



**Meniere's
Australia**

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

ABN: 30 128 195 371

SENATE COMMUNITY AFFAIRS COMMITTEE

PUBLIC HEARING PROGRAM

Meniere's Australia Senate Hearing Submission

TUESDAY, 8 DECEMBER 2009

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INTRODUCTION

We welcome the Senate interest in Hearing Health in Australia.

We acknowledge the support and assistance to hearing impaired Australians given by the Commonwealth through the Government Hearing Services Program.

However we believe the Scheme does not provide a Holistic view of Hearing Health in Australia nor appropriately meet the hearing health needs of Australians.

WHAT IS NEEDED BY HEARING IMPAIRED AUSTRALIANS

“there is more to hearing loss than fitting hearing aids”

Essentially the Commonwealth Scheme sees Hearing Impaired Australians as a “set of ears”, rather than recognising that hearing impairment impacts on a person’s whole of life experience and functioning as an individual, including their health, enjoyment of life, family and community participation.

Service Providers under the scheme are restricted or encouraged to only focus on the initial fitting and use of hearing aids & technology. This focus on technical aspects of hearing aid provision is a very narrow view of achieving effective personal communication and managing the impact of hearing loss on an individual. Furthermore hearing loss can be compounded by other conditions.

For example, Australians living with Meniere’s disease have to understand, manage and cope with the everyday consequences of the following:-

- hearing impairment – low frequency fluctuating; Recruitment, Diplacusis (pitch change)
- plus tinnitus
- plus spinning and vertigo
- plus maintain a low salt diet

We are concerned that it appears very few submissions to the Senate Inquiry have understood these factors or even considered Meniere’s disease.

Furthermore there is no current provision under the Government Hearing Services Program to address and solve the lifestyle consequences of Meniere’s disease.

THE IMPORTANCE AND ROLE OF CONSUMER & ADVOCACY GROUPS

We believe Consumer & Advocacy Groups (CAG’s) focused on conditions and causes of hearing loss have an important partnership role to play with the Commonwealth. This is because of their commitment, focus and energy on supporting and informing members and the public about the particulars of the disease they are concerned with.

Furthermore Advocacy and Peer Support is best done by Consumer Groups, rather than Governments.

Consumer Groups also represent an important community and economic asset for the Government in its role of promoting good health, wellness and living with disability and chronic disease.

Unfortunately there seems to be no Government policy or model to consistently and appropriately support Consumer & Advocacy Groups working with hearing impaired Australians.

A MODEL OF ASSISTANCE TO HEARING IMPAIRED AUSTRALIANS

Once correctly diagnosed with Meniere's disease, individuals require information about treatment options, information on the disease and its consequences, practical advice, individual counselling and encouragement to make the necessary lifestyle changes to maintain employment and cope with the everyday consequences of Meniere's.

There is also a need to develop targeted education and awareness programs for health professionals to better diagnose, advise and appropriately refer patients with Meniere's.

We would encourage the Commonwealth to think in policy terms how this type of essential consumer and advocacy information could be cost effectively provided to hearing impaired Australians.

At a micro level MA has grappled with this challenge.

The rationale for establishing MA was that a new approach was needed to the traditional model of local and State Consumer Advocacy Groups being established to provide consumer and advocacy support for a particular disease or condition.

Such groups do good work, but often duplicate each other's work in providing resource material, newsletters, holding meetings etc. They lack scale, and consume precious financial and human resources in Membership Administration, Fundraising & Corporate Administration etc. Often burn out of key leadership leads to decline of the group in a few years.

The formation of MA, taking the place of State Support Groups in NSW, Victoria and Tasmania, enables a national focus on delivering services to be undertaken. The model is one where there is a separation of roles and harnessing of people's interest and expertise. The National Body supports the encouragement & establishment of local support groups, who can use the National Resource materials and Service templates to provide local support.

The National Meniere's Information and Resource Centre commissions and produces the best resources & information material available, publishes a National Newsletter with local inserts and achieves economies of scale in handling membership administration, fundraising and raising public awareness. Importantly this duplex arrangement of a National Community Advocacy Group Program with local support at a local level allows volunteers to choose where to become involved.

Some people like dealing with strategy, administration, research, etc and others like to be involved locally with member meetings, local networks and one on one support. The MA Model enables this local support to be planned, resourced and supported with accurate information and mentoring.

We believe the Commonwealth could embrace a partnership whereby:-

1. The diagnosis and treatment of hearing impairment is handled by the health professionals.
2. Hearing aids provided with Commonwealth subsidy under OHS Scheme.

Consumer information, individual or group counselling, mentoring, support and encouragement to make the necessary lifestyle changes to cope with hearing impairment is provided and distributed by established and credible National Consumer & Advocacy Groups such as MA.

3. There are clearly defined clinical pathways for the above to occur.

Such a model would draw on the relevant strengths of the different groups and go a long way to providing a holistic model of care for Hearing Impaired Australians.

The extent, causes and costs of hearing impairment in Australia;

Our best estimates are that there are 40,000 Australians with Meniere's disease, with annual new cases of about 4000.

Research is needed on:-

- Causes of Meniere's disease.
- Incidence & prevalence.
- Accuracy of diagnosis.
- Treatment options.
- Impact on employment and lifestyle options.
- Personal management options.

There is potential for data collection at the entry point with a national register of patients presenting with the symptoms of hearing loss, vertigo and tinnitus at ENT and neurologist clinics and hospitals across Australia.

MA is actively pursuing strategic options to facilitate this research, but funding is low level and dependent on fundraising success.

Commonwealth funding of research into Consumer and Advocacy information required by hearing impaired Australians as well as hearing technology and the diagnosis of hearing loss etc would be welcomed by MA.

The implications of hearing impairment [Meniere's disease] for individuals and the community;

Hearing loss with Meniere's can fluctuate according to stage and attacks of Meniere's.

Dietary and lifestyle changes are important in managing the personal impact of Meniere's disease.

There is increasing evidence further loss of hearing can be prevented with receipt of the right information.

There needs to a greater understanding by health professionals, government and individuals of the mental health issues (e.g. stress, anxiety, depression) that are compounded when significant hearing loss and the vestibular component of Meniere's disease are combined.

- Acquiring Meniere's disease is not life threatening, but life changing.
- The impact of Meniere's disease is never inconsequential, often very distressing and ongoing.
- The latest Meniere's Research Survey (attached) of our members documents the personal impacts.
- Meniere's cannot be cured or reversed and fluctuates over time

The exciting news is that increasingly it is being recognised that further damage to hearing can be prevented if people learn the symptoms, take action and make appropriate dietary changes EG. a low salt diet.

Consumer and advocacy groups such as MA are ideally placed to provide this essential consumer information and this should be provided in a policy context and not haphazardly (see above).

The adequacy of access to hearing services, including assessment and support services, and hearing technologies;

Hearing Aids are a necessary, but not sufficient, solution for hearing loss.

We believe fitting of hearing aids without counselling on living with hearing loss and dealing with associated conditions is doing only half the job.

Adequate information on dealing with and successfully living with Meniere's is often not given to patients when they are diagnosed.

The Commonwealth Scheme does not provide for this information or assistance to be given.

People turn in desperation (when they can find us) to consumer groups such as MA for information, resources and support.

Consumer Advocacy Groups such as MA are not funded on a regular basis to produce and provide information or ongoing support.

Provision of required consumer information is haphazard and dependent on volunteer effort and self support, which should be augmented by the Commonwealth.

The adequacy of current hearing health and research programs, including education and awareness programs; and

- Unresolved issue of what causes Meniere's disease and little Commonwealth funding into finding cause.
- Undiagnosed or misdiagnosed Meniere's disease often reported by consumers.
- Consistent reporting by consumers that inadequate knowledge and information is given by health professionals to patients about Meniere's disease.
- Hunger for information about Meniere's disease across Australia, particularly in States outside Victoria and NSW where there were active self help groups. Establishment of MA now allows a national focus, but this outreach is not supported by sustained Commonwealth funding.

There needs to be a systemic and policy rethink about how Governments encourages, support and ensure information is received and passed on to consumers by Consumer & Advocacy Groups (see above).

Consumer & Advocacy Groups need to better organise and deliver their services more effectively and at a lower economic and volunteer cost.

We advocate:-

1. The Commonwealth makes a commitment to having the best available consumer and advocacy support given to Australians living with hearing loss.
2. The Commonwealth makes a commitment to properly supporting Consumer and Advocacy Groups to provide information and support to Australians living with hearing impairment.
3. The Commonwealth encourages and contract with established and credible CAG's to prepare accurate, appropriate and up to date information on hearing loss conditions. This could be labelled "Accredited Consumer Information".
4. The Commonwealth supports the distribution of Accredited Consumer Information through local Consumer & Advocacy Groups.

5. The Commonwealth requires Consumer & Advocacy Groups to demonstrate their effectiveness in providing and distributing consumer information to hearing impaired Australians.
6. Clinical pathways be developed to bring together Health Service Providers and Consumer & Advocacy Groups to provide a holistic approach to diagnosis, treatment and consumer & peer support.
7. Medicare and other Commonwealth funding arrangements be made to encourage this holistic approach to the hearing health of Australians.

Specific issues affecting Indigenous communities

We are embarrassed we have no idea of the degree and impact of Meniere's disease in indigenous communities.

When and if we receive financial resources and can identify appropriate personnel we will attempt to rectify this gap in service.

MENIERE'S AUSTRALIA

8th December 2009

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