

NATIONAL DEAFNESS SECTOR SUMMIT 2010.

**“Consumer Advocacy and Support Groups**

**DELIVERING LOCAL SUPPORT IN A NATIONAL FRAMEWORK**

**to future generations of hearing impaired Australians”.**

A Paper presented to 6th National Deafness Sector Summit, Sydney 23rd April 2010.

*The author advocates adoption of a Holistic Model of Assistance to future generations of hearing impaired Australians through:-*

*I. Consumer Advocacy and Support Groups adopting a National Structure and Focus in delivering services locally.*

*and*

*II. establishing clinical pathways to include a component of Consumer Advocacy and Support Group activity*

The experience and benefits of establishing a Meniere's Australia out of State Support bodies is given as a case study.

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23rd April 2010.

## INTRODUCTION

I would like to propose two Structural Reforms, that could assist members of the Deafness Forum in their ongoing quest to provide better services and support to the next generation of Australians who are Deaf, have a hearing impairment or chronic disorder of the ear.

Members of the Deafness Forum have a vital role to play in delivering good information, peer support and improving services for hearing impaired Australians.

We owe much to previous generations, who fought and worked hard to establish and develop our various Consumer Associations and Service Provider bodies.

Now it is the turn of our generation, which today has the responsibility to ensure that our organizations prosper, and are even better positioned to meet the future hearing health needs of Australians.

When I look to the future, I think that Consumer Associations and Service Provider Organizations should be focusing on delivering their support to individuals at a local level *in the context of a well developed National framework and policy focus.*

Indeed this approach is the flavour of the week.

On Tuesday we saw the Commonwealth and States reach agreement on Health Reform. The central mantra or rationale of health reform, in the words of the PM, is “funded nationally, run locally”<sup>1</sup>.

At Meniere’s Australia (MA) we have already gone down this track.

Drawing on the experience of MA, I propose two Structure Reforms we should consider.

- III. Community Consumer Associations and Service Providers, that are State, Regional or locally based, should adopt a *National Structure and focus, at the same time strengthening their capacity for supporting individuals at the local level.*
- IV. Members of the Deafness Forum should lobby for the services of Consumer Advocacy and Support Organizations to be an *integral part of clinical pathways* for hearing impaired Australians.

### **1st Reform: Adopting a National Structure and Focus**

The Deafness Forum is a good example of this strategy already in place.

There has been great benefits to past generations of hearing impaired and deaf Australians in having this National Forum and it’s national focus.

Today I want to show how a small Consumer and Advocacy Group (CASG), focussed on a particular hearing disability, has transformed itself from separate State Support Groups into one National Body, and the resulting benefits that have flowed.

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<sup>1</sup> Rudd, 7.30 Report 200410.

As I proceed you may like to think whether there are parallels with your own organization, and whether there are lessons to be learned.

## **‘Delivering local support in a national framework’**

### **Case History : MENIERE’S AUSTRALIA.**

Established in 2008, Meniere’s Australia is the newly created National Support Organization for Australians living with Meniere’s disease.

*Our Vision is that all Australians with Meniere’s disease and other vestibular conditions will receive and have equal access to support services, information and personal support, irrespective of geographical location*

#### **What is Meniere’s disease?**

Meniere’s disease is an incurable disease of the inner ear.

Australians living with Meniere’s disease have to understand, manage and cope with the everyday consequences of

- hearing impairment – low frequency fluctuating; Recruitment, Diplacusis (pitch change)
- tinnitus

In addition to these familiar hearing conditions, individuals with MD have to cope with:-

- spinning and vertigo
- lifestyle changes

EG maintaining a low salt diet and reducing stress etc.

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

#### **PEOPLE’S NEEDS.**

Once correctly diagnosed with Meniere’s disease, individuals require information about :-

- treatment options
- information on the disease and its consequences
- practical advice
- individual counselling
- encouragement to make the necessary lifestyle changes to maintain employment and cope with the everyday consequences of Meniere’s.
- etc etc

Unfortunately this practical help is usually not given when people attend their GP and their Specialist ENT and they most need it.

Research shows that the most valuable assistance people receive about living with Meniere's comes from MA .

In other words, the best practical help, peer support and information often comes from a Consumer Advocacy and Support Group, rather than from the medical profession!

Despite this, there is currently no formal clinical pathway for people to be referred to MA.

Whether they receive help is a hit and miss affair. Surely this is not good enough for future generations?

- People are desperate for help when they finally stumble over us.
- The awareness of Meniere's in the community needs to be raised.
- There is also an urgent need to develop targeted education and awareness programs for health professionals to better diagnose, advise and appropriately refer patients with Meniere's.

While there are exceptions to this scenario, with excellent medicos, audiologists etc taking time to refer and explain, this is too often not always the case.

I am sure the breakdown in referral for information and ongoing peer support is a familiar story, known to many Consumers and to Consumer Associations who are dealing with the various aspects of Deafness, hearing loss and chronic disorders of the ear.

We need to ask what can be done to improve the flow of information and support for future generations of Australians with a hearing loss?

I believe part of the answer in achieving change is State, Regional and local Consumer Associations developing a National structure and policy framework.

## **ESTABLISHING A NATIONAL MENIERES GROUP**

Historically, small independent Meniere's Self Help Groups were established on a State basis. They have attempted since 1983 to grapple with meeting the needs of individuals with Meniere's disease, with varying levels of success.

- The State Support Groups often duplicated each other's work in providing resource material, newsletters, holding meetings etc.
- They lacked scale, and consumed precious financial and human resources in producing newsletters, arranging meetings, Membership Administration, Fundraising and Corporate Governance.
- Often key people burned out after a few years, leading to a decline of the group.

The formation of MA in 2008, taking the place of State Support Groups in NSW, Victoria and Tasmania, has enabled a national focus on delivering services to be undertaken.

In July 2009 members of the NSW group voted to wind up and transfer their membership to MA.

The Victorian group also voted to transfer their membership to the National body and will in the future focus on providing regional peer support to members using national service templates.

Importantly a National Organization has now been established. It is not a Federation or Council of State Bodies. This avoids many problems of Federated Bodies, such as competing State interests, squabbles over money allocation and differing priorities etc.

The National Body can incorporate State Support Groups, but their focus is purely on providing local and regional support programs under the umbrella and guidance of MA.

- Australians living with MD are now members of one National Body
- MA retains 80% of annual membership fees and allocates 20% of fee income towards supporting local and regional activities.
- The model is one where there is a separation of roles and harnessing of people's interest and expertise. We obtain the benefits of economies of scale and division of labour.
- The National Meniere's Information and Resource Centre commissions and produces the best resources and information material available.
- National Newsletter is published with local inserts and a national website operated.
- There are significant cost savings from national handling of membership administration, fundraising and raising public awareness.
- With the cost savings, more qualified staff can be employed at the National Resource and Information Centre to provide better membership service.
- Speaking with one voice improves our reach into Government, and to national sponsors and funding bodies etc.
- Better use of Volunteers is achieved. The duplex arrangement of a National Body with a local program allows volunteers to choose where to become involved.
  - Some people like dealing with strategy, administration, research, etc and therefore can be involved at a national level.
  - Other Volunteers prefer more hands on activity and want to be involved locally with member meetings, local networks and one on one support.
  - A National body offers more opportunities for people to be involved at different levels.

The National Body supports the encouragement and establishment of local support groups,

- Service templates are developed and personal mentoring provided to volunteers to start up peer support programs and self help regional groups.
- The national structure allows local groups to be established, grow and decline as circumstances change, without putting long term organization development at risk.

The membership structure of MA allows for consumers, individual health professionals,

professional organizations and interested persons to join. MA thus captures the input and skills of all Australians affected by Meniere's disease, no matter where they live. Membership categories are similar to Deafness Forum.

Having a national focus and harnessing efforts of all Australians living with Meniere's disease increases the probability of long term survival of the Organization. It is better to recruit new Committee Members with required skills from 22 million Australians rather than only recruiting Committee Members from the smaller populations of States.

### **OUTCOMES FROM ESTABLISHING THE NATIONAL ORGANIZATION.**

While only operating for less than 18 mths, the benefits of having a National focus is already apparent.

- Greater access to funding has been achieved.
- Better linkages have been made with health professionals in the different States.
- Strategic partnerships with other community groups is underway.
- Members living outside Victoria have enjoyed greater access to services.
- A National series of Seminars titled "*Your Voice Counts*" on how to live successfully with Meniere's is being rolled out across Australia.
- More people with a greater range of interests and skills are becoming involved.
- Our capacity to deliver lower cost services is being enhanced.

### **SHOULD OTHER Consumer and Service Providers ADOPT A NATIONAL FRAMEWORK and FOCUS?**

Clearly some groups and service providers already have.

EG Vision Australia has amalgamated 5 or more separate blindness State organizations in recent years.

Likewise Deaf Children Australia has moved towards a national organization across all States.

Other groups have established National Councils etc.

Nevertheless other Consumer Associations and Service Providers remain State or Regional based.

If, and how they move to one organization with a National Focus and Structure will vary according to their creativity, but I believe it is an important strategic direction to take for the following reasons.

- V. Our past generations lived at a time when the Sovereign States were all important, and it made sense for organizations to be State based.

- VI. Since the establishment of the Commonwealth Government in 1901 there has been a steady transfer of power, finances and policies to Canberra. Hence the parallel trend towards cooperation of State based groups at a national level in recent years.
- VII. Technological developments eg Internet, telephone conferencing, telcap etc are increasingly providing the tools to allow Consumer Associations and Service Providers to effectively deliver services on a national basis with a local support.
- VIII. As Consumer Associations and Service Providers are impacted by hospitals, primary care and aged care policy, Deafness Forum Members will need to respond to new national Health Agreement.
- IX. The action is shifting to Canberra. I think the next generation of hearing impaired Australians will be best served by Consumer Associations and Service Providers that have a National Structure and focus, whilst improving their ability to deliver services locally.

## **2nd Reform: Clinical pathways to include a component of Consumer Advocacy and Support Group activity.**

How adequate is the present Commonwealth system of providing assistance to hearing impaired Australians?

- *Hearing Aids are a necessary, but not sufficient, solution for hearing loss.*
- MA believes 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 (and other hearing conditions) is often not given to patients when they are diagnosed.
- People turn in desperation (when they can find them) to consumer groups such as MA for information, resources and support.
- Provision of required consumer information is haphazard and dependent on volunteer effort and self support.
- Consumer Advocacy Groups are not funded on a regular basis to produce and provide information or ongoing support.

**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 and Advocacy Groups.**

While we appreciate funding support from OHS from time to time to distribute Information pamphlets etc, there needs to be a better strategic approach.

I suggest Deafness Forum members could consider lobbying the Australian Government and advocating the following initiatives to ensure Australians acquiring a hearing impairment in the future are provided *as a matter of course* with relevant and up to date information on how to live with the hearing loss and are put in touch with peer support opportunities.

1. The Commonwealth makes a **policy** commitment to properly supporting Consumer and Advocacy Groups to provide information and support to Australians living with hearing impairment.
2. The Commonwealth makes a **funded** commitment to having the best available consumer and advocacy support given to Australians living with hearing loss.
3. The Commonwealth enters into **contracts** with established and credible Consumer Advocacy and Support Groups 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 the health system and local Consumer and Advocacy Groups.

***Clinical pathways need be developed, to bring together Health Service Providers and Consumer and Advocacy Groups so that there is a co-ordinated approach to diagnosis, treatment and consumer and peer support of future generations of hearing impaired Australians.***

Medicare and other Commonwealth funding arrangements and incentives could be made to encourage medical practitioners and others to follow this co-ordinated approach to the hearing health of Australians.

## **A HOLISTIC MODEL OF ASSISTANCE TO FUTURE GENERATIONS OF HEARING IMPAIRED AUSTRALIANS**

If we are to take up the baton of change from previous generations and advocacy for the welfare of future generations of hearing impaired Australians, we need to campaign for a holistic model of assistance to hearing impaired individuals.

I believe the Commonwealth should develop a model of assistance for hearing impaired Australians whereby:-

- A. The diagnosis and treatment of hearing impairment is handled by the health professionals.
- B. Hearing aids are provided with Commonwealth subsidy under OHS Scheme.
- C. 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 and Advocacy Groups with expertise in hearing impairment.
- D. There are clearly defined clinical pathways within Medicare and the OHS for the above to occur and to be funded.

Such a model would draw on the relevant strengths of the Medical Profession, Hearing Professionals EG Audiologists, Service Providers and Consumer Advocacy and Support Groups.

A policy partnership and co-ordinated approach along these lines would go a long way to providing a holistic model of care for future generations of hearing impaired Australians.

I look forward to Members of the Deafness Forum taking a leadership role in developing this model and seeing that change occurs.

We owe it to the next generation.