

# Meniere's Support Group of Victoria Membership Survey 2006

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August 2006

## Contents

1.	MENIERE'S DISEASE IN CONTEXT	3
2.	BACKGROUND	4
3.	AIMS	4
4.	METHODOLOGY	4
	4.1 Questionnaire development	4
	4.2 Quantitative analysis	4
	4.3 Qualitative analysis	5
	4.4 Survey limitations	5
5.	RESULTS OF SURVEY	5
	5.1 Response rate	5
	5.2 Membership	5
	5.3 Gender	7
	5.4 Age	7
	5.5 Relationship to MSGV	7
	5.6 Respondents history of Meniere's disease	8
	5.7 Managing Meniere's disease	11
	5.8 Membership of MSGV	15
	5.9 The impact of Meniere's disease on quality of life	19
	5.10 Costs	21
6.	QUALITATIVE RESULTS	24
	6.1 Helpfulness of people and organisations	24
	6.2 Kinds of help people value	24
	6.3 Website	25
	6.4 Additional service people would like MSGV to offer	25
	6.5 Impact of Meniere's disease on people's quality of life	27
7.	CONCLUSIONS	30
8.	RECOMMENDATIONS	31

## 1. **MENIERE'S DISEASE IN CONTEXT**

Seventy-five per cent of all Australians are estimated to have a chronic illness (Australia's Health 2006: 39). Most of these illnesses are not life-threatening and have little impact on lifestyle, but others have a major impact on the health of Australia.

Australia's Health 2006 (AIHW 2006:148) reports that neurological and sense disorders account for some 19% of Years Lost to Disability (YLD). This predominantly relates to dementia and hearing loss. Additionally hearing loss is listed as one of the twenty leading contributors (out of a list of 193 diseases) to the burden of disease in Australia (AIHW 2006: 149). Deafness is one of the most commonly reported long term conditions, being ranked in fifth place by men and in the tenth place by women. Hearing loss is seen by the population as a whole to be one of the most important factors in limiting activities.

Loss of hearing and related problems are thus important areas of concern for the Australian community. These figures however, do not reveal the complexities of serious long-term health issues associated with hearing loss.

When people consider hearing loss they tend to consider complete or partial deafness to be the most significant aspects. However there are a range of conditions associated with the ears resulting in complex disabilities, of which hearing loss is only one.

Meniere's disease is one such condition affecting 3.3 in 2000 or **1 in 606** Australians (National Health Survey 2004-5) While it contributes to the incidence of hearing loss in Australia, its negative impact on the individual's life is more varied. This can be appreciated from a description of the disease trajectory.

The disease may progress through three major stages (Gibson 2006). In the first stage vertigo, lasting hours with associated nausea; usually vomiting; sweating and in some cases diarrhoea dominates, and people may be unaware of the hearing loss and tinnitus. Any head movement may aggravate the condition. After the attack symptoms subside and the ear returns to normal. There may be long periods of remission.

In stage 2 attacks of vertigo tend to occur in clusters and can last several months. Vertigo is still severe and hearing loss and tinnitus become permanent.

Stage 3 hearing loss becomes severe making recognition of speech difficult, tinnitus remains and the vertigo attacks tend to ease or stop. 50% of vestibular function in the affected ear has been destroyed leaving overall poor balance.

Meniere's disease impacts on quality of life. People with Meniere's disease are likely to become isolated, partly because of hearing problems but also because of anxiety about having an attack in public which may involve severe dizziness, vomiting and diarrhoea. Gibson (2006) makes the point that the impact of Meniere's disease is not always fully appreciated: "Many people including doctors underestimate the suffering caused by Meniere's disease". Similarly, it is likely that the community underestimates the difficulty involved in finding effective treatment and relief. There is a wide range of therapies available including stress management, medication and surgery. However, the efficacy of each depends on individual cases.

## **2. BACKGROUND**

Meniere's Support Group of Victoria Inc conducted a survey of its members in 1998 to find out how members viewed the support they received from MSGV. The results were used to determine future directions for MSGV. In this 1998 survey 208 of the 420 then members responded. Overall the survey demonstrated that MSGV provided information and support that was not available elsewhere. This service allowed newly diagnosed people to navigate a bewildering health system where correct diagnosis took time and persistence; it provided support and information as people tried various treatments and as they lived with the impact of the disease on their lives.

## **3. AIMS**

The aims of the 2006 survey were to:

- i) Quantify the impact of Meniere's disease on individuals and identify coping mechanisms employed to reduce its impact on lifestyle and quality of life.
- ii) Identify the sources of referrals and the level of assistance offered by health professionals to highlight areas MSGV need to target.
- iii) Determine how members view current levels of support offered by MSGV.
- iv) Document the importance and relevance of the various components of the MSGV Service Model.
- v) Identify future directions for service improvement and evaluation.
- vi) Provide information on the personal and financial cost to individuals attributed directly to living with the disease.

## **4. METHODOLOGY**

### **4.1 Questionnaire development**

The questionnaire design was based on a survey of the Meniere's Support Group of Victoria membership conducted in 1998. The MSGV executive undertook a review of the 1998 questionnaire updating several sections where necessary and adding several new qualitative questions. These questions sought to capture in the respondents' own words, the personal and lifestyle changes brought about by Meniere's symptoms. In addition to measuring the emotional and lifestyle costs, a section on the financial costs incurred was also added.

The 2006 questionnaire was piloted by 12 volunteer members before being finalised in January 2006. The MSGV mailed the survey to 902 members. Returned questionnaires were then forwarded to the Chronic Illness Alliance for data processing and analysis.

### **4.2 Quantitative data analysis**

Data were checked and cleaned on each survey prior to entry into the statistical package SPSS (Statistical Package for the Social Sciences) version 10.1. Where multiple responses were selected or there was incorrect completion of a question the data were coded as missing (99).

Data checks were undertaken to ensure accuracy of data entry. A subset of 10% of the entered data was checked against the surveys and the accuracy rate was found to be approximately 99%. In addition SPSS frequency checks were run on each variable to highlight any additional data entry errors.

Descriptive analysis of data was undertaken and included examination of frequencies, means, and standard deviations. Cross tabulations were used to examine the data by stage of illness, Victorian regions and Australian States.

### 4.3 Qualitative data analysis

Thematic data analysis was conducted for the qualitative questions contained within the survey. Themes used in the data analysis were developed by examining in detail 20% of the total surveys completed (N=120). Once the themes and accompanying codes were developed each survey was coded against the appropriate theme. Data were then entered into the statistical package SPSS and analysed.

### 4.4 Survey limitations

This survey is an 'opportunistic' survey, that is, it was completed by members of the Meniere's Support Group of Victoria who were most interested in completing it. It may not represent the views of people who have Meniere's disease and who do not access the services of MSGV. Limitations are imposed on implementing research, whether it is a randomised controlled trial or a survey such as this by ethical considerations of respecting people's privacy with regard to their health status and their membership of groups such as MSGV. Thus even if the researchers had access to medical histories from hearing services and medical clinics, it would not be ethical to use the data in them or to contact the people.

## 5. RESULTS OF THE SURVEY

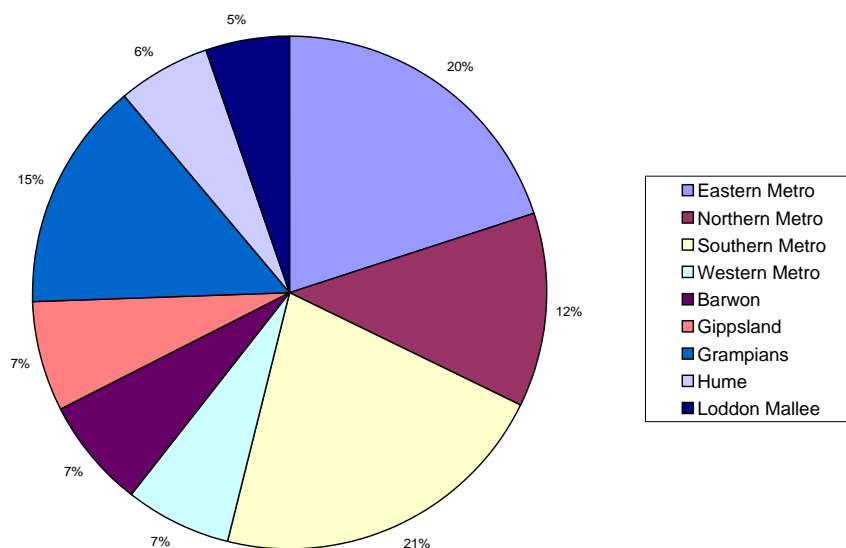
### 5.1 Response rate

There were 544 responses to the MSGV Membership Survey of 2006. These responses represent 60% of the membership of MSGV of approximately 870, in Australia and overseas. This response rate is excellent, particularly for mailed surveys, and suggests there is strong interest in and commitment to the Group's ongoing development. In 1998 there were 420 surveys mailed out on behalf of MSGV and the response was 49%, again a very good rate but much improved on in 2006.

### 5.2 Membership by region

Of the 544 responses there were 461 from all regions of Victoria, with the greatest response from the Southern (21.7%) and Eastern (20%) metropolitan regions. The Grampians region (14.5%) returned the greatest response from regional Victoria.

Figure 1 Membership by region



**Ménière's Support Group of Victoria Membership Survey 2006**

Table 1 Victorian responses

	<b>%</b>	<b>N</b>
Eastern Metro	20.0	92
Northern Metro	12.1	56
Southern Metro	21.7	100
Western Metro	6.7	31
Barwon	6.9	32
Gippsland	6.9	32
Grampians	14.5	67
Hume	5.9	27
Loddon Mallee	5.2	24
<b>Total</b>	<b>100%</b>	<b>461</b>

The remaining 83 (15.3%) responses were from members in other states and from overseas.

Figure 2. Membership by states

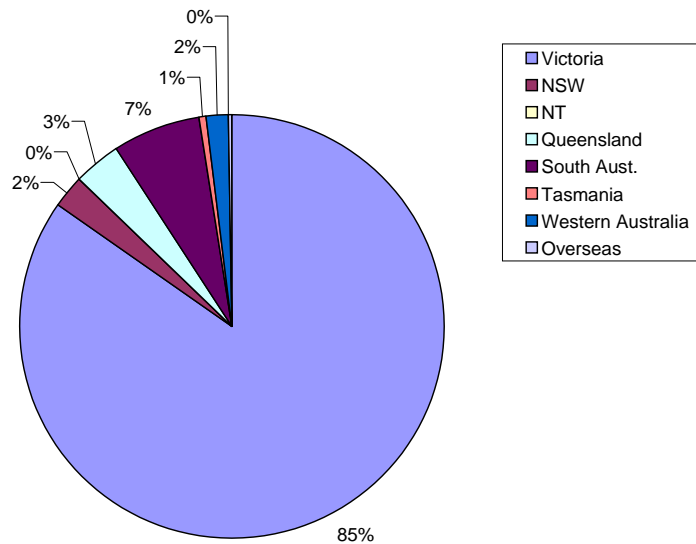


Table 2 Total responses

	<b>%</b>	<b>N</b>
Victoria	84.7	461
South Aust.	6.6	36
NSW	2.4	13
NT	0.2	1
Queensland	3.5	19
Tasmania	0.6	3
Western Australia	1.7	9
Overseas	0.4	2
<b>Total</b>	<b>100%</b>	<b>544</b>

### 5.3 Gender

Of the 520 respondents to this question, 73% were female and 27% were men. This is less than the 1998 survey where 32% of the respondents were males. Both surveys reflect the difficulty of involving men.

	<b>N</b>	<b>%</b>
Male	142	27.3
Female	378	72.7
<b>Total</b>	<b>520</b>	<b>100%</b>
Missing	25	

Table 3 Gender of respondents

### 5.4 Age

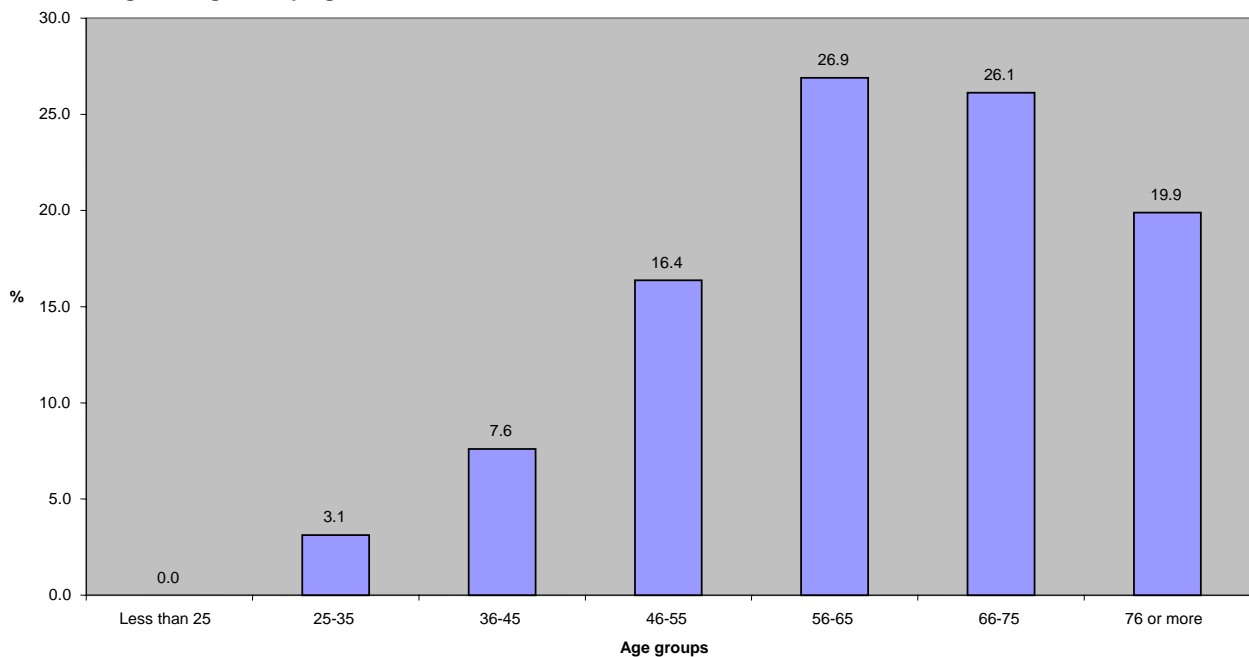
Meniere's disease may occur at any age but usually begins between the ages of 30 and 50.

54% of respondents are aged within the working age period when good health is important-

Table 4 Age range of members

	<b>%</b>	<b>N</b>
Less than 25	0.0	0
25-35	3.1	16
36-45	7.6	39
46-55	16.4	84
56-65	26.9	138
66-75	26.1	134
76 or more	19.9	102
<b>Total</b>	<b>100%</b>	<b>513</b>

Figure 3 Age Grouping of Members



### 5.5 Relationship to MSGV

Ninety-one per cent (n 494) of respondents were people who had Meniere's disease. The remaining 9% (n50) of respondents were family members or friends; health professionals; from allied organisations or members who had symptoms or conditions similar to Meniere's. They were asked to complete part 'c' only of the survey, which sought their views on MSGV's services.

## 5.6 Respondents history of Meniere's disease

[The results in this section correspond to Part A of the survey, 'You and Meniere's']

### 5.6.1 Diagnosis

Many people (n187 or 40.6%) were diagnosed at around the time they started having symptoms and sought medical help. These were the fortunate ones, as many others had to wait much longer, sometimes decades, to be diagnosed correctly. One hundred and thirteen people (24.6%) were diagnosed 12 months later, over a 100 were diagnosed two to five years later, another 30 waited between six and ten years and a further 30 respondents waited many years more, one diagnosed 45 years later.

Nearly three quarters of respondents (73.5%) had their Meniere's disease diagnosed by an ENT specialist while some 20% were diagnosed by a GP.

A very small proportion indicated that diagnosis was by another means.

Table 5 Years since symptoms appeared and diagnosis

	N	%
Diagnosed around time of symptoms	187	40.6
1 year later	113	24.6
2 years later	41	8.9
3-5 years later	60	13.0
6-10 years later	30	6.5
11-20 years later	21	4.7
21-45 years later	8	1.7
<b>Total</b>	<b>459</b>	<b>100</b>

As can be seen 10.6% of respondents had been diagnosed with Meniere's within the last year.

Sixty nine point two per cent (69.2%) of the respondents had been diagnosed within the last ten years, some (4.2%) were diagnosed more than 30 years ago.

Table 6 Year since diagnosed

	N	%
Less than 1 year	50	10.6
1-5 years	139	29.5
6-10 years	137	29.1
11-15 years	53	11.3
16-20 years	30	6.4
21-25 years	19	4
26-30 years	23	4.9
More than 30 years	20	4.2
<b>Total</b>	<b>471</b>	<b>100%</b>
<i>Missing</i>	23	

## Tests Used

Respondents were asked to indicate which tests were used to make a diagnosis. Their responses to this question demonstrate that there were multiple tests undertaken. The results suggest that the majority of people had a hearing test and a balance tests that are now available. As the figures suggest some respondents had all five tests.

Table 7 Test used to diagnose

	N	%
Hearing Tests	415	84.0
Balance Tests	307	62.1
MRI	221	44.7
Electrocochleography	208	42.1
CAT Scan	193	39.1
Other	33	6.7
<b>Total</b>	<b>494</b>	



### Ears Affected

More than one third of the respondents found their left ear was affected, another third had their right ear affected and a smaller proportion (28%) had both ears affected. These figures are consistent with those of the 1998 survey, although in this survey there are a slightly smaller number of respondents who have both ears affected.

Table 8 Ears affected

	N	%
None	14	2.9
Left	167	34.5
Right	169	34.9
Both	134	27.7
<b>Total</b>	<b>484</b>	<b>100%</b>

### 5.6.2 Stage of the disease reported

Respondents were asked to indicate which stage of Meniere's they were in. Over half the respondents (51%) believed they were in stage two (the acute stage) of their illness experiencing symptoms such as vertigo, tinnitus, feelings of pressure and fullness and hearing loss.

37% believed they had moved on to the 'burnt out' stage of Meniere's – stage three, when hearing loss is severe and although vertigo attacks have stopped or are decreasing the risk of Tumarkin Crises- sudden total loss of vestibular function is present.

The remaining 12% of respondents were experiencing the stage one symptoms of vertigo attacks with associated secondary symptoms and fluctuating hearing loss and tinnitus.

Table 9. Stage of illness

	N	%
Stage 1	51	11.6
Stage 2	226	51.5
Stage 3	162	36.9
<b>Total</b>	<b>439</b>	<b>100%</b>
Missing	55	

### 5.6.3 Symptoms experienced

Respondents were asked to indicate the symptoms they **currently** experienced. In 1998 the majority of respondents experienced tinnitus (65%), vomiting (61%), dizziness (49%), hearing loss (49%), vertigo (45%) and balance problems (37%).

In the 2006 survey, some symptom descriptions were slightly changed however; the results indicate that the 2006 respondents, with the exception of tinnitus, differed in their overall symptom profile.

The symptoms reported were tinnitus (64%), hearing loss (61%), loss of balance (60%), vertigo (55%), blurred vision (37%) and vomiting (37%).

Table 10. Symptoms

	N	%
Tinnitus	314	63.6
Hearing Loss	302	61.1
Loss of Balance	298	60.3
Pressure/Fullness	280	56.7
Vertigo	270	54.7
Blurred Vision	183	37.0
Vomiting	182	36.8
Drop Attacks	104	21.1
Recruitment	47	9.5
Other	27	5.5
<b>Total Members</b>	<b>494</b>	<b>100.0%</b>

*Note: Multiple Responses Indicated*

### 5.6.4 Levels of symptom distress

Respondents were asked to order their symptoms according to the levels of distress they experienced. From column number 1 in the following table it can be seen that by far the most distressing symptoms are vertigo, hearing loss and tinnitus, although 'loss of balance' is also ranked fairly high. However, when the first three columns are added together to include second and third levels of distress, vertigo (75.8%) and loss of balance (75.5%) are well ahead of tinnitus (61.5%) and hearing loss (57.6%). This indicates that these more episodic symptoms are, overall, significantly more distressing than chronic symptoms such as tinnitus and hearing loss.

Table 11. Symptoms: Level of distress experienced

Symptom	Total N	Level of Distress (%)									
		1	2	3	4	5	6	7	8	9	10
Vertigo	270	38.1	24.4	13.3	9.3	10.4	3.3	0.4	0.4	0.4	0.0
Hearing loss	302	26.5	17.2	13.9	13.9	10.3	10.9	4.3	2.0	1.0	0.0
Tinnitus	314	22.6	18.5	20.4	13.4	10.8	6.7	5.1	2.2	0.3	0.0
Loss of balance	298	18.1	30.9	26.5	14.8	6.0	3.4	0.3	0.0	0.0	0.0
Pressure/fullness	280	11.1	12.1	17.5	17.9	17.1	11.4	8.6	4.3	0.0	0.0
Vomiting	182	9.9	20.9	17.6	12.6	9.9	11.0	9.9	6.6	1.6	0.0
Drop attacks	104	9.6	5.8	6.7	14.4	10.6	15.4	13.5	19.2	1.9	2.9
Blurred vision	183	3.3	6.0	12.0	22.4	15.9	16.9	13.7	7.1	2.2	0.5
Recruitment	47	2.1	10.6	8.5	12.8	14.9	8.5	8.5	19.2	12.8	2.1

### 5.6.5 Surgery

Respondents were asked if they had undergone surgery for their Meniere's symptoms. If so, whether they considered it successful and would recommend it to others. In total, 94 respondents had undergone surgery. While 37 people had endolymphatic sac decompression, 62% considered it successful and 57% would recommend it. Eighteen people reported having chemical ablation, with 72% considering this successful and 61% recommending it to others. Twelve people had endolymphatic sac removal with two thirds (67%) considering it successful and 50% willing to recommend it to others. Six people had vestibular neurectomy and while all of them considered it successful for themselves only half would recommend it to other people. Twenty one people had had devices fitted such as grommets or a Menniett device with 94% considering them successful and recommending it to others. In some cases the lower recommendations to others is possibly based on the difficulties of the surgery or the differences in needs between people.

### 5.6.6 History of Meniere's attacks

Respondents were asked if they were currently experiencing Meniere's attacks. Two hundred and twenty five (47%) reported that they did, while the remaining 254 (53%) did not. Of those currently experiencing attacks 11% experienced them daily, 18% weekly, and 21% monthly. The remaining 50% indicated that they had them less frequently. Two hundred and ten respondents had experienced an attack in the last 6 months. Of those not currently experiencing attacks, 82.5% had experienced an attack since 2001.

### 5.6.7 Family history of Meniere's disease

Respondents were asked if anyone in their family had Meniere's. Of the 83 (17.4%) who answered yes, 39 had a parent with the illness, 23 had a sibling, 12 had an uncle/aunt, another 12 had a cousin, 8 had a child, 2 a grandparent and 2 a niece or nephew.

### 5.7 Managing Meniere's disease

[The results in this section correspond to Part B of the survey, 'Managing your Meniere's']

In this section we begin to build up a picture of where people who are diagnosed with Meniere's receive information and support to assist them in understanding their diagnosis and managing their condition.

#### 5.7.1 Understanding Meniere's disease

The survey asked respondents to rate their overall understanding of Meniere's and its management. While nearly half (48.8%) were satisfied with the level of knowledge they had attained, a substantial number – 169 (38%) - wanted to know more indicating that many people with Meniere's, or at least within the MSGV membership, are keen to learn and practice self help.

Table 12. Level of understanding of Meniere's

	N	%
Don't know much	14	3.2
Know as much as need	44	9.9
Know as much as want	216	48.8
Want to know more	169	38.1
<b>Total</b>	<b>443</b>	<b>100%</b>
Missing	51	

#### 5.7.2 Finding information

Members of the Meniere's Support Group appear keen to learn about their illness. To establish when and where knowledge is acquired, respondents were asked how difficult it was for them to find information to help them cope.  
2 in 3 people found it difficult or very difficult to get information and resources at the time of their diagnosis.

Table 13. Difficulty finding information & resources

	N	%
Not difficult	151	31.0
Some difficulty	163	33.5
Very difficult	173	35.5
<b>Total</b>	<b>487</b>	<b>100%</b>
Missing	7	

Where did members go for more information when they first experienced symptoms?

The following table shows who members approached and the order of contact that was used.

Table 14 Experiencing Symptoms: who members approached for further information

Organisation	N	Order of contact								
		1	2	3	4	5	6	7	8	9
GP	402	91.5	5.7	1.8	1.0	0.0	0.0	0.0	0.0	0.0
ENT	379	9.2	71.2	16.4	2.6	0.3	0.3	0.0	0.0	0.0
Audiologist	251	1.2	15.1	49.0	29.1	4.8	0.4	0.4	0.0	0.0
MSGV	362	3.0	10.2	33.7	35.7	14.6	2.5	0.3	0.0	0.0
Neurologist	109	0.0	25.7	35.8	19.3	15.6	1.8	1.8	0.0	0.0
Community Health Service	15	0.0	13.3	6.7	6.7	40.0	26.6	6.7	0.0	0.0
Vicdeaf HEAR Service	30	0.0	6.7	10.0	13.3	36.6	20.0	6.7	6.7	0.0
Better Hearing Aus.	64	2.3	2.3	15.9	13.6	29.6	25.0	9.0	2.3	0.0
Other	48	22.9	18.7	12.5	16.7	16.7	8.3	2.1	2.1	0.0

The above table indicates that for most people, the pathways to information start with their GP from where most will be referred to an Ear Nose and Throat specialist or far less likely, to a neurologist. From a specialist most will be sent to an audiologist and also around this stage, most respondents started contacting the MSGV. A much smaller group went on to contact services such as Better Hearing Australia, Vicdeaf Hearing Service or perhaps, their local Community Health Service. In summary, this table indicates that the first stage of information gathering is the diagnosis process including hearing tests, and from there people go looking for more information to help them manage their condition.

*"The only help I received was through the MSGV. My GP was sympathetic but offered little practical advice. My ENT specialist said "you are deaf in the right ear, you have Meniere's. There is nothing I can do for you. Oh – cut out salt"*  
 54 year old female

*The Meniere's Support Group was fantastic. When I first contacted them I was very distressed and the help I got was something I will never forget ... The ENT explains the medical problems but they don't help with the emotional problems.*  
 64 year old female

5.7.3 Helpfulness in providing information around the time of diagnosis.

Table 15 Level of helpfulness of healthcare providers at time of diagnosis

This table explores the helpfulness of healthcare providers in assisting people to understand their Meniere's disease at the time of diagnosis.

ORGANISATION	N	%Unhelpful	%Helpful	%Very Helpful
MSGV	357	1.1	16.2	82.7
Better Hearing Australia	35	8.6	57.1	34.3
CHS	9	11.1	55.5	33.4
Audiologist	216	11.1	57.0	31.9
Vicdeaf HEAR Service	25	12.0	36.0	52.0
Neurologist	93	19.3	48.4	32.3
ENT	362	21.5	41.5	37.0
General Practitioner	389	26.2	49.1	24.7
Other	50	10.0	16.0	74.0

The survey results show that respondents (n357) regard the MSGV as by far the most helpful provider of information with 82.7% of responses rating them as 'very helpful' and a further 16.2% as 'helpful'. Only one in a 100 responses rated the MSGV as 'unhelpful'.

General practitioners and ENT specialists elicited a large number of responses also (n 389 & n 362 respectively) but 26 in 100 responses rated GPs as 'unhelpful' and 21 in 100 rated ENTs as 'unhelpful'. The GPs 'very helpful' rating of 24.7% was the lowest of all the healthcare providers. ENTs fared marginally better with a 'very helpful' rating of 37%. Overall, at the time of diagnosis, GPs and ENTs were given the lowest helpfulness rating for providing information.

Better Hearing Australia, Community Health Services and Vicdeaf Hearing Service rated well but the numbers who used their services were quite low so it is difficult to give a more informed evaluation.

Audiologists rated quite well. Of the 216 responses, 11 in 100 rated them 'unhelpful' while 57% thought them helpful' and a further 31.9% 'very helpful' indicating that while they were perceived in a positive light, they were generally regarded as 'helpful' rather than 'very helpful'.

*Comments from respondents about unhelpful GP and ENT specialists:*

*ENT specialists and doctors appeared not to know or care how a patient was feeling and were very unhelpful. Live with it they say and get on with life.*  
 60 year old female

*I think there needs to be more and better education of Medicos of symptoms, management and importance of salt. I personally found that I was more informed than my GP, ENT and audiologist once I had contact with MSGV*  
 47 year old female

5 7.4 Helpfulness in providing ongoing support and information

Table 16 below explores the helpfulness of healthcare providers in helping people manage their Meniere's disease following diagnosis.

Compared to the previous table the most notable change is that considerably fewer respondents used health professionals to get their information for the ongoing management of their condition. In contrast, the MSGV continued to be heavily utilised and very highly rated thus reaffirming the important and valued role the MSGV plays in providing information both around the time of diagnosis and with the ongoing management of the condition.

ORGANISATION	N Total	Not helpful	% Helpful	% Very helpful
MSGV	364	0.3	14.0	85.7
Audiologist	98	10.2	58.2	31.6
Better Hearing Aust	30	16.7	53.3	30.0
General practitioner	261	18.4	49.0	32.6
CHS	10	20.0	30.0	50.0
ENT	263	21.3	37.6	41.1
Neurologist	44	25.0	45.5	29.5
Vicdeaf Hear Service	25	60.0	0.0	40.0
Other	64	4.7	25.0	70.3

Table 16: Helpfulness of healthcare providers in managing Meniere's disease

The number of people using a GP to get information dropped by one third from 389 at diagnosis to 261 for ongoing management but they seem a bit happier giving GPs a much improved 'not helpful' rating which dropped from 26.2% to 18.4%, and a greatly improved 'very helpful' rating which rose from 24.7% to 32.6%. These changes reflect many of the qualitative data comments that respondents had 'doctor shopped' until they had found more helpful GPs.

Table 16: Helpfulness of healthcare providers in managing Meniere's disease

The decrease in numbers consulting with their ENT specialists for information was similar to GPs –362 at diagnosis compared with 263 for ongoing management, a drop of 27%. While the percentage of respondents who thought their ENT specialist was 'not helpful' did not change, there was a moderate improvement in the 'very helpful' rating, 37% to 41.1%, suggesting a minor improvement in information provision by ENTs. This may have also resulted from respondents seeking alternate specialists or 'specialist shopping' following their initial diagnosis.

ORGANISATION	N Total	% Not helpful	% Helpful	% Very helpful
MSGV	364	0.3	14.0	85.7
Audiologist	98	10.2	58.2	31.6
Better Hearing Aust	30	16.7	53.3	30.0
General practitioner	261	18.4	49.0	32.6
CHS	10	20.0	30.0	50.0
ENT	263	21.3	37.6	41.1
Neurologist	44	25.0	45.5	29.5
Vicdeaf Hear Service	25	60.0	0.0	40.0
Other	64	4.7	25.0	70.3

The number of respondents using audiologists for information reduced by more than half after diagnosis [from 216 down to 98] and how they were rated changed very little. Most respondents thought they were helpful rather than very helpful but only 10% thought they were 'not helpful'.

The number of respondents using neurologists for information was also less than half after diagnosis (from 93 down to 44), but unlike the audiologists, there was an increase in the number of respondents ticking the 'not helpful' rating; it increased from 19.3% at diagnosis to 25% after. Other than the Vicdeaf Hearing Service who also had a substantial increase in their 'not helpful' rating, the neurologists rated the worst in the 'not helpful' category.

In regard to Better Hearing Australia, Vicdeaf Hearing Service and Community Health Services, the numbers of responses were again small although the increase in 'not helpful' ratings for all three agencies suggested that some individual respondents may have met with indifferent or unpleasant experiences. Of those who reported that "other" healthcare providers were very helpful, twelve people had found Internet sources very helpful, while individuals reported receiving help from various complementary therapists.

5.7.5 MSGV as a source of information

The following table explains in more detail why the MSGV is highly valued as a source of information. Respondents were asked where they got information about various aspects of Meniere's and its management.

The various aspects are listed in column one of the table. The ENT specialists were the most valuable source of information about the importance of diagnostic tests, what tests are available and medication, but for all other aspects of Meniere's and its management, the MSGV was a substantially more utilised source of information.

Even in regard to surgery for Meniere's, 187 respondents got their information from MSGV compared to 159 from their ENT specialist and 16 from their GP. Another topic that indicates that the MSGV is informing its members better compared with health professionals, is how Meniere's can progress over time. 344 respondents went to the MSGV for this information, 146 went to their ENT and 41 went to their GP.

Where diet and lifestyle changes were concerned, respondents relied heavily on the MSGV. For getting information about managing a salt-free diet, 379 respondents relied on the MSGV while 69 went to their ENT, and 42 to their GP. Other aspects reflect very similar numbers and the one that MSGV was the most relied on was keeping up to date; 411 respondents went to the MSGV compared to 12 to their ENT and 12 to their GP.

Table 17. Where Respondents Found Information About Meniere's

TYPE OF INFORMATION	GP		ENT		MSGV		CHS		Audiol.		
	N	%	N	%	N	%	N	%	N	%	%
How Meniere's affects ear and can disturb bal.	114	23.8	252	51.0	307	62.1	3	0.6	48	9.7	9.3
How Meniere's can progress over time	41	8.3	146	29.6	344	69.6	3	0.6	15	3.0	6.7
Importance of diagnostic tests	62	12.6	207	41.9	168	34.0	2	0.4	25	5.1	4.9
What diagnostic test are available	48	9.7	207	41.9	164	33.2	2	0.4	18	3.6	4.7
Managing vertigo and dizziness	87	18.1	127	26.5	307	64.0	3	0.6	8	1.7	8.8
Managing tinnitus	34	7.1	61	12.7	267	55.6	2	0.4	30	6.3	8.3
Managing hearing loss	25	5.2	61	12.7	209	43.5	7	1.5	109	22.7	7.3
Medication for Meniere's symptoms	147	30.6	251	52.3	192	40.0	1	0.2	8	1.7	7.1
Surgery for Meniere's	16	3.3	159	33.1	187	39.0	2	0.4	7	1.5	5.6
Chiropractic methods of managing Meniere's	8	1.7	8	1.7	137	28.5	3	0.6	8	1.7	9.8
Alternative medicine treatments for Meniere's	16	3.3	7	1.5	166	34.6	4	0.8	11	2.3	12.5
How to manage a salt-free diet	42	8.8	69	14.4	379	79.0	4	0.8	10	2.1	10.6
Importance of making lifestyle changes	39	8.1	49	10.2	322	67.1	9	1.9	4	0.8	6.5
Balance rehabilitation	13	2.7	39	8.1	178	37.1	8	1.7	8	1.7	5.8
Keeping up to date information	12	2.5	12	2.5	411	85.6	3	0.6	5	1.0	6.0

*Note: Multiple Responses Indicated*

## 5.8 Membership of the Meniere's Support Group of Victoria

[This section corresponds with Part C of the survey 'You and the Meniere's Support Group']

### 5.8.1 How Respondents Found Out About MSGV.

This table shows us that despite the MSGV being an excellent source of information to help people manage their condition better, there is no ordered referral system.

Instead, more than a third (38%) heard about the support group through their health professional (GP, ENT, neurologist or audiologist), 26% heard from a friend or relative, 14% via the Internet and 22% through advertising or interviews in various media avenues, but mostly through newspapers.

This last source could be understated because it is possible that the friends and relatives seeing or hearing an advertisement passed on a cutting or phone number.

Table 18 How found out about MSGV

Source	N	%
GP	57	11.7
ENT	97	19.8
Neurologist	11	2.2
CHS	10	2.0
Magazine	14	2.8
Hospital	8	1.6
Audiologist	21	4.3
Website (MSGV)	47	9.6
Better Hearing Australia	23	4.7
Friend/relative	127	26.0
Radio	8	1.6
Telephone directory	15	3.1
Television	4	0.8
Newspaper	69	14.1
Newsletter	3	0.6
Australian Hearing Service	7	1.4
Website (other)	23	4.7
Other	53	10.8
<b>Total Completing Question</b>	<b>489</b>	
Missing	5	

**Note: Multiple Responses Indicated**

This spread of sources strongly suggests that for many people discovering MSGV was fortuitous and that there may be many more people needing the help the MSGV offers who have no idea the group exists.

*I know I have coped much better when I do have an attack of Meniere's after joining MSGV than before, just knowing I am no longer alone helps a lot. And also, less attacks in the last three years, knowing about diet (which I was never told in 20 years) is probably the greatest help.*

63year old female

### 5.8.2 People's responses to MSGV once they had discovered it.

Table 16 demonstrated that MSGV was the most helpful organisation people contacted after their diagnosis. The data below demonstrates people's responses to that helpfulness and their need for continuing information.

Ninety-one per cent (n494) of respondents were people who had Meniere's disease. The remaining 9% (n 50) of respondents were family members or friends, health professionals, from allied organisations, or members who had symptoms or conditions similar to Meniere's. They were asked to complete part 'c' only of the survey which sought their views on MSGV's services. The following tables show the results for the two groups separately.

The respondents with Meniere's disease have been called 'MSGV members' and the 9% of members without Meniere's disease have been called 'MSGV associate members'.

5.8.3 Membership of MSGV.

Table 19 shows that once people had discovered MSGV they became members and remained, with 45% of members remaining from 3 to 10 years and a further 16% remaining for 10 to 15 years.

Table 20 shows associate members are also loyal with nearly 60% remaining in contact between 3 and 10 years.

Mirroring members who have Meniere's disease, more than 16% of associate members had remained in contact with the MSGV for 10 to 15 years.

Table 19 MSGV Members:  
Length time members or associated with MSGV

	N	%
<1 year	60	12.7
1-3 years	119	25.2
3-5 years	93	19.7
5-10 years	122	25.9
10-15 years	78	16.5
<b>Total</b>	<b>472</b>	<b>100%</b>
Missing	22	

Table 20 Associate MSGV members:  
Length time member or associated with MSGV

	N	%
<1 year	4	8.2
1-3 years	8	16.7
3-5 years	14	29.2
5-10 years	14	29.2
10-15 years	8	16.7
<b>Total</b>	<b>48</b>	<b>100%</b>
Missing	2	

5.8.4 Satisfaction with the service provided by MSGV.

Table 21 MSGV members:  
Level of service provided meets need

	N	%
Yes	466	97.7
No	11	2.3
<b>Total</b>	<b>477</b>	<b>100%</b>
Missing	17	

Table 22 Associate members:  
Level of service provided meet need

	N	%
Yes	45	100%
No	0	0.0

Respondents were asked if the MSGV had provided the level of service they need. The vast majority of members and all associate members found that their needs were met by the services provided by MSGV.

MSGV's ability to meet their needs most likely accounts for the degree of loyalty shown.

5.8.5 First contact with MSGV.

Most of the members, including those who did not have Meniere's disease themselves, first contacted the MSGV through the metropolitan centre.

These contacts were largely by telephone (63%).

Table 23 MSGV members:  
Location of first contact with MSGV

	N	%
MSGV Resource Centre	388	86.0
Ballarat	25	5.6
Geelong	12	2.7
Gippsland	11	2.4
South Australia	10	2.2
Horsham	3	0.7
Yarrawonga	2	0.4
<b>Total</b>	<b>451</b>	<b>100%</b>
Missing	43	



## Ménière's Support Group of Victoria Membership Survey 2006

Interestingly people also contacted MSGV by letter (15%) with a relatively small number accessing MSGV through email and the website, even though two thirds of the members had access to the Internet. Access via website and email may reflect the age range of the respondents, the majority of whom are 55+. If this is the case, use of these contacts will continue to grow. On the other hand, this table may simply reflect that people preferred the immediacy of the telephone.

Table 24 Associate members:  
Location of first contact with MSGV

	N	%
MSGV Resource Centre	37	86.1
Ballarat	3	7.0
Geelong	1	2.3
Horsham	1	2.3
Gippsland	1	2.3
Yarrawonga	0	0.0
South Australia	0	0.0
<b>Total</b>	<b>43</b>	<b>100%</b>
<i>Missing</i>	7	

Table 25  
Method of first contact with MSGV

	N	%
Telephone personal	291	63.4
Letter	69	15.0
Telephone message	22	4.8
Website	20	4.4
Email	19	4.1
Fax	1	0.2
Other	37	8.1
<b>Total</b>	<b>459</b>	<b>100%</b>
<i>Missing</i>	35	

### 5.8.6 The importance of MSGV's services.

People were asked to rate the importance to them of MSGV's services. The results are shown in table 26.

Table 26 Importance of the following services

	Rating in Percentages (%)					N (Total)
	1 [not important]	2	3	4	5 [very important]	
Access to Whirligig newsletter	3.6	1.3	5.3	13.6	76.2	343
Printed information sheets/brochures	3.1	1.7	6.6	18.2	70.4	423
Membership Resource Pack	4.7	3.1	8.0	16.8	67.4	386
Being able to talk with someone to obtain information	10.5	4.6	9.7	8.7	66.4	390
Being able to talk with someone when feel can't cope	17.2	6.1	13.4	10.5	52.8	343
MSGV Website	23.4	4.5	16.6	19.3	36.2	290
Hearing from and meeting speakers at meetings	15.9	9.0	17.4	23.7	34.1	334
Meeting other people with Meniere's at meetings	20.7	10.8	19.2	16.8	32.4	333
Information videos, audio tapes, CDs	20.4	16.0	21.7	14.1	27.8	313
Library services	20.5	15.6	23.2	13.6	27.2	302
Being able to contact/meet MSGV members nearby	27.7	13.6	17.8	16.9	24.1	332
Access to Regional Co-ordinators	35.4	13.4	19.9	10.0	21.3	291

### Printed Information

According to the survey respondents, the most important service provided by the MSGV is the provision of printed information: its fact sheets, brochures and the Whirligig newsletter. Out of the 423 respondents who rated the information sheets and brochures 88.6% (n375) thought the service either 'important' or 'very important' to them.

The membership resource pack was also well supported with 84.2% (n325) of the 386 responses rating it important or very important. The Whirligig newsletter was also seen as 'important' or 'very important' by 308 of the 343 respondents.

### **Personal Contact**

- Personal contact was supported by fewer responses but was still highly valued.
- 293 members rated being able to talk to someone to obtain information as 'important' or 'very important'
- 217 (63.3% of 343 responses) rated talking to someone when they were unable to cope as 'important' or 'very important'
- Although somewhat fewer thought meetings were important, 57.8% (193) of the 334 respondents to this question thought hearing from speakers 'important' or 'very important'.
- Meeting other people with Meniere's at meetings was important/very important for 49.2 % (164) of the 333 respondents. This demonstrates a strong support for face to face contact among the membership surveyed.
- Having contact with members living near them was important/very important for 41% (136) of the 332 respondents to this question.

### **The MSGV Website**

292 members have access to the internet and 290 rated the importance of the website. Of these, 161 thought it was important or very important but only 158 had actually visited the site which suggests that once visited, it is highly valued. Members who do not have Meniere's disease had greater access to the website (75%), possibly through places of employment but fewer (42.6%) accessed it. Perhaps their need was not as great.

### **Library Services**

Library services, information videos, audio tapes and CDs overall attracted the least support but were still valued by a significant number of members: 123 respondents rated library services as important or very important, 131 respondents rated the tapes, videos & CD's as important/very important.

### **Regional Services**

Responses from Regional Victoria were very similar to metro. Printed material including the newsletter was very important to them. Being able to talk to some one for information and support was also important particularly in the Barwon, Grampians and Hume regions. Access to regional coordinators was important/very important to the following number of members from each region: Barwon 9 out of 15; Gippsland 6/15; Grampians 21/38; Hume 10/14 and Loddon Mallee 2/15. Overall, 39% rated regional coordinators as important/very important, 25% rated them as not important or of low importance.

## 5.9 The Impact of Meniere's disease on people's lives

[This section corresponds with Part D of the survey 'The Impact of Meniere's on Your Life']

### 5.9.1 Impact on lifestyle

The importance of information and support services from MSGV is reinforced when one looks at the results of the impact of Ménière's on people's lives.

Table 27 demonstrates that for three quarters of the respondents (75.3%), Meniere's had had a major or significant impact on their lives.

Table 27 Impact on lifestyle

	N	%
Minimal	116	24.7
Significant	233	49.7
Major	120	25.6
<b>Total</b>	<b>469</b>	<b>100%</b>
<i>Missing</i>	25	

Table 28 demonstrates just how much impact Meniere's has had on people's lives causing them to make changes in their lifestyles to compensate for the conditions accompanying Meniere's.

Hearing loss, tinnitus, vertigo and nausea and vomiting have clear implications for lifestyle, placing limitations on the employment people can undertake, the distances, means and destinations of travel, the leisure activities people can access.

While fewer people experienced diarrhoea, panic attacks, drop attacks and agoraphobia, the impact on the lives of those who experienced them would have been as debilitating as the more common ones.

Table 28

Conditions causing members to make changes to lifestyle

	N	%
Vertigo/dizziness	359	76.7
Hearing Loss	320	68.4
Fear of having an attack	309	66.0
Tinnitus	284	60.7
Nausea	251	53.6
Light-headedness	238	50.9
Vomiting	197	42.1
Vision disturbances	182	38.9
Headaches	134	28.7
Feelings of isolation	133	28.4
Panic attacks	115	24.6
Drop attacks	100	21.4
Diarrhoea	88	18.8
Agoraphobia	39	8.3
<b>Total Completing Question</b>	<b>468</b>	
<i>Missing</i>	26	

Note: Multiple Responses Indicated

### 5.9.2 How Meniere's disease has affected people's lives.

Respondents were asked to indicate the areas of their lives that had been affected by having Meniere's. Table 29 shows the results.

Table 29 Impact on members' lives

	Degree of Change				N total
	No Change % (n)	Slight Change % (n)	Substantial change % (n)	Major change % (n)	
Abilities and relationships					
Work in paid employment	36.5 (120)	19.5 (64)	18.5 (60)	25.5 (84)	<b>329</b>
Ability to eat foods you enjoy	21.5 (96)	29.1 (130)	24.9 (111)	24.4 (108)	<b>446</b>
Ability to travel locally by car or public transport	41.0 (177)	30.8 (133)	13.9 (60)	14.4 (62)	<b>432</b>
Ability to pursue interests and hobbies	28.5 (123)	31.3 (135)	26.4 (114)	13.9 (60)	<b>432</b>
Ability to stay away from home for extended period	44.9 (195)	28.1 (122)	15.4 (67)	11.5 (50)	<b>434</b>
Relationship with friends/extended family	43.5 (187)	32.3 (139)	16.0 (69)	8.2 (35)	<b>430</b>
Work around home: housework & light maintenance	32.8 (150)	35.9 (164)	23.2 (106)	8.1 (37)	<b>457</b>
Relationship with partner	51.6 (196)	29.2 (111)	11.6 (44)	7.6 (29)	<b>380</b>
Ability to leave house by self	53.8 (229)	27.9 (119)	11.3 (48)	7.0 (30)	<b>426</b>
Relationship with children	57.4 (228)	28.0 (111)	10.1 (40)	4.5 (18)	<b>397</b>
Ability to care for self	51.0 (223)	30.4 (133)	14.4 (63)	4.1 (18)	<b>437</b>
Other	7.9 (3)	10.5 (4)	18.4 (6)	63.2 (22)	<b>35</b>

The areas where change was most significant (i.e. substantial or major) in order of number of people affected were: eating (219), hobbies & interests (174), paid employment (144), work around the home (143), and local travel (122).

### Eating

The ability to enjoy eating was the biggest change for most people. 219 (49.3% of the 446 respondents) reported it being a substantial (n111) or major (n108) change for them. For most people, adapting to a low salt diet was a hardship particularly in social situations, but for others a new healthy diet regime was seen as a positive change.

### Interests & Hobbies

The ability to pursue interests and hobbies became significantly different for 174 people. For some it meant that long enjoyed pleasures had to be given up due to balance or other Meniere's symptoms, while for others it was a chance to learn a new craft or activity as more time was devoted to relaxation and stress reduction.

### Paid Employment

144 (or 44% of the 329) respondents had substantial (n 60) or major (n 84) changes to their paid employment which in itself indicates several more lifestyle changes relating to income, self esteem, psychological well being, work friendships and other areas.

### Housework & Maintenance

There had been a substantial change to 106 respondents' ability to carry out chores around the home - housework and maintenance, and a major change for another 37 respondents, totally 143 in all. Many talked of pacing themselves and taking much longer to get their work done, others commented that they made good use of their good days and rested on their bad.

### Travel

Travelling locally by car or public transport was an area of major change for one in four respondents. 122 of the 432 responses noted a substantial (n 60) or major (n 62) change and many spoke of the limits this had placed on their social lives while for others it had meant a change of job.

### Relationships

In terms of numbers affected, the area of least change was relationships. Relationships with partners changed significantly for 73 respondents, with children for 58, and with extended family and friends for 108. Relationships with partners in particular changed positively for some and negatively for others. Relationships with children and other family members and friends tended to deteriorate due to poor hearing and lack of understanding about Meniere's symptoms.

Of the 35 respondents who noted 'other' areas that had been affected by their Meniere's, the most common one was the ability to socialise, while another important area was their self-esteem, confidence and independence.

#### **5.9.3 Relationship to Stress and Depression**

Respondents were asked to describe the relationship between stress and their Meniere's symptoms, and between depression and their Meniere's symptoms.

Many people considered there was a strong relationship between being stressed and their symptoms, with more than 78% (n 377) viewing this as a strong relationship.

**Table 30**  
**Relationship b/w stress & symptoms**

	N	%
Low	74	15.4
Medium	135	28.1
High	242	50.4
N/A	29	6.1
Total	<b>480</b>	<b>100%</b>
Missing	14	

Thus many of the respondents were likely to consider symptoms would appear or become more severe if they were placed in stressful situations.

**Table 31**

The relationship between depression and Meniere's disease was not as strong, though clearly there were high numbers of people (n 260) for whom this was a personal association and more than half those who responded considered the relationship played a part in the experience of their symptoms.

Relationship b/w depression & symptoms		
	N	%
Low	118	25.1
Medium	150	31.8
High	110	23.4
N/A	93	19.7
<b>Total</b>	<b>471</b>	<b>100%</b>
Missing	23	

## 5.10 Costs

### 5.10.1 Health Care Cards

There were 243 (53.4%) of 455 respondents with a health care card (HCC). Health care cards are income-tested and consequently this suggests that some families were on lower incomes, were possibly pensioners and had higher health care needs.

Table 32 Health care card

	N	%
Yes	243	53.4
No	212	46.6
<b>Total</b>	<b>455</b>	<b>100%</b>
Missing	39	

Table 33 below demonstrates that there is no one medication that works for all people with Meniere's disease. The figures also demonstrate that for relief some people rely on multiple medications. A substantial number of people found many of the drugs prescribed in their care were not very helpful, but equally the same drugs worked well or very well with other people.

### 5.10.2 Costs of medications, medical devices and doctors visits

For a small number of people surveyed, costs of medications, devices and doctors' visits are onerous.

An average of 10% of the survey had spent between \$26 and \$50 on PBS and non-PBS medications in the month. Smaller proportions had spent in excess of \$51 in the month.

Depending on income and health care card status families in these categories may have found these expenses to be a larger proportion of their total income.

A similar pattern emerges with GP consultations; generally those surveyed had spent little in this area in over 6 months but for a small proportion (6.6%) of the survey GP costs were high, in excess of \$150. For those who sought allied health services (12%) the costs were also high.

Similarly, when survey members (13%) consulted specialists the costs were in excess of \$150 over twelve months. Where devices such as hearing aids (12% of those surveyed) were required these also were expensive, far exceeding \$150 in the year.

Table 33

Medications members have taken for Meniere's

	% Not helpful	% Helpful	%Very Helpful
<b>Anti-emetics</b>			
Stemetil	17.0	42.1	40.9
Maxalon	23.6	45.5	30.9
<b>Vestibular Sedatives</b>			
Valium	21.5	40.2	38.3
Ducene	50.0	33.3	16.7
Serepax	32.0	32.0	36.0
<b>Antihistamines</b>			
Phenergan	45.0	35.0	20.0
Avomine	14.3	57.1	28.6
<b>Vasodilators</b>			
Serc	31.4	29.4	39.3
Isoptin	75.0	12.5	12.5
Minipress	100.0	0.0	0.0
Vorvasc	0.0	100.0	0.0
Plendil	50.0	50.0	0.0
Felodur	16.7	33.3	50.0
Stugeron	30.8	15.4	53.8
<b>Dehydrating Drugs</b>			
Urea	48.3	25.9	25.9
<b>Diuretics</b>			
Lasix	34.9	36.5	28.6
Moduretic	34.4	43.8	21.9
Midamore	33.3	50.0	16.7
Diclotrite	54.5	27.3	18.2
<b>Other</b>	10.8	50.0	39.2

## Ménière's Support Group of Victoria Membership Survey 2006

Table 34 Medication costs incurred in a month (estimated by respondents)

Medication Type	\$0	\$1-25	\$26-50	\$51-75	\$76-100	\$101-125	\$126-150	\$151+	Total	N
PBS	58.7	28.4	8.6	2.4	0.9	0.0	0.2	0.9	100%	465
Non-PBS	66.5	12.0	11.2	6.0	2.2	0.6	0.6	0.9	100%	465
Over the counter	81.3	11.6	4.3	0.6	1.1	0.0	0.4	0.6	100%	465

Table 35 Medical practitioner costs incurred in last 6 months (estimated by respondents)

Med. Practitioner	\$0	\$1-25	\$26-50	\$51-75	\$76-100	\$101-125	\$126-150	\$151+	Total	N
GP	79.2	1.3	5.1	1.7	4.1	1.3	0.6	6.6	100%	467
Diagnostic tests	93.6	0.0	1.1	0.2	1.3	0.4	0.2	3.2	100%	467
Counselling	97.0	0.0	0.4	0.2	0.4	0.0	0.2	1.7	100%	467
Allied health	78.6	0.6	3.0	1.1	2.1	0.6	1.5	12.4	100%	467

Table 36 Other medical costs incurred in last 12 months (estimated by respondents)

Other Medical	\$0	\$1-25	\$26-50	\$51-75	\$76-100	\$101-125	\$126-150	\$151+	Total	N
Specialists	77.3	0.2	0.9	2.1	3.0	1.5	2.1	12.8	100%	467
Hearing aids	84.8	0.0	1.7	0.4	0.6	0.0	0.4	12.0	100%	467
Meniett Pressure	98.5	0.0	0.2	0.0	0.0	0.0	0.0	1.3	100%	467
Pulse Device										
Tinnitus Treatment	98.5	0.0	0.2	0.2	0.0	0.2	0.0	0.9	100%	467
Programs										
Other	92.3	0.4	1.1	0.0	0.4	0.0	0.2	5.6	100%	467

### 5.10.3 Changes to employment and income

Another aspect of the cost of Ménière's relates to the ability to earn income. Ninety five people (or 20.8% of the total survey) reported that they had to leave paid employment because of their Ménière's disease, while others (73, or 16% of the total) reported that they had to reduce the hours they worked. A smaller number (37, or 8% of the total) changed their occupation to one that better suited their health status. For those who left paid employment or reduced their hours of work, this loss of income represents a hidden cost that may affect a whole family's access to home ownership, educational and vocational opportunities and a possible descent into poverty. This statement is supported where eighteen respondents reported that they had lost incomes in excess of \$46,000, while another 33 reported losing incomes between \$16,000 and \$45,999.

### 5.10.4 Strategies that assisted in managing Ménière's

Given that Ménière's disease has the potential to reduce people's ability to work, to function as community members or to socialise, strategies to manage Ménière's are very important.

The most useful strategy for the greatest number of people responding to the survey was advice about a low salt diet, followed by stress management.

Where respondents reported "other" they qualified this response by showing that some of them benefited from Tai Chi, chiropractic, massage and exercise.

Table 37 Strategies used that have been beneficial in managing Ménière's

Strategies Used	% who used	No. who used
Low salt diet	88.8	373
Stress Management	21.9	92
Meditation	17.4	73
Counselling	9.5	40
Yoga	8.8	37
Osteopathy	6.4	27
Hypnosis	2.1	9
Other	20.2	85
<b>Total Completing Question</b>		<b>450</b>
Missing	74	
Note: Multiple Responses Indicated		

5.10.5 How Meniere's Support Group of Victoria assists its members to cope with their condition.

The following tables indicate that MSGV has contributed substantially by providing its members with information to develop their overall understanding of how Meniere's disease affects them physically and in terms of their quality of life. Table 38 shows how respondents assessed their level of coping *before* contacting the MSGV and Table 39 shows their level of coping *after* contacting the MSGV.

Table 38

Level of understanding BEFORE contacting MSGV

	Self assessment (% of Respondents)			Total	No: Respondents
	Poor	Good	Excellent		
Overall understanding of how Meniere's can affect the body and general health	81.2	16.1	2.7	100%	446
Overall understanding of how Meniere's can affect one's lifestyle	75.6	20.3	4.1	100%	439
Ability to accept the diagnosis and work positively towards living with it	67.8	26.8	5.4	100%	426
Knowledge of strategies to help cope with Meniere's	76.9	19.4	3.7	100%	432
Knowledge of other organisations to contact for assistance with problems associated with Meniere's	90.6	7.2	2.2	100%	404

Table 39

Level of understanding AFTER contacting MSGV

	Self assessment (% of Respondents)			Total	No: Respondents
	Poor	Good	Excellent		
Overall understanding of how Meniere's can affect the body and general health	0.4	37.5	62	100%	453
Overall understanding of how Meniere's can affect one's lifestyle	0.9	41	58.1	100%	446
Ability to accept the diagnosis and work positively towards living with it	2.3	44.4	53.2	100%	432
Knowledge of strategies to help cope with Meniere's	1.3	35.7	62.9	100%	445
Knowledge of other organisations to contact for assistance with problems associated with Meniere's	13.6	43.9	42.4	100%	396

Most people reported that before contacting MSGV their knowledge in the areas of how Meniere's affected their general health and their lifestyle; their knowledge of strategies such as a low salt diet and managing stress; their ability to be positive and their knowledge of other organisations to assist them were poor. After contacting MSGV survey respondents reported that their ability to manage on all four levels had gone from poor to either good or excellent, with the higher proportion reporting the leap was from poor before contact to excellent after. This indicates that the relationship with MSGV has an important impact on people's lives and their ability to manage their condition.

## 6. QUALITATIVE RESULTS

Those themes that drew the strongest response were around the helpfulness of people and organisations and the most useful forms of help they provided; the value of the website and its contents; what other services MSGV could offer; the impact of Meniere's disease on people's lives; the positive life changes produced by having Meniere's disease and medication issues.

### 6.1 Helpfulness of people and organisations.

Receiving information was important to people with Meniere's disease. MSGV rated as the most helpful in terms of providing information about symptoms and symptom management.

*Meniere's Support Group was most helpful with prompt delivery of information, which I can refer to on a 'bad day' or when symptoms have changed and articles I overlooked become more relevant to me.*

46 year old female

*I do not know what I would have done without MSGV. As far as I am concerned it is the only true help for our problem.*

63 year old male

Some people considered it the "only" source of information they had, while others who lived at a distance found it a valuable source of information. "Whirligig" received several mentions, in terms of providing information in a readily accessible form. Another facet of MSGV that was praised was that information was delivered in a timely fashion. People appreciated they could get information in a hurry, through phoning and requesting it. Comments from respondents suggested that the information from MSGV was of an extremely high standard and that it constituted an important part of their total care, filling the gaps left by medical practitioners. While GPs and ENT specialists were usually considered helpful by most respondents, they also drew comments that they lacked knowledge, lacked empathy and their knowledge was not up to date. Often respondents had changed their medical practitioner after initial negative experiences. This suggests that as groups, ENTs and GPs were far more inconsistent than MSGV in their provision of information and support.

### 6.2 The kinds of help people value

Information comes in many forms and respondents identified the most important help from information that included details about symptoms, stages of the disease, diet, lifestyle, medical and self-management and recently published articles. MSGV was able to deliver all of these forms of information, while other healthcare professionals generally were only able to deliver some parts of this information. This was emphasised by the comments about health professionals and health organisations that were not helpful. Where respondents were concerned they lacked help about diet and lifestyle. Lack of help was compounded by receiving only limited advice and little sympathy about the impact the condition had on their lives which was sometimes expressed by telling them to get on with their lives. Finally an exclusive focus on medical care failed to meet their expectations.

Additionally, respondents wanted support, which included sympathy, empathy and someone they knew who would be available when needed. Some people spoke of feeling devastated after receiving their diagnosis, or losing confidence when they first experienced attacks. Some spoke of being left to deal with feelings of hopelessness or feeling lost following specialist consultations. Others were clearly very angry at the unsympathetic response they had had from medical practitioners. The supportive response from MSGV was very important in addressing these areas; it gave people hope, practical advice and new strategies to try out.

*The counselling service at MSGV got me through an incredibly difficult time. I am forever thankful.*

41 year old female.

*Very understanding and had a lot of knowledgeable explanations.*

60 year old female.



Being able to have contact with other people with Meniere's disease, either in person or through newsletters and the website was also important. Respondents felt the MSGV provided support when they felt "alone" or "lost". Even for those who consider they are doing well at present, previous contact with MSGV provides comfort for the future, knowing they can call on it if they need to.

*The MSGV was vital for me at a time when I was devastated by what the specialist told me. The Group gave me hope and a way for me to help myself.*

59 year old male

*Without MSGV I would be lost. I first spoke to Lyn after being diagnosed. I don't feel as if I'm alone with this now. I cope quite well with my regular medication and low salt diet, I'm even working some casual hours for an employer who knows I've got Meniere's.*

61 year old female

In terms of outcomes for individuals, the comprehensive support services from MSGV have resulted in people with Meniere's disease being able to better self-manage their conditions and optimise their quality of life. It is clear from the responses that no other service on its own was able to achieve this.

### 6.3 Website

While not all respondents accessed the MSGV website, those who did, found it very valuable. The response to the website mirrored responses to the telephone and other information services generally provided by the MSGV. People valued the information, the general advice, dietary information and strategies. Stories about other people coping with Meniere's disease were also important and this suggests that it was another way of realising one was not alone. The website also provides a place for people to return to refresh their knowledge, and when they experience different symptoms. The plain language used on the website was also valued.

Some of those who accessed the website had ideas of how it could serve them better. A small group of people thought there could be a members' section where members could view information on-line. This would cut MSGV's postage costs. Others suggested information on travelling, both by car and air. Others wanted to read articles on recent research and drug side-effects. Developing on-line chat groups was also another suggestion.

### 6.4 Additional services respondents would like from Meniere's Support Group of Victoria

Most people responded that they were very happy with MSGV services and saw no reason for a change. However, there were others who sought additional services. There was a strong response regarding increased regional and interstate activities reflecting that more than 40% of the respondents lived outside of metropolitan Melbourne. For many regional members, driving was a problem so that attending meetings at a distance from home was not possible. Despite this, meetings were seen as important for both the social opportunities and opportunities to hear guest speakers.

*Being in the country, we have limited resources (I am not confident on the website) and travelling is not much fun and the distance to a group is a problem.*

63 year old female

A small number of respondents would like to see increased social activities and support, or pastoral activities. There was a suggestion of barbeques and opportunities to make new friends, since Meniere's had changed some people's abilities to socialise.

*Provision of written material such as Whirligig is useful / valuable aid but nothing substitutes for personal contact. MSGV is supposed to be a SUPPORT group, not exclusively as information dissemination / education service, and frankly I believe it has failed in the first objective, while being outstandingly successful in the second.*

52 year old male

*Even social get-togethers, like a BBQ or movie groups. Meeting others, making new friends.*

54 year old female

Another important theme to emerge related to the need for MSGV to continue working with the community and health professionals to improve knowledge and awareness of the condition. This theme was prompted by the many negative responses people had experienced while attending health professionals. Complaints that GPs knew little of the condition, ENTs were generally unhelpful with information on how to live with the condition and some respondents had been misdiagnosed. This meant the person's misery was more prolonged.

*Neither my GP here or in the UK could diagnose my problem. Both said they couldn't find anything wrong. Finally referred by my GP here to an ENT specialist who diagnosed it as Meniere's. ENT specialist was not helpful after diagnosis. Gave me a photocopy of information book and advised me to come back in 6 months to see how much my hearing had deteriorated. No helpful advice-only "move to Sydney; it's louder there and you won't notice the tinnitus as much".*

28 year old female

*I kept being told I was having anxiety attacks, put on Zoloft tablet, ended up in hospital, nurses wouldn't help because I refused more medication, signed myself out after 6 days of hell and no help. It took another 4 years before a GP sent me to the ENT specialist.*

47 year old female

Community awareness is also seen as suboptimal; respondents reported having attacks in public places and being shunned by passers-by, while Centrelink received a number of mentions that the staff was uninformed and unsympathetic. Respondents suggested that MSGV could deal with these community deficits by providing more information to the general community and to healthcare professionals.

*When not working I applied for a pension, Very distressing interview etc. with government bodies. Now choose not to put myself through this. I try to work part-time to support myself rather than have the pension. Big educative program required for all agencies as you need their help when you are lowest and very ill.*

56 year old female

*Centrelink most unhelpful in times of need and draconian*

63 year old male

*I once had an attack in a supermarket...an elderly chap came to offer help but his wife grabbed his sleeve and pulled him away. "Leave her alone" she said. How humiliating and depressing! Did she think I was drunk or on drugs?*

67 year old female

Because health professionals are generally poorly informed about Meniere's disease, another service respondents wanted from MSGV was a list of both medical and alternative therapists who had a specific interest in the condition.

Other responses can be generalised as more information. This includes research articles; information relating to travelling and dining out; information on complementary therapies and products and finally up to date information.

## 6.5 The impact of Meniere's disease on the person's quality of life

This area drew strong, emotionally charged responses from the majority of respondents. Many spoke of how Meniere's had 'devastated my life', how it was like living a nightmare, and a couple of respondents even spoke of how they had contemplated suicide.

### 6.5.1 Social Impact

The social impact was the most commonly expressed theme. This theme covers social isolation, the impact of Meniere's disease on family relationships, loss of independence and its impact on finances and the ability to work.

For many people, symptoms of Meniere's disease contribute to social isolation. Some commented that the simple pleasures they had taken for granted, such as a drink with friends in the pub, or dinner in a restaurant were now lost to them. It was difficult to attend social occasions either because driving there was no longer an option or it was hard to hear in public venues or among large gatherings. Fear of being unwell while out socially was also reported as a strong contributor. People reported that Meniere's disease restricted their social activities, if it did not wholly stop them. Travelling on holidays was severely restricted and going out for shopping days was no longer a pleasure, while another restriction relates to the need to be disciplined about eating habits and late nights.

*I have found the disease to be very isolating as I live in a retirement village. I'm unable to attend club dinners, lunches owing to the noise and high salt foods. With my husband and family communication has become difficult as they find it hard to remember to face me when talking and to speak clearly and loud enough for me.*

63 year old female

*Having Meniere's has restricted the many types of activities that I once enjoyed eg playing tennis, dancing, lengthy shopping trips, gardening and visiting restaurants, just to name a few. Any activity other than walking is now very restricted and I find it very frustrating. I now have to consider very carefully my daily activities so that I don't try to fit too much into one day.*

53 year old female

For some people, these severe social restrictions led to their marriages breaking up, but for others the result has been the development of deep gratitude towards their partners for their support. There was some mention of the condition causing disruption in other family relationships such as with children and siblings.

*My children were born before I had any symptoms. I wouldn't have had children if I knew what was to come! My partner is not very supportive and my children suffer because of my symptoms. I can't plan ahead without worrying about good/bad days. If my symptoms didn't affect the kids as much I would be happier (but) I don't grieve for my pre-Meniere's life anymore. I know there are other people with more problems than me.*

39 year old female

Becoming dependent on other people is another social impact. Dependence related to not being able to drive, not being able to shop alone, relying on a partner to assist when they were unwell. Many regretted becoming dependent on their partners and friends suggesting that they were more comfortable when they had a measure of independence. One person saw the problem in the reverse -she felt uncomfortable about placing family members in the position of having to come to her aid.

Another social impact relates to finances particularly in relation to reduced income due to the loss of employment or having to work reduced hours. Some people reported reducing their working hours as a means of coping with Meniere's disease while others reported changing positions to less stressful work. Some have been able to keep their employment though they have had to make some changes.

*My position as a full time deputy manager and mother of two children keeps me very busy but I have cut down my work hours to a strict 8 hour day...*

41 year old female

*I have been able to continue as a secondary teacher without too many problems. I have had to disappear from the classroom quickly on several occasions...*

53 year old female

### 6.5.2 Psychological impact of Meniere's disease

Meniere's disease can be very unpredictable and respondents reported having attacks such as vomiting and dizziness when they were least able to deal with them. It was compounded when they occurred in public. Many feared having an attack and reported that it was hard to predict when they would have a good day or a bad day. This created anxiety, depression and a loss of self-confidence. Having to cope with physical problems such as poor balance and lack of stamina also reduced self-confidence. This anxiety and loss of self-confidence often led to greater social isolation. Anger and frustration were words that appeared when respondents spoke of the impact on their lives. One younger woman was distressed at the way Meniere's disease had impacted on her appearance as she had lost weight and it had affected her hair and finger nails. She no longer liked the way she looked.

*At first the fear of an attack limited my lifestyle. Social events and holiday presented problems as I often had to 'force' myself to go. Over the years I have regained confidence and now participate in most activities.*

70 year old male

*It's taken a good six months or more to not open my eyes each morning and think "am I going to have an attack today?" When I do have these thoughts I try to stay positive, knowing I haven't eaten anything I shouldn't have.*

39 year old female

### 6.5.3 Physical problems of Meniere's disease

For some respondents the physical impact of Meniere's disease was more paramount than the social and psychological impact. Problems of vomiting, nausea, dizziness, hearing loss, visual disturbance, and generally feeling unwell were more problematical than the anxiety related to the symptoms.

*I have lived with Meniere's for 13 years now and tinnitus for about 15 years prior. I have to say the tinnitus is the worst aspect. It's there all the time. Sometimes it drives me crazy (not really) but there's never quietness – there's always noise in my head so I can never enjoy peace and quiet.*

53 year old female

Some respondents reported that they never felt fully well, one person describing himself as functioning between 58 and 90% all the time. Severe attacks of Meniere's disease were reported as leading to complications such as hospital admissions, or dehydration or collapse.

### 6.5.4 Impact of medications

Some people had experienced adverse reactions to medications such as anti-nausea drugs where they had ended up in hospital, while others reported that they had been prescribed sedatives that had done little to address their problems with Meniere's disease.

### 6.5.5 Self-management activities

Most of the respondents reported that they found many of the self-management activities beneficial in minimising the impact of Meniere's disease on the quality of their lives. Adhering to these activities had an impact on their lives. Foremost for impact was the need to change their diet to one of low-salt. It made it difficult to eat out, either at restaurants or at friends' houses. When friends and family did not acknowledge the need to reduce salt in food it created negative feelings. Having to analyse food items for their salt content was onerous for some, while others simply did not enjoy the taste of low or no salt foods.

## Ménière's Support Group of Victoria Membership Survey 2006

Other people had also reduced their intake of caffeine and alcohol, finding this assisted relief of their symptoms. They felt frustrated when there were no options to tea and coffee at public venues, while some missed alcohol as part of overall good dining and socialising. Many people expressed the view that these dietary restrictions contributed to their social isolation.

Other self-management activities include stress reduction, regular exercise and daily routines that provided for adequate rest and sleep. This could include changing employment or stopping it altogether; it might mean taking up yoga and meditation. For those who enjoyed being busy, as well as those who combined working and caring for children, these lifestyle changes are difficult to adopt and maintain. Bitter experience had taught some people that it was not wise to ignore their bodies' needs. They needed to prioritise their daily activities instead of trying to do everything.

*Meniere's has had a profound effect on my life. I have had to learn to relax and not to worry if I can't do things at the right time. I now do housework, go shopping- whatever, when I am able, not when I should.*

Anonymous

*I get a bit down when I have an attack. I usually can't do much and find resting and doing nothing unusual as I am a very busy and active person.*

41 year old female

*I live a healthier lifestyle, eat well and exercise daily... stress is the main trigger for an attack and salt causes pressure. Avoiding both makes for a better life.*

36 year old female

### **6.5.6 Positive impact of having Meniere's disease**

Not all respondents considered that Meniere's disease had a completely negative impact on their lives. Some spoke of the greater insights into their own lives and the lives of others they had achieved through their experience. Some respondents considered their diets were far healthier now, while one person found the taste of food was better without salt. Others learnt to value their families and friends, while others found that what appeared at first as limitations imposed by the condition, had opened up new areas in their lives, such as being able to meditate and relax. These new insights and more positive attitudes developed over time, as people learned to cope with their symptoms and adjust their lives. One person described that being able to control her symptoms through lifestyle changes had given her a new confidence in her own abilities.

## 7. CONCLUSIONS

The survey undertaken in 2006 of members of the Meniere's Support Group of Victoria establishes the following:

- Respondents to the survey demonstrated that Meniere's disease is a serious, debilitating condition that has the potential to change people's lives where they suffer loss of income, self-esteem, depression and become socially isolated. Most of the respondents had made the necessary adjustments to their lives in order to live with Meniere's disease.
- Membership loyalty was demonstrated by the respondents to the survey and indicates that MSGV is a highly valued agency.
- The survey results demonstrate that there is no simple clearly defined referral path for people to have their Meniere's disease diagnosed. Referrals to health professionals may lead to a diagnosis but do not necessarily lead to people receiving information on treatment, care and daily management of Meniere's disease. Health professionals do not necessarily refer people to MSGV following diagnosis. A referral to MSGV will depend on health professional's knowledge of its existence and/or their views of its value.
- Respondents to the survey recognised that MSGV provides high quality information to assist them manage the impact of Meniere's disease. Information relating to treatment, care and lifestyle is available from MSGV and is the most highly valued service.
- Many of those who were surveyed did not find out about MSGV or its services for some time. They made the point that had they been in contact with MSGV earlier, they would have begun to cope earlier.
- There are no clear or established referral patterns to MSGV. Many find out 'by accident' rather than as a routine part of their care and treatment.
- It was evident from the survey that MSGV is an ideal referral point for all people who are newly diagnosed with Meniere's disease.
- When people receive a diagnosis of Meniere's disease they value emotional support as well as information. Emotional support is often lacking from other sources.
- There were calls from respondents to the survey for MSGV to extend its services further into regional Victoria and interstate; to provide more support services and opportunities for member interactions.
- Provision of information by MSGV saves the government money in health services, since well informed people with Meniere's disease opt to make lifestyle changes and receive information about appropriate treatment options.
- The telephone remains an important means of contact for people with Meniere's disease, though Whirligig and information sessions are all highly appreciated.
- The website has not been visited by many members. Only 54% of respondents to the survey with access to the Internet have visited the site. Those who did visit it, rated it as an important or very important service. The website has the potential to provide more information and support to rural and regional members and its use will increase in the future.

## **8. RECOMMENDATIONS**

Based on the results of this survey we recommend that MSGV

- continues to provide high standard information to its members through its current forms including Whirligig, website, telephone services and information sessions
- expands its information provision to include updated information on treatments, new research, and any other items likely to interest its members
- expands its support services, when and where possible, to assist its members deal with the social, emotional and physical impact of Meniere's disease on their lives and the lives of their families
- continues to work with health professionals to establish itself as the central agency for information and support to all people with Meniere's disease
- continues to work with health professionals to establish a clear referral path from health professionals to MSGV so that those who are newly diagnosed or who have not been referred in the past, receive information and support that they cannot receive elsewhere
- dependent on resources, expands its work in regional Victoria and interstate, offering people more opportunities to attend information sessions and to meet one another
- continues to make its services known through media and any other promotional materials it has access to
- undertakes more work with the community to promote an understanding of Meniere's disease and its impact on individuals and their families, as this would assist its members to cope in their communities.