided by a local support group in relation to help in managing a chronic, potentially debilitating condition.*
- *The recognition, acknowledgement, and respect previously afforded to the Eastern State organisations will now be available via Meniere's Australia and its State and regional Branches.*

Submitted by Tricia

27.7.09

Name of Organisation: Meniere's Australia Inc.

Contact Person: Tricia

Position/Title: WA Coordinator