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# **Complementary and Alternative Medicine (CAM) Therapies in the Treatment of Ménière's Syndrome: Illness Narratives**

## **Final Report**

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February 2008



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# EXECUTIVE SUMMARY

## Background

Ménière's syndrome is a long term, progressive disease which damages the balance and hearing parts of the inner ear. Whilst conventional treatment includes drugs, exercise and changes to diet, some people who suffer from this syndrome have explored complementary and alternative medicine (CAM) therapies to alleviate their symptoms. As there was little published information on which CAM therapies might help those with Ménière's, in the autumn of 2004, we began a research project to find out more about how complementary and alternative (CAM) therapies might help those with Ménière's.

## Methods

Participants were invited to take part via the project's web site, the web sites of the Ménière's Society UK and the Ménière's Support Group of Victoria, Australia, (MSGV) and the newsletters of these organisations. In addition, the Ménière's Society UK searched past issues of its monthly newsletter, *Spin*, for letters related to the use of CAM therapies. Two members of the research team closely read and re-read all the stories and letters to identify the main themes.

## Key Findings

### ***Study Participants***

Twenty persons wrote a personal story, five from Australia and the rest from the UK; a further 23 letters relating to different ways that the writers found CAM had helped them to manage their Ménière's symptoms were located from *Spin*.

### ***1. The Impact of Ménière's on their Life***

All the personal accounts demonstrate the challenges faced by those with Ménière's, from the first experience of some of the symptoms to early diagnosis and treatment and thereon, and the dramatic effect the condition had on their lives.

### ***2. The Need to Widen Horizons to Look Beyond Conventional Medicine***

Few GPs, and fewer consultants, suggested to the Ménière's sufferer, to '*look more widely*' and to advise, '*perhaps try alternative / CAM treatments.*' This is particularly significant, in a

context where conventional medical treatments do not appear to improve the condition sufficiently.

### **3. *The Role of Significant Others***

Participants' stories often pointed to a particular individual or individuals who were influential in encouraging them to try alternative treatments. On a few occasions, this 'significant other' was the GP or a consultant (for example, ENT, rheumatologist). More commonly, the 'significant other' was a family member or a friend. In addition, many of the participants talked about the substantial support provided by their partner or a close friend, for example, in enabling dietary changes and/or providing long-term personal support.

### **4. *Critical Events as a Catalyst***

Other participants drew attention a critical event or set of events that provided a strong prompt to their seeking alternative treatments. Commonly, this was an increased frequency and severity of attacks, their ongoing nature or an increasing impact of Ménière's on their lives. For some, it was being told that there was no cure.

### **5. *The Journey with Ménière's***

All the personal accounts illustrate the range and variety of journeys that people with Ménière's have travelled, and continue to travel, in locating a satisfactory way to manage the condition (their 'CAM fixes'), the time taken to locate a helpful fix, the role of others or the self in its location, and the type and nature of the fixes. It is evident that some participants tried one therapy (for example, acupuncture) and, if it did not have the desired effect, then tried another in order to find their eventual 'best' or 'better' fix. It was also notable that some informants continued to use drug therapy alongside their use of CAMs; for others, their use of CAM enabled them to stop taking the drug(s).

### **6. *Many CAM Approaches, No Single Approach***

The journeys and the range of CAM approaches used demonstrate that no single CAM approach works for all. The findings are indicative of the possible benefits of CAM as part of self-care of Ménière's.

- *Dietary-related approaches:* Commonly, dietary related approaches are reported as beneficial. This option may arise from talking with one's GP, a friend or family member or from reading and searching the Internet, as well as or instead of a CAM practitioner.

- *Explicit CAM approaches:*
  - *'Energy-related'* therapies (such as acupuncture, Bowen therapy, reflexology and acupressure) were most mentioned. Acupuncture formed at least part of the CAM 'fix' for 10 out of the 43 informants, but positive benefit was experienced only by six of these.
  - *'Body alignment related'* therapies (such as cranial osteopathy, chiropractic, Bowen therapy, Alexander technique) were next most mentioned.
  - *'Toxicity related'* therapies (including Chinese herbs, chemical and food sensitivities, nutritional therapy) were also important, along with *'dietary-related'* approaches
  - Least mentioned were *'mind-body related'* therapies (such as yoga, reiki and meditation) and *'air-water-nutrition related'* therapies (such as homoeopathy)
- *Experience of Positive Benefits:* Participants reported positive benefits from their use of the particular CAM 'fix(es)'. For some, this entailed a reduction in the symptoms, for others an elimination of the symptoms and a much reduced impact of Ménière's on their lives.

## **7. 'Finding Your Own Way'**

*'Finding your own way'* best characterises people's journeys. This raises the question of whether the person with Ménière's *has to* find their own way. Is there an inherent value in *'finding your own pathway'* in terms of personal awareness and personal growth and development? Alternatively, and more realistically, there is the need, value and potential of early signposting, in particular by conventional medical practitioners, to enable the person with Ménière's to *'look more widely'* and to advise: *'perhaps try alternative / CAM treatments.'*

<p>The full report is available at the following web address: <a href="http://www.healthcare.leeds.ac.uk/pages/research/documents/CAMMeniere.pdf">http://www.healthcare.leeds.ac.uk/pages/research/documents/CAMMeniere.pdf</a></p>
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## **ACKNOWLEDGEMENTS**

We thank all those who wrote to us sharing details of their personal experience with Ménière's syndrome and their use of complementary and alternative therapies in helping them to cope with the illness, and to the willingness of the Ménière's Society UK and the Ménière's Support Group of Victoria, Australia, to publicise the research on their websites. We gratefully acknowledge the small grant received from the University of Salford which enabled the research to be taken forward.

We hope that the information contained in the research report will help people with Ménière's find ways that reduce the impact of the condition on their lives and to suggest that CAM treatments may offer some additional ways to do this.

## Section One: Introduction and Methods

### Introduction

Ménière's syndrome is a long term, progressive disease which damages the balance and hearing parts of the inner ear. Whilst conventional treatment includes drugs, exercise and changes to diet, some people who suffer from this syndrome have explored complementary and alternative medicine (CAM) therapies to alleviate their symptoms. However, there is little published information on which CAM therapies might help those with Ménière's.

The initial idea for the project arose from the interest and enthusiasm of a long-term sufferer from Ménière's (TB); he has had Ménière's for more than 25 years. His personal experience of conventional medical treatment and the continuation of his symptoms with their major impact on his life led him to try CAM therapies, in particular given their general approach of exploring the individual person as a whole and within the context of their life environment. His positive experience with such therapies had led him to make his journey available to others in order to indicate that there were options beyond conventional medicine and just living with the deleterious effects of Ménière's.

While his original interest was to develop a project exploring the benefits of acupuncture, a CAM therapy which had helped him considerably, the project took a wider thrust. Part One involved the undertaking of a comprehensive literature review of published evidence on the safety and effectiveness of acupuncture treatment for Ménière's disease, across both English language and Chinese language sources. Part Two took the form of the collection and analysis of the narrative accounts of a self-selecting sample of persons with Ménière's disease who have used CAM as part of their treatment and care journey, recruited through newsletters of the Ménière's Society UK (*Spin*), the Ménière's Support Group of Victoria, Australia, (MSVG) (*Whirligig*) and via the Internet.

The research was undertaken as a collaboration between the Universities of Leeds and Salford and an expert patient. Initial funding for the research came from a small grant from the Research Development Fund of the University of Salford, to whom grateful acknowledgement is made.

This report provides details of the methods and findings from the personal narratives, the focus of Part Two of the research project. It is divided into four sections. Section One outlines the methods used in the study, in particular, the way that personal narratives from people with Ménière's were generated and the search of past letters from the quarterly

newsletter of the Ménière's Society UK. Section Two presents the findings for the personal narratives. Beginning with a short cameo of each participant, it provides insight into their journeys with Ménière's syndrome, their search for a CAM approach to help them, the nature of the CAM therapies that they found helpful (their CAM 'fix' / 'fixes') and the ways that they helped. Section Three presents the findings from the accounts provided in the letters from *Spin* and provides information on the fixes and their benefits. Section Four draws out the main conclusions and key messages arising from the research.

## **Methods: Illness Narratives**

### *Recruiting Informants*

A fourfold strategy was used to recruit participants to find out about their use and experiences of CAM therapies in the treatment of Ménière's syndrome, each pursued contemporaneously.

1. Web-page material providing information about the study (Appendix One), a guide to writing a narrative (Appendix Two) and consent form (Appendix Three) were drawn up. This information was posted on the University of Salford's web-site in the autumn of 2004. With the lead investigator (AFL) moving to the University of Leeds, web-page material was also posted on the University of Leeds web-site, linked to the core site at the University of Salford.
2. Contact was made with the Ménière's Society UK and the Ménière's Support Group of Victoria, Australia, (MSGV) to seek their help in making the project known to people with Ménière's. Each agreed to post an entry on their own web-sites which drew attention to the research and indicated how to take part in the research (a contact point and web-link to project materials at the University of Salford). Contact was made with MSGV given its known proactive role in providing information, advice and support to people with Ménière's.
3. Short articles were published in three relevant publications: *Spin*, the quarterly newsletter of the Ménière's Society UK; *Whirligig*, the newsletter of MSGV; and the monthly newsletter, *British Acupuncture News*, of the British Acupuncture Council. The latter publication was chosen given the base of the original idea for the project, to explore participants' experience of acupuncture for the condition. The aim was to draw the attention of the project to acupuncturists so that they might tell any of their own clients with Ménière's about the project (Appendix Four).
4. Past issues of *Spin* were reviewed for the years 2001 to 2006 inclusive by a member of the society to identify articles or correspondence relating to the use of CAM therapies in

the treatment of Ménière's. A copy of the material was then provided to the research team.

*Guide for the Narrative*

Potential participants were asked to write up their experience in their own words and send this to the research team. While there is debate in the literature about whether or not to give guidance to participants in writing their narrative (see, Elliott 2005, Robinson 1990), it was decided to provide a brief indication of the material that was being looked for and thus provide pointers to help the person write their story, while encouraging them to write their personal history in any way that they wished. It was suggested that they might find it helpful to think of their writing as a letter to a member of their family, or to a friend, with whom they would like to share their experiences. The guidance asked them to provide some background information (demographic details, symptoms of Ménière's, date of diagnosis and treatments advised by the GP and/or ENT consultant) and then to write up their personal history (impact of Ménière's on their life, use and experience with CAM, any recommendations for others) (see Box One).

**Box One: Guide for Writing Your Narrative**

**A: Background Information**

Please tell us about yourself and your Ménière's syndrome.

- Personal details (age, gender, approximate date diagnosed with Ménière's)
- Please can you give a brief description of your symptoms, their pattern over time and their severity.
- What treatments were you advised to have by your ENT consultant? And, which ones did you have?
- Were you advised to try any CAM therapies? If so, by whom, when and which ones?
- Which CAM therapies have you tried, and for approximately how long?

**B: Your Personal History**

Feel free to write your personal history, or journey with Ménière's syndrome, in any way that you wish. You may find it helpful to think of it as a letter to a member of your family, or to a friend, with whom you would like to share your experiences. Below we have listed some general pointers which you might find useful.

- The effect Ménière's syndrome has had on your life. The impact the symptoms have had on, for example, your family life, work, life-style and quality of life.
- The different types of CAM treatments you have used. Why did you try them? How did you hear about them – for example, through your GP, family, a friend, a magazine article, book or advertising
- The complementary medications or therapies you think were beneficial to you. The benefits experienced. The approximate length of time you have received the CAM therapies. If you are continuing with the CAM treatment. (You may have tried different treatments at different times and come back to them. Try and tell us about your whole journey.)
- A description of the difference that specific CAM treatments have had, or continue to have, on your condition.
- Other effects that you think the CAM treatments may have had on your life in addition to the impact they have had on your Ménière's syndrome - for example, on life-style, attitudes, etc.
- Any recommendation or advice for others about using CAM for Ménière's syndrome.

Following receipt of the personal narrative, it was read by two members of the research team (AFL, TB). Where appropriate, one or two further points of clarification were sought from the informant. These covered aspects of fact (for example, techniques used for relaxation, content of a 'healthy' diet or the total number of treatments) rather than requests to amplify their stories. The latter were perceived, as Frank (1995 and 1998) describes, as statements taken as the person's 'subjective interpretation of her or his situation' at that time and with a truth value at that time and from that perspective.

In one instance, after a detailed telephone conversation and subsequent writing of a short personal history, the informant expressed his wish to be interviewed. Using a semi-structured interview, questions aimed to enable him (and his wife who also took part in the

interview) to speak freely about his experiences and to follow up aspects from his short written account (Box Two). In another instance, the informant indicated that she was the subject of a published case report of long-term chiropractic care (Cowin and Bryner 2002), and a copy of the paper was retrieved.

### **Box Two: Interview Guide**

1. Can you tell me when you first became aware of the Ménière's symptoms?
2. Can you briefly describe how the symptoms have affected you?
3. Who diagnosed your Ménière's disease?
4. Can you say who, specifically, advised you to seek help from alternative medicine?
5. What types of alternative medicine have you tried?
6. You say that you saw a Dr [ ] 'once a week for nearly three years'. What did the actual sessions comprise? Can you describe the treatments that Dr [ ] uses/used?
7. You refer to 'additional support' from Dr [ ]. Can you describe the additional support provided?
8. You say that Dr [ ] advised a review of the medication you were taking in connection with epilepsy symptoms. Can you briefly describe this process?
9. Did Dr [ ], as far as you know, think there might be a connection between the medication you were taking for epilepsy and the Ménière's symptoms?
10. Do you want to make any other comments about your treatment from Dr [ ]?
11. Are you still receiving treatment from Dr [ ]?
12. If you have stopped receiving treatment, why have you stopped?
13. What particularly distinguishes the approach taken by Dr [ ] from that which you received from the NHS doctors?
14. Do you feel that you have played some part in your recovery and subsequent stability in your health or were you a passive recipient of the treatment from Dr [ ]?
15. Do you wish to make any further comments about your CAM treatment or treatment in general?

### *Ethical Issues*

Ethical approval for the research was provided by the University of Salford Research Ethics Committee. Potential informants were assured that their personal contact details would be kept secure (locked filing cabinet and password protected electronic database), their personal stories would only be read by members of the research team, and that their experiences would be anonymised in all oral and written outputs from the study. They could also withdraw their consent over the use of their stories at any time. To ensure anonymity, each individual has been given a pseudonym, drawn from Australian indigenous plant names and British wild flowers.

### *Data Analysis*

All the personal stories and any additional information from the informants were independently read and re-read by two members of the research team (AFL, TB). Initially,

particular interest lay in identifying the stages informing their narrative. Summaries of each narrative were drawn up, based around common headings representing distinct phases in the illness trajectory (first experience of symptoms, diagnosis and initial conventional medicine treatment, subsequent treatment experience including CAM treatment) and, for each, effects on quality of life and lifestyle in general.

Alongside, one of the team (TB) drew together a theoretical framework exploring 'the aspects and purposes' of CAM therapies. Five discrete aspects on which a complementary or alternative therapy might work were enumerated (mind-body connection; affecting the energy in the body; air water and nutrition; toxicity; and, physical structure and alignment) and CAM therapies which might fall into each was outlined. For example, the 'toxicity' aspect draws attention to the origins of possible toxins (for example, food processing, water, dead cells that accumulate as the body renews itself) and the ability of the body to deal with toxins. CAM therapies that address this factor would include: herbs (liver and kidney cleanses); massage (working on the lymphatic system); colonic therapy through fasting; and, diet changes.<sup>1</sup> The framework was used to aid understanding of the use of CAM therapies by informants.

Reading and re-reading the narratives and their summaries lead to the identification of a number of more abstracted and theoretical categories centred on the individual in the context of their own experience of Ménière's and treatments, environment and life (Box Three). The data were then reorganised under each theme and sub-theme to aid comparison in looking for differences and similarities.

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<sup>1</sup> A therapy might of course address more than one aspect (for example, Traditional Chinese Medicine); it would thus be mentioned under each.

**Box Three: Abstracted Categories and Themes and Contributory Categories**

**1. Journeys with Ménière's Syndrome**

- First Symptom to Diagnosis (diagnosis as key event; other key events in this phase?) and Early Treatment (its nature, their response, their feelings about it retrospectively)
- Recognising Triggers to Ménière's
- Overall Effect of Ménière's on their Life

**2. The CAM Therapies and their Effects**

- Prompts to Searching for a CAM 'Fix' (role of significant others; critical ill-health event)
- Locating a Satisfactory CAM 'Fix' (insight into the nature of personal trajectories)
- The CAM 'Fixes'
- Nature of the CAM 'Fixes'

**3. Living with Ménière's: Personal Change**

- Finding ways to manage (living with Ménière's)
- Personal journey / development (changing attitude to health, becoming a more proactive client, supportive doctor/practitioner-client relationship)
- Being open / opening up to other / becoming aware of new possibilities

## Section Two: Findings from the Personal Stories

### The Participants: Overview and Brief Cameos

Twenty participants were recruited and wrote a personal story, five from Australia and the rest from the UK. A few of the contributions were very brief, comprising only a short letter or e-mail; in contrast, following both a telephone conversation and submission of a personal story, one was extended to include a face-to-face interview. The search of *Spin* identified one other personal story and another personal story was provided by one of the research team.

A brief cameo of each of the informants is provided below. These aim to provide a short overview of each informant, their Ménière's journey and any CAM therapies that have helped. Box Four relates to the five cases from *Whirligig*, Box Five to ten arising from *Spin* and Box Six to the five recruited from the web-sites.

#### Box Four: Brief Cameos from Australia, Whirligig

**Acacia:** Female aged 55 years. Travels a long way to her clerical job work. First symptoms in 1974, told it might be Ménière's. Re-diagnosed with Ménière's in 1996, 9 years ago. Around 2003, she chose acupuncture; this, together with pranic healing and massage, has helped.

**Banksia:** 54 year old female, University Lecturer in English. First symptoms in April 1991, diagnosed with Ménière's later that year, 24 years ago. Participant in a seven-year case study report on the benefits of chiropractic treatment in relieving the symptoms of Ménière's. In 1993, found that manipulation via a chiropractor, has helped, a treatment with which she continues.

**Waratah:** Female, possibly an older lady. Diagnosed with Ménière's in 1984, 21 years ago. Bowen therapy has helped.

**Coolabah:** Female, aged 61 years. Diagnosed with Ménière's in 1989, 36 years ago. In February 2002 found Traditional Chinese Medicine (TCM) with herbs helped.

**Grevillea:** Female, aged 58 years. First symptoms in 1983 attack, diagnosed with Ménière's later that year. In 1996/7, began to seek alternative treatments (healing by prayer, TCM acupuncture plus herbs, and naturopath). Changes in diet (use of dietary supplements), together with conventional medicine (Stugeron) has helped.

**Box Five: Brief Cameos from the UK, Spin**

**Primrose:** Female. Diagnosed 3 years ago with Ménière's. Cranial osteopathy has helped.

**Aconite:** Male, in mid-40s. First symptoms and epilepsy when a student at University and diagnosed with Ménière's there around 25 years ago. His GP advised him to try alternative treatments, alongside drug therapy. He kept returning to his GP to check out that he was doing 'the right thing' – his GP indicated, 'yes ... and it is fascinating.' Found an experienced Peking, PhD-trained Pakistani doctor, who used acupressure, accompanied by some manipulation, suggestions on diet and natural remedies. These have helped and he has had no drug treatment for Ménière's for the last year.

**Amaranth:** Female, aged 50 years old. Worked as a machine operator but had to stop work due to her Ménière's. First symptoms around 1998, with hearing lost in left ear, diagnosed by ENT consultant in May 2001. Tried CAM before diagnosis (reflexology and reiki) but for a different reason (depression). A year or so after diagnosed with Ménière's, she decided to try alternative treatment. Found that acupuncture, massage, Chinese herbs and dietary changes all helped.

**Bellflower:** Female hotel manager, aged 47 years old. First experience of symptoms when she was first pregnant (nausea, vertigo, vomiting). Diagnosed with Ménière's 10 years later. Had surgery and has a hearing aid. More recently, she had changed her lifestyle and used reflexology and acupuncture which have helped.

**Bugle:** Older man. First symptoms about 20 years ago; after diagnosed with Ménière's and ear operation, he became deaf in his left ear. Tried homoeopathy, plus dietary changes (in particular, avoiding chocolate), both of which have helped.

**Campian:** Female, aged 56 years old, working as a staff nurse in a psychiatric ward. First symptoms in 1995; five years later, she self-diagnosed herself with Ménière's; the diagnosis was confirmed in 2001, after a bad attack. Tried medical herbalist, homoeopathic remedy and yoga, and began to recognise some of the triggering factors. Herbs have led her to be symptom-free.

**Chamomile:** Male aged 48 years old, working with/on computers for a living. Experienced first symptoms in 1993 and diagnosed with Ménière's two years later, now 10 years ago. Studied the disease on the Internet, and changed his diet, stopped drinking alcohol, and avoided food additives, especially mono-sodium glutamate. Tried homoeopathy and dietary changes, both of which have helped.

**Eyebright:** Female aged 38 years old, now training to become a homoeopath. First experience of symptoms in 1997 and diagnosed with Ménière's soon after (nine years ago). Following up the suggestion of her ENT consultant, she tried acupuncture and, from her own research, reflexology, chiropractic and homoeopathy. Each in different ways and at different times helped to control her symptoms.

**Angelica:** Woman in her 40s, who has had Ménière's for 10 years or so. Had to leave secondary teaching due to the effects of the illness. Sought alternative ways to cope, and has found that a change in diet (low salt, absence of pork products) and regular meditation has helped her.

**Daffodil:** Male aged 54 years, who experienced his first drop attack, aged 10. Diagnosed with Ménière's when aged 21, over 30 years ago. Over seven years had a number of medical procedures, with little perceptible benefit. Took early retirement from town planning profession when aged 37, only returning to regular work one year ago. Sought alternative approaches. Found that TCM including acupuncture and herbs, change in diet and NLP helped, along with growing self-awareness of the inter-relationship of mind-body and environment.

**Box Six: Brief Cameos from the Websites**

**Foxglove:** 67 year old, married woman, who worked as a health visitor. First attack in 1979 and definitive diagnosis of Ménière's in 1982. At that time, she became interested in alternative medicine for migraine attacks with an environmental allergist. Tried acupuncture and reflexology but their only value was for pain relief and relaxation.

**Hollyhock:** 87 year old woman. First symptoms in 2001, when she was aged 83 and diagnosed with Ménière's the following year. Started shiatsu for relaxation and general relief of tension, and the practitioner recommended TCM for Chinese herbal remedies, which initially she found helpful. She remains confident that TCM can help her.

**Honeysuckle:** 88 year old, married woman. Diagnosed with Ménière's in 1995. Tried acupuncture six months ago and no attacks since then.

**Saxifrage:** 60 year old man. Diagnosed with Ménière's in 2000. Prior to this, self-employed management consultant, and now a part-time Open University Business School tutor. In the early stages, he tried acupuncture, but apart from general relaxation did not detect any effect on his Ménière's.

**Speedwell:** 66 year old woman who is a retired lecturer in psychology. First symptoms in 1995 and diagnosed with Ménière's a year later. Had four sessions of acupuncture but no improvement; gave up, not pursued CAM route since. Relief eventually found a year ago from taking a mild anti-depressant.

## Journeys with Ménière's Syndrome

### *First Symptom to Diagnosis and Early Treatment*

#### *Initial Symptoms*

All the participants pointed to the sudden onset of their Ménière's with the occurrence of a number of physical and sensory effects. These included: ringing in the ears; severe hearing loss in one or both ears; tinnitus; dizzy spells; balance problems ranging from loss of balance to balancing difficulties when reaching or shutting their eyes; spinning; inability to stand or walk; nausea and vomiting; and vertigo. Typical comments included the following:

*A loud ringing in my ears and lost my balance. (Acacia)*

*I could not bear loud noises. (Banksia)*

*Orchestra in my head ... (Waratah)*

*Very dizzy, I could not get out of bed. (Primrose)*

*I suffered symptoms akin to being drunk ... (Symptoms occurred on and off)  
One day I suddenly went deaf in my right ear. (Campian)*

*Very violent attack when waking up - the room appearing to whiz round at high speed and sense of vomiting. (Foxglove)*

*Dizzy attacks ('I had to go to bed'), world spinning around; attacks accompanied by sickness and diarrhoea. (Honeysuckle)*

A few of the informants provided more extensive accounts. For example, on return from a holiday in Egypt, Eyebright developed a high fever and hearing loss in her left ear. She had a series of GP consultations followed by ENT specialist follow-up. There was a feeling of pressure and fullness in her left ear, which led to extremely loud tinnitus, severe hearing loss and hyperacusis. She commented: '*I become completely drained and can be withdrawn and depressed during a bad attack, as I am unable to bear any noise or contact with anyone.*' Her symptoms flared up with her first pregnancy, and about six months after the birth of her second child. Another (Daffodil) had been profoundly deaf in his left ear since childhood. He reports experiencing his first drop attack when aged ten. Whilst at work, 21 years old now, he experienced a sudden and almost complete loss of hearing in his right ear. Hearing returned after a month, but episodes of deafness and tinnitus lasting about two weeks occurred frequently every two months or so.

Some mentioned particular events or aspects of their lives that seemed linked to the beginning of their Ménière's. These included noise triggers (the symptoms coming on at an air show, Grevillea) or occurring after having an ear infection while on holiday (Speedwell).

It was notable that a number of the informants indicated that they also suffered from migraine (for example, Grevillea; Honeysuckle; Angelica).

Effects on work, social life and lifestyle would only be expected. The following examples illustrate this:

*The symptoms made for considerable difficulties at work and lack of understanding. (Acacia)*

'I became very introverted and anti-social', irritable, nervy, 'clenched jaw'; in summary, '(I became) impossible to live with'. It also affected her work. (Banksia)

*Couldn't walk without a stick or drive a car. Stopped work and affected social life. (Aconite)*

*(Vertigo attacks) stopped my working and kept me trapped at home.' Now need hearing aid. (Bellflower)*

*Unable to tolerate high noise levels (hyperacusis) that often triggered tinnitus and vertigo, it became progressively harder to teach effectively. Angelica)*

*Impacted on family and social life. (Daffodil)*

*Interrupted lifestyle. (Coolabah)*

*The initial impact on my personal and professional life was pretty devastating. The realisation that I no longer had control over my body hit me hard'. Impossible to maintain job as self-employed management consultant. (Saxifrage)*

*I lost confidence in travelling on my own. (Campian)*

In contrast, Grevillea commented that, initially, while the symptoms were 'unpleasant and inconvenient, but by and large it didn't stop me doing too much.' Her Ménière's 'had an effect on me and my family but not a huge one.'

Another extended account was provided by Bellflower, who had written about her experience in an article in *Good Housekeeping*, a copy of which she enclosed. It provides an illustration of the journey that some experienced before getting a definitive diagnosis. Early on she writes: 'I was six months pregnant and walking home when the whole world seemed to turn upside down.' This was accompanied by nausea, vertigo and vomiting. The GP diagnosed food poisoning, but the symptoms continued. The GP then diagnosed pregnancy-related low blood pressure and 'once I gave birth, the symptoms stopped'. Six years later, she had a recurrence - 'brain fog', nausea; 'I knew instinctively that if I moved the room would start spinning.' The GP diagnosed an ear infection. Ten years later, she had another attack, 'lying on the bathroom floor too scared to get up.... I felt fine by the end

*of the day.*' Then she seemed to be okay for the next two years but '*I began to develop an odd sensation when I was walking ... meant I had to stop and regain my balance*' – fuzzy head, nausea. The attacks were then happening daily and getting worse. The GP prescribed antibiotics for ear infections and pain killers and also offered anti-depressants. Eventually she saw a locum who referred her onto an ENT specialist, had a MRI scan, and she was finally diagnosed with Ménière's.

### *Early Treatment*

Nearly all were advised to take *Stemetil*<sup>2</sup> and *Serc*<sup>3</sup>, drugs which purport to help, respectively, with nausea and vomiting and pressure on the inner ear. The drugs initially seemed to provide some help. Typical comments were:

*Stemetil appeared to manage the symptoms, particularly episodes of vertigo and nausea. (Acacia)*

*(The drugs) worked for a short time. (Bellflower)*

*Stemetil helped to reduce impact of vertigo attacks and relieve dizziness. (But) took Betahistine for many years. Not sure it had any positive benefit. No change when stopped taking it. (Daffodil)*

It is notable that for some, as Bellflower put it, '*getting a diagnosis was fantastic.*'

Another was told at diagnosis by the consultant that there was '*no treatment*' and recommended to continue with *Beta-histamine* (*Serc*) which had been prescribed by the GP (Honeysuckle). Yet another (Chamomile) only contacted the NHS to get confirmation of his diagnosis. He wrote: '*no advice from any consultants in the NHS but have studied the disease on the Internet.*' (Chamomile)

Three of the informants were advised to adopt a *salt-free* diet (Aconite, Saxifrage) and to avoid *caffeine* (Grevillea, Aconite, Saxifrage), either by the ENT consultant or their GP. Another, who consulted privately, commented that the advice was minimal (Saxifrage). He was offered *Serc*, given dietary advice and advised to come back if vertigo attacks become disabling; then '*we can discuss surgical possibilities.*'

Three of the informants had a saccus decompression operation.<sup>4</sup> For one, this, together with *Stemetil*, '*improved the symptoms ... but my hearing was definitely impaired*'

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<sup>2</sup> *Stemetil* is a drug that is used to control severe nausea and vomiting.

<sup>3</sup> *Serc* is a drug whose active ingredient is betahistine, a medicine that closely resembles the natural substance histamine. *Betahistamine* aims to increase blood flow to the inner ear and is a diuretics, which may help decrease the pressure of fluid in the inner ear.

<sup>4</sup> This is a surgical operation on the endolymphatic sac of the inner ear. There are several variations. They aim to reduce the pressure of the fluid in the semi-circular canal.

(Grevillea). For another (Bugle), the operation left him deaf in his left ear, though, he comments, *'this could have been because I picked up the good old hospital infection.'* For Daffodil, *'the operation had no perceptible benefit.'* Two had a grommet inserted (*'this seemed to calm things down for a while'* – Amaranth; it *'relieved build-up of pressure in middle ear'* – Daffodil) while another informant refused one.

In only two instances was the informant advised to try CAM therapies. The first, Aconite, was diagnosed with Ménière's by his GP. The GP advised against *salt* and *caffeine*, prescribed *Serc* and recommended him to try alternative treatment. Aconite commented that he stopped taking *Serc* following consultations with his alternative practitioner. The second, Eyebright, was diagnosed by the ENT consultant who suggested she try *acupuncture*, which *'was fantastic for about four years.'* She was symptom-free after four months, but her Ménière's returned with another ENT consultant recommending *Serc*, and yet another at a later date steroid treatment directly injected into the ear (*'I have turned this down for the time being, as I am doing so much better'*).

One other informant (Campian) herself went to a herbalist, after initially being offered *Serc* by her GP, which she stopped after one week. She returned to the NHS for subsequent confirmation of Ménière's (following her own self-diagnosis) and she was offered drug treatment (intratympanic gentamicin) and later draining off fluid and a grommet; she refused all of these.

### **Recognising Triggers**

A number of the informants explicitly mentioned their growing appreciation of possible triggers to an attack or factors that aggravated their condition. Stress and physical factors (noise, movement, hormonal changes, and ill-health events) were particularly notable. More generally, Daffodil became more aware of the inter-connection between his emotional and physical states.

*I began to realise ... a negative emotional state led to a lower energy level, which in turn affected my hearing and tinnitus level. (Daffodil)*

Stress was identified by Acacia, Aconite, Campian and Speedwell (along with tiredness) as the main factor triggering an attack. For Aconite, it was the CAM practitioner who pointed to the significance of stress.

*He's told me that I'm under too much stress, I've got to relax, and I shouldn't be doing as much as I am doing. (Aconite)*

In his interview, while acknowledging the advice, Aconite is more sanguine about any change in his lifestyle:

*And in some ways I've taken note of it, but can't say I've responded to it as much as he would like, in that I probably should stop doing a lot of the work I do.' And: 'I should have seen him yesterday, but I got tied up in meetings all day, so I never saw him. He'll tell me off when I see him. And he will tell me off, he's quite categoric, he's no hesitation to tell me off. (Aconite)*

Physical factors might be multiple. Campian talked about the effects of loud music or noise 'that I could feel bounce off my eardrum,' getting angry or frustrated, motion as in a car journey or having one window open in the car (change of air pressure). Chamomile found that attacks would come after sitting still for a while (when he got up in the morning or after working on the computer which he does for a living). Chamomile and Eyebright also pointed to other physical ill-health triggers, including being congested, hormonal changes or colds and throat infections.

Two of the informants explicitly indicated how they had changed their lifestyle in order to manage better:

*If I even suspect a vertigo attack is on its way, I find a quiet place, sit down and do some special exercises I've been taught. (Bellflower)*

Hollyhock commented in a similar vein that she has 'learned to minimise the effect of vertigo' by lying down at once and, if possible, sleeping, thus avoiding spins and vomiting. She has also learned to distinguish between 'incipient' spins and more minor symptoms. At the same time:

*I have tried to discover what may bring on attacks, but without success (not stress, not seasonal – e.g. winter only) ... (but) I am generally better for plenty of rest, food, fresh air and the company of other people. (Hollyhock)*

Hollyhock had also changed her diet (as had a number of other informants) reducing her salt intake, coffee, chocolate and milk, and had cut out cheese.

### Overall Impact of Ménière's

Graphic insight into the overall impact of Ménière's on informants' lives was provided by a number of the stories. Some examples are presented below.

Acacia draws attention to other people's lack of appreciation of her problems and her constant fear of having an attack 'wherever I go.'

*Ménière's has changed my life in that people do not understand the problem or recognise I have a hearing problem and the fear of an attack is ever present*

*wherever I go. I always carry with me a plastic bag in case I am sick, plus my Stemetil. At work, my boss is not understanding of the problem.... And other staff members are disrupted with me needing assistance to get to the ladies or the sick room. (Acacia)*

A number of informants speak of the effects on their emotions, fear of an attack and confidence. Eyebright talks about Ménière's unpredictability and the impact of emotional symptoms, even more than the physical.

*Ménière's is a dreadful illness – it is the unpredictability which is so awful, and the fact that you live in fear of what is going to happen next .... The emotional symptoms are probably worse than the physical on really bad spells. (Eyebright)*

The effect on emotions is reiterated by Campian, who commented that 'I lost confidence in travelling on my own.' Similarly, Hollyhock talks about her fear of 'being caught out' by an attack.

*I am rarely free of anxiety about Ménière's; fear of being "caught out" by an attack in the wrong place, constant awareness of little signs and symptoms.... I feel that it is good that I recognise these psychological effects and try to remain positive.... I suppose all this has affected my quality of life... but it has not seriously affected my family life and I continue to work as a gardener. (Hollyhock)*

Saxifrage wrote in a similar vein:

*The initial impact on my personal and professional life was pretty devastating. The realisation that I no longer had control over my body hit me hard and I had to seek treatment for clinical depression in the first year or so. (Saxifrage)*

A number of the informants had to give up their jobs because of their Ménière's (for example, Saxifrage, Angelica, Daffodil). Saxifrage was a self-employed management consultant, Angelica a teacher and Daffodil a town planner. Saxifrage later started to run a Ménière's Support Group,

*(which) has helped me come to terms with my condition. It has also demonstrated that there are many sufferers from this condition who are far more severely affected than I am. (Saxifrage)*

Daffodil, aged in his mid-30s, gave up his job and moved with his family to a rural location in the North of England. He was able to take up regular paid working just one year ago, aged 53.

## The CAM 'Fixes': The Search for an Alternative and Its Outcome

### ***Prompts to Searching for an Alternative: The Roles of a 'Significant Other' and Significant Events***

Sometimes participants' stories pointed to particular individuals or events that were significant influencing factors in their seeking alternative treatment to that provided by their GP or ENT consultant. This is contextualised against the common situation where no alternative treatment apart from drugs or surgery (and, more rarely, dietary changes) was mentioned to informants. As Coolabah simply stated, '(I was) never advised to try any complementary or alternative medicine.'

The most 'significant other' for Aconite was his GP. In his interview, Aconite commented:

*My GP said to me that he recommended alternative medicine as being good, sound and well worth trying. I asked him for a name and he said he wasn't allowed to give me a name. He suggested that I looked round and tried to find someone myself, but he would certainly recommend the ... value of going to this. (Aconite)*

Perhaps as recognition of the symbolic importance of the GP's suggestion, after consultations with the CAM practitioner, Aconite went back to the GP to keep him informed and check out with him what was being recommended. The alternative practitioner also encouraged him to do this.

*Certainly every time I saw him [CAM practitioner] I would go back to my GP and say "Look, this is what he's recommended me to have, are you happy with this?" My GP always said to me, "No objection at all, go ahead with it". ... And on several occasions, as a result of Dr [CAM practitioner]'s recommendation, I went back to my GP who said "OK, we'll check it out with the consultant". And I've subsequently seen the consultant on the national health. (Aconite)*

For another, the 'significant other' was her employer, a chiropractor. In her short account, Primrose wrote:

*I have tried chiropractic, and homoeopathy without success. I actually work for my Chiropractor and she recommended that I try Cranial Osteopathy. (Primrose)*

For two other cases (Bugle and Honeysuckle) it was a family member who suggested trying a CAM therapy. For Bugle, it was his son, who suggested trying a homoeopathic remedy which he had located on the Internet. Use of the Internet is noteworthy as it was this route alone that Chamomile followed; he contacted the NHS only to confirm his diagnosis. Again, as it happened, he also chose a homoeopathic remedy. For Honeysuckle, it was her daughter, who suggested trying acupuncture.

For Daffodil, a number of significant others were evident. He recounts:

*A friend for whom I have tremendous respect said to me one day that it was not necessarily the case that my condition would deteriorate and that he might be able to help me. That was about 7 years ago. (Daffodil)*

The significant other, a NLP Master Practitioner, introduced him to the idea: '*think about my condition in a different way ... start by thinking caring thoughts about my ear.*' His friend also talked about the connection between thoughts, emotions and one's physical state. '*My friend ...succeeded in setting me on a different road – the road to taking greater responsibility for helping myself and my well-being.*' Another friend, a practising Buddhist, introduced Daffodil to meditation; a chance encounter of his wife in the local Post Office led to contact with a reiki practitioner; and later on, he was introduced to a Chinese doctor, practising TCM. All of these influences contributed to Daffodil's own personal growth, awareness and sensitivity to '*the relationship between emotional state and my symptoms.*'

Most commonly, it was a critical event or series of events that led informants to seek out alternative treatment: for example, an increased frequency of attacks, their ongoing nature or the increasing impact/severity of their Ménière's. For some, it was a desire not to pursue invasive treatments:

*Not wanting to take “drastic measures” of injections into the ear drum or more medication, I chose to seek further help myself. (Acacia)*

Together with the increasing frequency of attacks (3-4 times a week), Acacia wrote:

*I needed to do something to stop the attacks or at least alleviate them to a more manageable level. (Acacia)*

Another (Angelica) pointed to '*a notable deterioration of my quality of life caused by Ménière's*', leading her to '*seek alternative ways of living*'. She began meditation, searching through the *Spin*, other fact sheets and literature, eventually coming across a book on migraine and epilepsy.

For others, it was being told that there was no cure. For example, two years or so after diagnosis, Banksia was also told that she had tinnitus and that there was no cure. She wrote:

*Medically, nothing could be done ... I was left to determine whether “non-medical” treatments would give me any relief. (Banksia)*

She decided to try chiropractic, following some neck massage. '*I thought there had to be some connection with the ear and the spine!*' (Banksia)

For yet others, it was the occurrence of a major critical event. Ten years or so after her diagnosis with Ménière's, Coolabah '*blacked out whilst nursing my 4 month old grandson*', fell and fractured her skull. The blackout was put down to Ménière's. '*I then felt it necessary to take a more proactive approach to my problem.*' Again, ten years or so after her diagnosis, Grevillea writes:

*Intermittent attacks 'caused increased disruption and concern for family ...It was very hard on my husband in particular and there were times when we both felt quite desperate. (Grevillea)*

For Campian, it was the occurrence of the critical event of going deaf in her right ear, confirmed by a senior house officer work colleague, which led to the following:

*And so off to the consultant again. By early 2000 [five years after her first symptoms] I sat down and looked through my medication books and came up with a self-diagnosis of Ménière's syndrome and went off to the herbalist for a cure. (Campian)*

For one other informant (Amaranth), whose life had been effected by multiple personal trauma (breast cancer; 50 year-old sister-in-law dying of a brain haemorrhage; husband's collapse, falling down the stairs, fracturing his skull and dying; auntie and mother dying – all in the space of a year or two), these, together with deterioration in her Ménière's, led her to try alternative treatment.

For yet another informant (Foxglove), it was her migraine that sought her to seek alternative treatment. She consulted an environmental allergist, who was also medically trained, who tested for food and chemical intolerances. '*When informed of my MD (Ménière's Disease), (he) advised strongly against any surgery*', pointing towards the possible risk of permanent deafness in the affected ear). He '*connected migraine with MD attacks*', saying the two often occurred in the same patient, and that the same treatment would relieve the symptoms of both.

Finally, as part of her search for an alternative treatment, Speedwell indicated that, soon after diagnosis and given her previously successful use of acupuncture for menopausal water retention, she tried acupuncture for her Ménière's. As it turned out, this did not provide any additional benefit.

*I did not pursue the CAM route as the medication prescribed by the ENT consultant was reasonably successful. (Speedwell)*

Nine years later, after a recurrence and more general deterioration in her health, she '*did not want to bother anyone (the medics) again*' commenting on some medics' attitude of '*go away and live with it.*' But at her husband's insistence when she became even more ill, she

was recommended to take a low dose of an anti-depressant. Here, the 'significant other' became a '*very supportive and conscientious*' senior GP partner.

While this section has focused on the role of a significant other in helping to identify an alternative treatment, significant others, in particular, family members or close friends, may have played a highly supportive and thus 'significant' role for the person with Ménière's. The case of Speedwell provide one example ('*without my husband I do not think I would have survived*'); others include Aconite (the role of his wife, for example, at a minimum in enabling dietary changes) and Daffodil (his wife, '*who stood by me in very difficult times*', and his two children, '*who show sympathy and understanding towards (my) communication difficulties*'). In addition, once a possible alternative was identified, the importance of the nature of the relationship or strong bonding with a practitioner achieved enormous significance. For example, Eyebright talks of her '*brilliant therapist*', Grevillea of the importance of who to choose as a therapist ('*not just anyone ... one that had completed acupuncture at recognised colleges, as opposed to doctors who do a day course*'), Hollyhock that '*I have confidence in my therapist*' and Aconite of the impact of his long-term involvement with the same CAM practitioner (for example, in also enabling a reduction in his medication for epilepsy).

### ***Insight into their Journey: Locating a Satisfactory CAM Alternative 'Fix'***

To illustrate the diversity of the journeys taken by informants in locating a satisfactory alternative way forward to manage their Ménière's, a set of short case studies are presented. These are characterised by the term 'fix' or 'fixes'. This is used to have the connotation of 'sticking together to help "mend" something' and 'something being mended with someone else' (the notion of partnership in a client-practitioner interaction). It is not meant to imply or to be taken to imply that the person with Ménière's disease has been fixed, that is, their Ménière's had been resolved and sorted out. It represents rather the person's current way(s) of managing and coping with their Ménière's. The three sets of case studies were chosen to illustrate a number of dimensions: the length of time taken to locate a helpful 'fix' (short vs. longer time); the role of others in locating the 'fix' (own vs. other's suggestion); and the type and nature of the 'fix' (CAM vs. non-CAM, simple vs. complex).

#### **CAM Fix, Self-Found in a Shorter Time Frame**

The first set of case studies looks at four cases where the informants had found a way to assist and manage their condition in a shorter time frame using one or another CAM modality (Amaranth, Chamomile, Aconite and Hollyhock).

### Case Study: Amaranth

Experiencing her first symptoms of Ménière's when aged 43, Amaranth experienced multiple personal traumas over the next three years, including personal ill-health and multiple bereavements. She sought advice from an ENT consultant for her Ménière's and was diagnosed aged 46. A grommet was inserted and she used Serc. Initially, this seemed to '*calm things down for a while*' but four months later the Ménière's came back. '*I decided to try alternative therapy*', in particular, acupuncture where the practitioner gave her acupuncture, massage and some Chinese herbs. '*In one month I spent £600. But the relief was worth it.*' She had used reflexology and reiki before for depression. Subsequently she had a number of free acupuncture sessions, offered by a voluntary group and then through attendance at a student, supervised University clinic. '*I also changed my diet to Low-salt and did research of what things to avoid.*' She has not been able to return to work (she worked as a machine operator).

### Case Study Chamomile

Chamomile experienced his first symptoms when aged 36 years old and was diagnosed with Ménière's two years later. A more serious set of attacks occurred eight years later. He suffered an attack every other day: '*they would last for several hours and completely incapacitated me.*' He took *Stemtil* to control them, '*which I had not needed before.*' Being keen to avoid medicines in general, he '*... studied the disease on the Internet.*' He identified a homeopathic remedy (*Nat Mur*) for nasal congestion ('*useful in reducing the severity of attacks*'), and used sea sickness wrist bands, when flying and during the last set of attacks ('*helps reduce the vertigo*'). He has not consulted a homoeopath, but examined a self-help book at *Boots, The Chemist*. He has also made '*several other changes to help,*' including changing his diet to vegan, stopping drinking alcohol and avoiding food additives, particularly mono-sodium glutamate.

### Case Study Aconite

Aconite experienced his first symptoms when studying at University and was diagnosed soon after. His GP prescribed Serc and advised him to avoid salt and caffeine; '*this had an effect and improved the situation.*' The GP also recommended that he try alternative medicine. Aconite had no prior knowledge of Eastern medicine, food therapy or any alternative therapy. Having talked to a friend whose wife had been having complementary therapy for some time, he was recommended to an experienced Peking, PhD-trained Pakistani practitioner who has treated him ever since.

*Within a few weeks I had gained strength dramatically and following regular treatment, the symptoms, which included a missing heart beat, slowly disappeared and my life began to return to normal.*

Treatment included acupuncture (sometimes accompanied by manipulation), dietary changes and some natural remedies (for example, one based on musk). The practitioner also advised a close focus on food, asking Aconite to keep a food diary, and making recommendations at subsequent appointments about trying to cut out one food or another, reintroducing it, and so on. The approach could be characterised as *'try this gradually, see what happens. If it works carry on.'* In consequence,

*X's treatment has removed the bulk of my symptoms arising from Ménière's disease and I am now able to walk unaided and travel by public transport without difficulty. I have been able to return to work and my life is slowly returning to a peaceful way of living without constant concern ...*

The practitioner also queried Aconite's earlier diagnosis of epilepsy and recommended reduction of the medication he was taking, an approach that Aconite checked out with his GP and the consultant neurologist and then adopted: *'(this) has again made an enormous impact on my life.'* For the last year, he has been able to stop taking Serc.

### **Case Study Hollyhock**

Having her first symptoms of Ménière's when aged 83 years old, following diagnosis two years later, Hollyhock began, and continues, to take Serc, reducing the number of tablets from time to time. Aged 86, being relatively symptom-free, she began to have *shiatsu* for relaxation and general relief of tension. However the symptoms returned a few months later. After reading a book about TCM, she talked with her *shiatsu* practitioner, who recommended a TCM practitioner for herbal therapy. She has since had eight visits over the last eight months, involving a 12-day course of Chinese herbs, each time adjusted to her current situation. She wrote: *'I enjoyed taking the herbs, had confidence in my therapist and recognised a definite improvement.'* She notes that the number of spins has decreased, and minor symptoms such as blocked ears and tinnitus occurred off and on (but *'these don't greatly bother me, my major concern always being "spins"'*). As advised, she then stopped taking the herbs, but the spins restarted, though were not so severe. She then saw the TCM practitioner again, retook the herbs, and also received

*acupuncture* for the first time. She concludes: *'Although the resumption of symptoms was a disappointment, I remain confident that TCM will help me.'*

#### Non-CAM and CAM Fix, Medium Time Frame

The second set of case studies looks at three cases where the informants had found a way to assist and manage their condition over the medium term; two (Hollyhock and Saxifrage) had found a non-CAM 'fix' and one (Eyebright) a CAM solution.

#### **Case Study Speedwell**

Experiencing her first symptoms aged 53, and diagnosed a year later, Speedwell was prescribed *Serc* and *Stemetil*. *'No mention was made of complementary medicine.'* She had previously received successful acupuncture treatment for menopausal water retention, and so tried acupuncture for her Ménière's. After four sessions, there was *'no improvement whatsoever and no help with the Ménière's symptoms.'* She did not pursue the CAM route as the prescribed medication was *'reasonably successful'* (having only occasional days of vertigo, no vomiting and her hearing in the left ear improved a little after six months). She writes: *'I learned to live with these occasional bouts as during the periods in-between I felt "normal".'* She was able to carry on her job as a lecturer. A year ago, Speedwell had to cease work following two severe bouts of flu, with vomiting and vertigo, which exacerbated her Ménière's. She recounts:

*I did not consult any doctor as I was taking the maximum medication recommended by [ ] (ENT consultant) and understood from him that there was no other medication available. I did not consider any CAM – if prescribed medication did not work, I didn't consider that alternative therapies had a chance! Also with the attitude of "go away and live with it" from some medics, I did not want to bother anyone again!*

Finally, falling desperately ill, her husband, who had become her carer, contacted the GP. Soon she was a little better and had a consultation with a *'very conscientious and supportive senior partner.'* He prescribed a low dose anti-depressant, *Dosulepin*. A year or so on, she was much improved: *'I can function normally within boundaries and life feels good again.'*

#### **Case Study Saxifrage**

Saxifrage was diagnosed with Ménière's when aged 55. He consulted privately; he described the advice given as *'minimal'*: to reduce the salt in his diet, take *Serc*, consider eliminating caffeine and to come back *'if vertigo attacks become disabling.'* Some time afterwards, he went to an acupuncturist, twice a week for a month, then

once a week for three more months. But, *'apart from helping with general relaxation, I did not detect any positive benefit... so (I) terminated it by mutual consent with my acupuncturist.'* Other than a dietary supplement (Ginkgo), he does not now take any specific CAM therapies. Ménière's had a major impact on his life, forcing him to give up his job as a self-employed management consultant. Following his experiences, he started to run a local Ménière's Support Group *'which has helped me greatly to come to terms with my condition.'*

### **Case Study Eyebright**

Experiencing her first symptoms of Ménière's aged 28 and diagnosed soon after, Eyebright writes: *'being told ... that there was basically nothing I could do to improve my quality of life, and that I would have to "just cope with it", I started looking into complementary and alternative therapies.'* Her first ENT consultant suggested trying acupuncture, which she did. This *'was fantastic for about four years, I found a brilliant therapist.'* Eyebright was symptom-free after four months and continued this way until she became pregnant with her second baby; she returned for acupuncture which helped again. Six months or so after the birth of her baby, her symptoms recurred. Her previous acupuncturist had left, so she tried three others but without experiencing the same success. In this time period, she also saw another ENT consultant, who prescribed Serc (which helped for a couple of months and then did nothing, *'so I stopped taking it'*).

All this led her to try other therapies, chosen from her own research. Firstly, there was reflexology *'which was great for about one year.'* Then she hit another *'bad spell ... everything I did led to an aggravation in my symptoms.'* Secondly, she increased the number of foods she was avoiding (wheat, alcohol, salt, dairy, gluten), and then tried chiropractic monthly for 18 months. *'This helped a lot, although I would experience flare-ups after each treatment.'* Thirdly, three years ago, she began training to become a homoeopath and has had regular homoeopathic treatment since then. She comments: *'(this was) particularly helpful to cope with the emotional symptoms - the withdrawal, loneliness and depression ... (and) acute episodes.'* The remedy, *Nux Vomica*, helped to speed up the episodes and decrease their severity. Fourthly, she saw yet another consultant who suggested a steroid treatment directly injected into her ear (which she turned down *'for the time being as I am doing so much better'*). Finally, she returned to having a weekly reflexology session, which she has continued for the last eight months.

### CAM Fix, Ongoing Search, Self-Found

The third set of case studies looks at two cases where the informants took a long time to find a positive way forward; both involved an ongoing search. The first (Foxglove) used a predominantly CAM fix and the second (Daffodil) initially went down a non-CAM route with marginal success and over time found a CAM fix.

#### **Case Study Foxglove**

Foxglove's journey has similarities with Aconite in her progressive, but continual search for an ongoing resolution of her problems with the same practitioner. She experienced her first symptoms aged 41 and was diagnosed three years later. She notes: *'at the time I had become interested in alternative medicine for migraine attacks, with an environmental allergist who was also medically trained. When informed of my MD (Ménière's), (he) advised strongly against any surgery'*; he connected her migraine with the Ménière's attacks, saying the two often occurred in the same patient, and that the same treatment (desensitising, foods to avoid, *Mycostatin* drops for intestinal candidiasis) would relieve the symptoms of both. Over the next ten years, she re-attended the clinic for re-testing and supplies of the drops, with further intolerances being identified (for example, to mould). More recently, aged 65, her balance was severely affected by her Ménière's. While confined to bed, and taking *Stemetil*, she read about the potential benefit of *Valium* for vertigo and asked her GP to prescribe some. This *'reduced further attacks of vertigo to two hours! And even reduced the vomiting.'* She also re-contacted the allergy clinic, was re-tested and found sensitive to dust-mite, recommended a regular injection and to adopt a sugar and wheat-free diet. During these years, she also tried acupuncture and reflexology, *'but as far as MD is concerned the only value was in relaxation or pain relief.'*

#### **Case Study Daffodil**

Diagnosed with Ménière's aged 21, Daffodil initially had a range of treatments from conventional medicine. These included taking *Serc*, having a sacchus decompression operation, taking *Urea* salts, having a grommet inserted and *Stemetil* tablets and suppositories over a 7-8 year period. They had varying effects, from *'no perceptible benefit'* from the operation to *Stemetil* helping to reduce the impact of vertigo and tinnitus. Before his sacchus decompression operation, he had tried a number of complementary therapies, including reflexology, acupuncture and homoeopathy; but *'the practitioners talked about things like change in lifestyle, which unnerved me.'* Just 7 years ago, a friend, a NLP Master Practitioner, introduced him to two ideas: to think *'caring thoughts about my ear'*; and the connection

between thoughts, emotions and physical state. *'My friend ...succeeded in setting me on a different road – the road to taking greater responsibility for helping myself and my well-being.'* Another friend introduced him to meditation; another, to contact a reiki practitioner and yet another, three years ago, to contact a Chinese doctor, practising TCM. *'By this time, my attitude towards, and belief, in the healing process had changed.'* He was making connections between energy levels, hearing and tinnitus and developing his own awareness and sensitivity to *'the relationship between emotional state and my symptoms.'* He concludes: *'I have been treated with acupuncture and herbs and a prescribed diet for just over three years'*. This has led to stability in his condition. He maintains this through diet (nutrition), deep relaxation, Tai Chi Qigong, along with his own continuing *'personal development to promote positive mental and emotional activity.'*

### **The CAM 'Fixes'**

Each of the case study illustrates the diversity of journeys and pathways taken by the informants to find a 'fix' or set of 'fixes' that helped for some or all of the time. They also demonstrate the struggle that individuals had gone through to find what might work for them, and the importance of others' in guiding, influencing and supporting their choices. No single CAM solution or pathway was evident.

Using the 'aspects and purposes' framework, the CAM 'fixes' that informants arrived are summarised in Box Seven. This reinforces the message from the case studies, that there was no single 'fix', but rather a range of therapies and several in combination with one another. *'Toxicity related'* therapies, such as Chinese herbs, multi-vitamins, anti-oxidants and personal dietary changes were most mentioned (these forming part of the chosen treatment path for 13 of the 20 informants). Next most important were *'energy related'* therapies (mentioned by 9 out of the 20 informants), including CAM therapies such as acupuncture, shiatsu, acupressure, Bowen and reflexology; next most mentioned was *'body alignment'*, through use of chiropractic, manipulation or cranial osteopathy.

It is notable that two informants found relief in use of a non-CAM treatment, one (Speedwell) through use of a low-dose anti-depressant, after unsuccessful, if very short, use of acupuncture, and another (Foxglove) a tranquilliser. Another (Saxifrage) initially had acupuncture but with little success, but found that the personal support he gained from the Ménière's Support Group he started and ran was highly significant. Finally, it is important to note that a number of the informants continued use of *Stemetil* or *Serc* alongside their use of CAM therapies (for example, Acacia, Grevillea and Hollyhock).

Box Seven: Overview of the Individual Fixes

CAM Fixes	Example	Cases
Mind-Body + Toxicity	Meditation (positive thinking), dietary changes (low salt and no pork), multi-vitamins (Niacin and trace elements)	Angelica
Energy Related	Acupuncture Acupuncture, pranic healing and head massage (plus non-CAM, <i>Stemetil</i> ) Acupuncture plus lifestyle changes Bowen therapy	Honeysuckle Acacia Bellflower Waratah
Energy Related + Toxicity	Acupuncture, massage, Chinese herbs	Amaranth
Energy Related + Air / Water / Nutrition + Toxicity	Reflexology, dietary and homoeopathic remedies	Eyebright
Energy Related + Body Alignment + Toxicity	Acupressure, manipulation, dietary and natural remedies	Aconite
Energy Related + Air / Water / Nutrition + Toxicity + Mind-Body	Acupuncture, herbs, NLP, dietary changes, personal self-awareness	Daffodil
Air / Water / Nutrition + Toxicity	Homoeopathy (tinnitus remedy) and dietary Homoeopathic remedy, dietary changes	Bugle Chamomile
Toxicity	Herbs from TCM practitioner Multi-vitamins, anti-oxidants ( <i>Revenol</i> ) (plus non-CAM, <i>Stugeron</i> )	Coolabah Grevillea
Toxicity + Air / Water / Nutrition	Herbal predominantly and homoeopathy	Campian
Toxicity + Energy Related	(Shiatsu), Chinese herbs, acupuncture, dietary (plus non-CAM, <i>Serc</i> )	Hollyhock
Toxicity + Non-CAM	Chemical and food sensitivities (plus, non-CAM, use of <i>Valium</i> )	Foxglove
Body Alignment	Cranial osteopathy	Primrose
Body Alignment + Toxicity	Chiropractic, Feldenkrais exercise and dietary	Banksia

Non-CAM Fixes		
Drug	<i>Dosulepin</i> : low-dose anti-depressant <i>Valium</i> , a tranquilliser	Speedwell Foxglove
Other		
Personal Support	Tried acupuncture; now use only herbs (gingko) – personal support	Saxifrage

## Effects of the 'Fixes'

As the previous section has illustrated, multiple pathways to the various 'fixes' were followed. The different 'fixes' worked to different degrees and lengths of time for the informants. One of the major messages arising is that of the *personal nature of the journey*. The current section tries to separate out and summarise the positive or other experience of the various CAM alternatives used by the informants, using the fivefold 'aspects and purposes' classification, building on Box Seven.

### 'Energy Related' as Dominant Aspect

Experiences from those who tried *acupuncture* were varied. There was no perceived effect for four informants (Grevillea, Primrose, Saxifrage and Speedwell); for two others (Primrose and Saxifrage) its benefit was only in '*helping with general relaxation*' (Saxifrage) and '*pain relief*' (Primrose). One of these (Speedwell) only had four sessions before giving the therapy up, while another (Saxifrage) had treatment over a four-month period (twice a week for a month, then once a week for three months). In contrast, five informants (Acacia, Amaranth, Bellflower, Honeysuckle and Daffodil) found that acupuncture (for some in combination with other therapies) had a noticeable benefit on their Ménière's (and other aspects).

*I have just completed a course of acupuncture and at the moment my health is excellent. All I can say is, I hope it continues. (Bellflower)*

*I have not had an attack since...and am continuing with the acupuncture. (Honeysuckle)*

*The whole process was 'very relaxing'. 'The treatment appears to have managed the symptoms along with the use of Stemetil. (Acacia, acupuncture, pranic healing and massage)*

*I have had a big improvement in my quality of life. I still get the tinnitus and vertigo but not to the extent that I was hurting myself (due to falling over). It has changed the way I do things. (Amaranth; acupuncture and herbs)*

*TCM acupuncture and herbs and nutritional regime over a period of time brought about stability in (my) condition. (Daffodil)*

Other energy therapies found beneficial were *acupressure*, *Bowen* and *reflexology* (Aconite, Waratah and Eyebright) though one other informant (Primrose) only experienced general relaxation and pain relief, rather than any reduction in her Ménière's symptoms.

*X's treatment has removed the bulk of my symptoms arising from Ménière's disease and I am now able to walk unaided and travel by public transport without difficulty. I have been able to return to work and my life is slowly*

*returning to a peaceful way of living without constant concern. (Aconite, acupuncture, alignment, plus dietary, homoeopathic / natural remedies)*

*I am able to stand with my eyes closed for a short space of time (e.g. when showering and washing hair) ... (I still don't use escalators) as when I step off escalators, the world spins! (Waratah, Bowen therapy)*

*I have now reached a stage where I am only having a couple of bad days a month. The difference is fantastic, and I would definitely put this down to reflexology this time. (Eyebright, reflexology currently, together with homoeopathy)*

#### 'Air / Water / Nutrition Related' as Dominant Aspect

Homoeopathy and/or self-chosen homoeopathic remedies was tried by five informants (Primrose, Bugle, Campian, Chamomile and Eyebright), all but one (Primrose) with some success.

*(It was) particularly helpful to cope with the emotional symptoms - the withdrawal, loneliness and depression ... (and) acute episodes.' Regular homoeopathic treatment for last three years. (Eyebright)*

*These (remedies) had varying success. (Campian)*

*(After one month's supply of the tinnitus remedy) I could listen to my car CD and converse quite well with everybody... the spin attacks and drops, which I had been having, stopped and have not returned to this date. (Bugle, self-care, not under a homoeopath)*

*(The homeopathic remedy was) useful in reducing the severity of attacks. (Chamomile; self-care, studied on Internet and consulted self-help book at Boots; he also uses sea-sickness write bands)*

#### 'Toxicity Related' as Dominant Aspect

For three informants (Coolabah, Hollyhock and Campian), use of Chinese herbs had a profound benefit.

*After a time I began to feel sufficiently confident to venture out and not experience an attack. I gradually reduced the dosages ... (and had) no further attacks. (Coolabah; note that the product then became unavailable and the symptoms returned; then it became available again; she retook the herbs and has been attack-free for the last three years.)*

*Over this period, the number of 'spins' gradually decreased, leaving what I call 'wobbles'; but these too grew less, leaving just occasional 'floaty feelings' (Hollyhock - eight visits over the last eight months, receiving a 12-day course of Chinese herbs, each time adjusted to her current situation)*

*When I went to see the herbalist I thought that I would come away with just ease of symptoms until the op. After six months treatment I was symptom-free and have been so to this date. (Campian)*

Another made extensive use of anti-oxidants and multi-vitamins, while continuing with his non-CAM treatment. He comments:

*So that is seven years, no attacks, having a life.... Maybe it was the combination of Stugeron + Revenol + me = Success.... I am now able to hold down a full-time job (for the past 5½ years), have travelled overseas twice, and take part in many other activities. (Grevillea)*

Taking multi-vitamins containing Niacin and trace elements formed one part of Angelica's approach. While she remained sceptical about the extra vitamins, when running out of her medication, '*within five days the vertigo and tinnitus crept back like old ivy up the drainpipe.*'

Another (Foxglove), following advice from her environmental allergist, made substantial changes to her diet. After her first set of desensitising sessions and take-up of the advice, she writes:

*After six weeks I was able to leave off my medication and the tinnitus and deafness had dramatically subsided ... [She had more tests over the next ten years.] I was practically symptom-free except for the odd dizzy day for a number of years. (Honeysuckle)*

Upon resurgence of some of the symptoms, she had more sensitivity tests and made further changes.

#### 'Body Alignment Related' as Dominant Aspect

Three informants (Banksia, Primrose and Aconite) had used one or another body alignment therapy. Banksia reported substantial success with chiropractic. She continues to have chiropractic care with the same practitioner as a form of '*health maintenance*'.

*The support and reassurance of the chiropractor has given me back my lost confidence and my self-esteem. I am now able to work more effectively, socialise normally (except to avoid loud concerts and noisy restaurants) and to cope with my life again. (Banksia – used over the longer term)*

While Primrose tried chiropractic '*but without success*', following advice from her chiropractor she tried cranial osteopathy which worked for her.

*I have a treatment every 3-4 weeks and have a life back again. Still get attacks but not as many, can walk for 45 minutes, and periods when she can concentrate for an hour at a time, before needing a break. (Primrose)*

For Aconite, his alternative practitioner occasionally supplemented acupuncture with manipulation. Together, with other approaches including dietary changes, the treatment(s) '*removed the bulk of my symptoms.*'

### 'Mind-Body Related' as One Aspect

Only two informants (Angelica, Daffodil) mentioned *mind-body* related therapies. In neither instance was it evident that these were dominant, as opposed to one part of a multi-faceted approach (especially Daffodil) to managing their Ménière's symptoms and its effects on their lives. Angelica talked in terms of using meditation which was '*beneficial by switching to a more positive thinking but it was not enough*'. Dietary changes, which she made later, led to an enhanced effect. She comments:

*Cautiously I decided to try a diet of fresh fish,... (and) cut down on sugar .... For six months, I experimented and monitored my progress. To my surprise after three months of cutting out all pork products, switching to decaffeinated tea and taking multi-vitamins containing Niacin and trace elements, I actually felt some improvement. (Angelica)*

She continues, '*combined with meditation, I felt better than I had done in years.*' For Daffodil, discussions with a NLP (neuro-linguistic programming) therapist over a number of years, leading onto his own informal training in NLP, provided one part of his approach to managing the illness. Foremost were issues relating to perceiving a linkage between attitudes and beliefs to health and lifestyle affecting his own physical state.

### Non-CAM Approaches

Two informants (Speedwell and Foxglove) eventually found a predominantly non-CAM solution, having tried other CAM therapies without success.

*I can function normally within boundaries and life feels good again. (Speedwell, taking a low dose anti-depressant)*

*(This drug) reduced further attacks of vertigo to two hours! And even reduced the vomiting. (Foxglove, talking about the benefits from taking Valium)*

It must be remembered that a number of informants were continuing to take, either 'off and on' and/or at a reduced dose, the medication originally supplied by the ENT consultant or GP, for example, *Serc*, *Stemetil* or *Stugeron*.

### Other Approaches

A number of other approaches were mentioned by informants, either in addition to or as a 'follow-on' to their dominant 'fix'. These can be grouped under four heading: *dietary changes, making space to relax, personal support, and proactivity*. For all, a beneficial effect on their Ménière's or ability to cope with their symptoms was realised.

Informants quite commonly mentioned either *avoidance* of particular foods (for example, a salt-free diet, avoid caffeine and dairy products, avoid any with mono-sodium glutamate) or

the importance of *monitoring* what they eat in order to identify which foods, or their components, they might be sensitive (Aconite, Foxglove). Two informants (Banksia and Bellflower) specifically talked about *making space* to relax every day or if an attack was anticipated.

*I need to set aside time each day for relaxation: raising the neck on a "Chinese Pillow", finding quiet time, etc. (Banksia)*

*If I even suspect a vertigo attack is on its way, I find a quiet place, sit down and do some special exercises I've been taught. (Bellflower)*

Another (Saxifrage) started to run a local Ménière's Support Group '*which has helped me greatly to come to terms with my condition.*' Finally, one informant (Aconite) explicitly raised the question of whether or not he was a passive recipient of the advice and therapy. In his interview, he comments:

*Not too sure if (I was) a passive recipient or a reactive recipient. I think I've questioned everything he's done, without any doubt. Initially I was purely receptive to anything anybody could do to try and improve my condition, I know this. (Aconite)*

When asked by the interviewer if his attitude towards his health has changed, he replied: '*I don't think so.*'

The proactive role that many of the informants played in locating their own 'fixes' suggests the importance of this dimension in the illness journey. A number of the informants explicitly raise this in their stories:

*I have not allowed it (Ménière's) to affect my life greatly but I have made several changes to help. (Chamomile)*

*I have the outlook that 'my cup is half full, not half empty.' (Primrose)*

*I firmly believe that, no matter what type of medication is used, a positive state of mind is part of the treatment. (Campian)*

*Patients with Ménière's SHOULD NOT ACCEPT the statement 'learn to live with it.' Better alternatives are available, rather than the traditional medications, which do not treat the underlying causes of MD, merely the symptoms....I have found it IS possible to live a full and healthy life with Ménière's. (Banksia, emphasis as in original story)*

*My experience of complementary therapies has been completely positive – there has been so much hope and positivity, that this gives you the incentive to stay on top of things. (Eyebright)*

*I feel that it is good that I recognise these psychological effects and try to remain positive.... (I) believe it is important to put complete trust in whichever CAM therapy one is receiving. (Hollyhock)*

Personal outlook, a positive outlook / attitude of mind and confidence in the therapy and practitioner, all have positive effects on the informants' managing their Ménière's and their experiences. It is noteworthy that two of the informants (Primrose and Saxifrage) had started Ménière's support groups. The case study of Daffodil also illustrates the need to be *ready to change*. This is illustrated through his early use of a variety of CAMs, but being '*unnerved*' by their suggestions of a need to change his lifestyle and onto the influence of a number of significant others. Over time, his own approach to managing his Ménière's, and health and well-being in general, changed with his growing self-awareness and widening and extensive knowledge of a range of CAM therapies.

## Section Three: Findings from the *Spin* Letters

### The Respondents

Twenty-three letters relating to different ways that the writers found had helped them to manage their Ménière's symptoms using CAM therapies were retrieved from past issues of *Spin*. Most of the letters were fairly short (two or three paragraphs) with a few being longer (a page of two-columned text). It is important to note that the letters pages of *Spin* are being used to inform other readers of approaches that may have worked for the particular person or asking others advice or responses to articles in the newsletter about particular ways to manage Ménière's disease. This section of the reports provides information on the types of CAM modality used by correspondents and reported benefits.

### The CAM 'Fixes': The Search for an Alternative and Its Outcome

#### ***Prompts to Searching for an Alternative: The Roles of a 'Significant Other' and Significant Events***

While two correspondents just made mention of the fact that either '*I started looking into complementary therapies ...*' (2002:21) or their having looked for a long while at '*trying to improve my health using complementary therapies*' (2002:24), around a half of the letters made reference to the importance of a particular individual or event that acted as a catalyst in their seeking complementary and alternative treatment to that provided by their GP or ENT consultant.

The most mentioned significant other was a friend.

*A friend suggested I try acupuncture. (2006:1)*

*A friend suggested I try tablets called Quiet Life, by Lanes, ... a herbal medication available at ordinary pharmacists. (2005:5).*

Another pointed to the role of a casual acquaintance:

*I was explaining the illness to a casual acquaintance a few weeks ago and she convinced me to try the Bowen Technique. (2003:16).*

One other followed through the recommendation of another person with Ménière's.

Three of the correspondents drew specific attention to the significance of their consultant or GP. One ENT consultant suggested the importance of a low sodium diet; in another instance, following referral from her GP, the consultant rheumatologist who, '*noting my extremely tense muscles*' (2004:11), suggested that she tried the Alexander technique.

Unfortunately, the third commented that, though she was using a CAM therapy (acupuncture), *'my doctor doesn't really want to know.'* (2002:22)

Other letters pointed to a critical event or series of events that prompted them to seek alternative treatments. For one, it was the level of pain:

*I have tried painkillers; however, I have to find a better way of controlling the pain. (2005:6)*

For two others, stress-related factors contributed to an exacerbation of symptoms:

*Five spins a day recently. (2005:5)*

*Dizzy spells every day and the odd severe vertigo attack in between ... balance and hearing affected. (2006:4).*

### **The CAM 'Fixes' and Their Benefit**

Box Eight provides an overview of the range of CAM-related 'fixes' that the various letters highlighted. Each is linked back to the 'aspects and purposes' framework. The most commonly mentioned was 'dietary-related'. This advice could have come from a conventional medical practitioner or from the person's own reading and experience. Diet changes related, in particular, to salt (low salt or salt free), avoidance of caffeine, chocolate and drinking more water. Next most mentioned were 'energy-related' therapies, in particular, acupuncture. 'Body alignment-related' therapies was also important (including the Alexander technique, chiropractic and Bowen therapy<sup>5</sup>) and 'mind-body related' therapies (meditation, yoga, reiki and general enhanced body awareness arising, in this instance, from use of the Alexander technique). The range of different CAM therapies used is again indicative that no single CAM 'solution' or pathway had been found.

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<sup>5</sup> Note that Bowen therapy is mentioned twice in the table, as it has both an energy-related and body alignment aspect. It was mentioned by two persons.

**Box Eight: Overview of CAM Therapies Identified**

<b>CAM Fixes</b>	<b>Individual CAM Therapies</b>	<b>Number of Cases</b>
<b>Mind-Body</b>	Meditation	1
	Yoga	1
	Reiki	1
	Body awareness	1
<b>Energy Related</b>	Acupuncture	6
	Reflexology	1
	Bowen therapy <sup>1</sup>	2
	Massage (foot)	1
<b>Air / Water / Nutrition</b>	Homoeopathy	1
<b>Body Alignment</b>	Alexander technique	1
	Chiropractic	1
	Bowen therapy <sup>1</sup>	2
<b>Toxicity</b>	Herbal medicine	2
	Dietary sensitivities – dairy (identified by homoeopath), citrus (self-identified)	2
	Nutritional therapy	2
	Nutritional supplements – ginkgo biloba	2
<b>Dietary Related</b>	Dietary changes: salt- caffeine- chocolate-free, more water	8
<b>Other</b>	Travel sickness bracelets, sea bands	2 each

***Nature of the Effects of the CAM 'Fixes'***

From the commonly brief details provided in the letters, only limited indication of the benefit experienced from the CAM therapy can be gleaned. In some instances, the letter writer was telling others about their relatively recent experience; this might then result in their being able to describe their short-term benefit from the treatments; this benefit may or may not be carried forward into the longer term.

'Mind-Body Related' as Dominant Aspect

Four persons were using one or another mind-body therapy. For one, yoga '*helps with my balance*' (2006:3); this was used alongside travel wristbands (which '*help reduce my spins*'). Another used reiki which had enabled the writer to sleep on either side (whereas before this

was not possible). For another, her use of the Alexander technique had enhanced her overall body awareness. She commented:

*I see now that I have been digging myself into a hole by fighting to lead a normal life and keep my balance ... how important rest (is). (2004: 11)*

Another had just begun meditation, which was being used alongside acupuncture; it was too early to report on benefits.

#### 'Energy Related' as Dominant Aspect

Ten persons were using one or another energy-related therapy, with acupuncture being most mentioned. Acupuncture had been used by six persons, over an extended period of time, often beginning weekly, then bi-monthly and continued over many months or years (as part of a health maintenance approach). Benefits were many:

*The one consistent therapy, which has helped. (Regular visits) keep me in control of stress and give me a sense of well-being which in turns helps to overcome the symptoms of Ménière's. (2002:27 – acupuncture had a direct improvement on vertigo and tinnitus; used alongside low sodium diet)*

*I stuck with acupuncture and can truthfully say that it has been wonderful. (2006:1 - free of attacks for last two years)*

*It keeps me from having full-blown attacks of Ménière's ....My confidence has returned and the panic attacks have stopped. (2002:22 – hearing is better)*

One other, while acupuncture was helping with the management of the Ménière's symptoms, its effect was now fading. She commented:

*(I am beginning) to lose faith in this ... When my tinnitus was really bad even this treatment wouldn't t help. (2002:25)*

She was now following on with meditation and awaited benefits.

Two others were using acupuncture alongside other nutrition-related therapies, and both therapies led to the difference. One followed the *Salt Skip* programme, involving detoxification for salt and food additives, together with acupuncture. There had been no attacks for the last year.

*I am no longer on medication ... am confident and outgoing and no longer dreading the days when I would not know if I was to suffer spins, drops and sickness.... (Acupuncture) helped enormously with the sickness initially and then (had it) monthly just to help my body heal itself. At the last appointment my acupuncturist could not find any symptoms that needed treatment. (2005:7)*

The other saw a nutritional therapist as well as using acupuncture.

*Within a very short space of time, I have had complete remission of my symptoms. (2006:4)*

Two others experienced relief through use of the Bowen technique:

*I am in remission at the moment ... (Has two more treatments booked). It has helped me. (2003:16 - improved flexibility and balance)*

*It (Bowen) appears to be very helpful. (2002:18)*

One person used reflexology.

*I feel so much better in myself that I can honestly say I feel like me again... My therapist is brilliant. (2002:21 – five treatments over last three months; – no attack for nearly 2 months, reduced symptoms)*

Another had foot massage, administered by his girl-friend. The massage 'improved things ... buzzing had gone altogether' (2005:8). If the buzzing reoccurs, he had another foot massage.

#### 'Body Alignment Related' Therapies

These were used by four persons, two of which involved Bowen therapy, which has both an energy and body alignment aspect (see above for its benefits). One writer had had recent success with a McTimoney chiropractor, having had two sessions over a four week period to date. Since the treatment, there has been no vertigo:

*I feel so much better and able to get on with my life. (2002:23)*

Another had used the Alexander technique over the longer term, firstly through accessing a therapist and then following the technique herself and doing some of its various exercises. She commented:

*(It has) eased the pain and helped with my balance problems ...Applying the Alexander technique of relaxing instead of pressing on helps but slows things down greatly. (2005:9)*

In an earlier letter, she had written:

*It took an Alexander therapist to suggest that my body said it had had enough and just shut down. (2004:11)*

#### 'Toxicity Related' Therapies

Eight correspondents mentioned one or another toxicity-related therapy. One had seen a herbalist over a twenty-month period and wrote:

*After 6 months treatment from the herbalist I was symptom free and remain so. Herbalism a placebo? No, I don t think so. (2002:26)*

Two others had consulted a nutritional therapist. One of these, writing of his experience of using CAM over a nine year period, and who had consulted over a six year period, coupled with his own reading, commented:

*I am convinced of the success that I have enjoyed in this area. (2002:24)*

One other had had a cow dairy product intolerance identified by a homoeopath and changed her diet. The remainder had identified a nutritional supplement or herbal remedy themselves. One used a herbal medication, *Quiet Lives*, following up advice from a friend:

*Within a week the severity and frequency of the spins reduced. (2005:3)*

On running out of the remedy, the spins reoccurred. Others were using Gingko Biloba, one taking a high dose and noticing '*a considerable reduction in my tinnitus.*' (2002:19)

#### Other 'Fixes'

Foremost in this area are changes in *diet* (salt reduction or avoidance, caffeine and chocolate-free) and use of *travel sickness bracelets* or *sea bands*. The latter helped one with nausea, and another for spins and dizziness.

## Section Four: Conclusions and Issues Arising

This report has explored the narrative accounts of a self-selecting sample of persons with Ménière's disease who have used CAM as part of their treatment and care journey. The final section of this report draws out the main conclusions and key messages arising from the personal accounts.

Before doing so, it is important to remember that the stories analysed in Section Two were provided by volunteers who were prepared to put pen to paper and write down some of their journey. The others, reported in Section Three, arose from people with Ménière's who wanted to share their experiences with others, for others to benefit and to see if their approach might help others. Personal narratives were not sought from those who may have been satisfied with conventional medicine and/or found conventional medicine resolved their symptoms sufficiently.

### Conclusions and Key Messages

A number of conclusions and key messages are evident from the personal accounts provided by the 20 participants who submitted written personal narratives and from the 23 letters located in past issues of *Spin*.

#### **1. The Impact of Ménière's on the Person's Life**

All the personal accounts demonstrate the challenges faced by those with Ménière's, from the first experience of some of the symptoms to early diagnosis and treatment and thereon, and the dramatic effect the condition had on their lives.

#### **2. The Need to Widen Horizons to Look Beyond Conventional Medicine**

Few GPs, and fewer consultants, suggested to the person with Ménière's, to '*look more widely*' and to advise, '*perhaps try alternative / CAM treatments.*' This is particularly significant in a context where the conventional medical treatments do not appear to resolve the condition sufficiently. The benefits that the study participants experienced from CAM suggest its potential to help the person manage their Ménière's, at a minimum alongside their conventional drug-based treatment. It is notable that some of the informants continued to use drug therapy alongside their use of CAMs; for others, their use of CAM enabled them to stop taking the drug(s). This must be understood in a context where the aim of treatment and care is to reduce the impact of the condition and enable their living as normal a life as possible.

### **3. The Role of Significant Others**

Participants' stories often pointed to a particular individual or individuals who were influential in encouraging them to try alternative treatments. On a few occasions, this 'significant other' was the GP or a consultant (for example, ENT, rheumatologist). More commonly, the 'significant other' was a family member or a friend. In addition, many of the participants talked about the substantial support provided by their partner or a close friend, for example, at a minimum in enabling dietary changes and/or providing long-term personal support. This is well illustrated in the following extract:

*I have been lucky in having a husband who has supported, encouraged me to push the boundaries and view Ménière's Syndrome as a passing phase rather than a chronic disability. (Campian)*

Given its long-standing nature, persons with Ménière's may well need substantial motivation and/or a supportive 'significant other' to move beyond the boundaries of conventional medicine, even though the latter is not resolving their condition.

### **4. Critical Events as a Catalyst**

Other participants drew attention a critical event or set of events that provided a strong prompt to their seeking alternative treatments. Commonly, this was an increased frequency and severity of attacks, their ongoing nature or an increasing impact of Ménière's on their lives. For some, it was being told that there was no cure.

### **5. The Journey with Ménière's**

The set of nine case studies in Section Two illustrate the range and variety of journeys that people with Ménière's have travelled, and continue to travel. They illustrate the diversity of the journeys taken by informants in locating a satisfactory way to manage the condition (their 'CAM fixes'), the time taken to locate a helpful 'fix', the role of others or the self in its location, and the type and nature of the 'fixes'. It is evident that some participants tried one therapy (for example, acupuncture) and, if it did not have the desired effect, then tried another in order to find their eventual 'best' or 'better' fix. This picture is well stated in the following extract:

*The therapies that I have described all have their place in helping me to overcome this illness, and it seems that at some times I need gentle therapies (reflexology, homeopathy) at others more dynamic and 'physical' (acupuncture, chiropractic). I would definitely recommend trying them to others – acupuncture was the one that started me on the road to recovery. Reflexology produces similar effects for me, but less intense and somehow gentler. Homoeopathy supports me emotionally. I would recommend them all wholeheartedly. (Eyebright)*

## 6. Many CAM Approaches, No Single Approach

The journeys, and the range of fixes listed in Boxes Seven and Eight, demonstrate that no single CAM approach works for all. The boxes are also indicative of the possible benefits of CAM as part of their self-care of Ménière's.

- *Dietary-related approaches:* Commonly, dietary related approaches are reported as beneficial. This option may arise from talking with one's GP, a friend or family member or from reading and searching the Internet, as well as or instead of a CAM practitioner. Indeed, there is nothing particularly 'alternative' about a dietary approaches; reducing salt, avoiding caffeine and so one may also form part of a wider 'healthy eating' awareness, in relation to 'what works best for my own health and well-being.'
- *Explicit CAM approaches:*
  - *'Energy-related'* therapies (such as acupuncture, Bowen therapy, reflexology and acupressure) were most mentioned. Acupuncture formed at least part of the CAM 'fix' for 10 out of the 43 informants, but positive benefit was experienced only by six.
  - *'Body alignment related'* therapies (such as cranial osteopathy, chiropractic, Bowen therapy, Alexander technique) were next most mentioned.
  - *'Toxicity related'* therapies (including Chinese herbs, chemical and food sensitivities, nutritional therapy) were also important, along with *'dietary-related'* approaches
  - Least mentioned were *'mind-body related'* therapies (such as yoga, reiki and meditation) and *'air-water-nutrition related'* therapies (such as homoeopathy)
- *Experience of Positive Benefits:* Participants reported positive benefits from their use of the particular CAM 'fix(es)'. For some, this entailed a reduction in the symptoms, for others an elimination of the symptoms and a much reduced impact of their Ménière's on their lives.

## 7. 'Finding Your Own Way'

*'Finding your own way'* best characterises people's journeys. This raises the question of whether the person with Ménière's *has to* find their own way. Is there an inherent value in *'finding your own pathway'* in terms of personal awareness and personal growth and development? Alternatively, and more realistically perhaps, there is the need, value and potential of early signposting, in particular by conventional medical practitioners, to enable the person with Ménière's to *'look more widely'* and to advise: *'perhaps try alternative / CAM treatments.'*

It seems most fitting to end this report with a linked set of extracts from a personal narrative from one of the informants which illustrates both the qualities of those providing treatment and support and the possibility of finding a way to manage Ménière's through use of an alternative treatment approach:

*In conclusion, I would add that I have been happy with the care I received from my doctors and specialist, but I never received any suggestion that I should try any CAM therapies. In fact I usually feel from doctors that they really aren't that interested in anything other than pharmaceutical medication.*

*So, any attempts to find other ways of dealing with this most horrible disease were my own.... The medical profession have been at times wonderful, at times very unsympathetic and seemingly heartless....*

*The therapies have given me new hope, and my quality of life is so much better.... My experience of complementary therapies has been completely positive – there has been so much hope and positivity, that this gives you the incentive to stay on top of things. (Eyebright)*

## References

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## **Appendices**

## **Appendix One: Web Participant Information Sheet**

**A project to find out about the benefits of Complementary and Alternative Medicine and therapies in the treatment of Ménière's syndrome.**

### **What is the purpose of this study?**

We want to find out about your use and experiences of Complementary and Alternative Medicine (CAM) in the treatment of Ménière's syndrome. We will use this information to identify possible supportive CAM treatments for this syndrome and to develop further research to explore how they benefit persons with this condition.

### **What will happen if I take part?**

You will write up your own experience in your own words and send this to the research team. We will examine both your and others' experiences and draw up a report. If we need further information or elaboration on parts of your account we will write to you and ask you to provide this.

With your permission only, we will also draw together an edited, anonymised summary of your experiences to be made available to others via a dedicated web site. We will send you this summary for you to check and change as appropriate prior to its inclusion on the web site.

Your written experiences will only be read by members of the research team. Your document will be kept in a locked filing cabinet.

We will write up and present the analysis of your and others' experiences in articles in journals, and conference presentations. In these presentations, it will not be possible to identify individual persons who have taken part. While presentations and articles may include quotes from your written material, your own comments will be kept anonymous.

### **Will the information I give be confidential?**

Any information that you give will be kept confidential and your name will not be mentioned in any reports.

### **What happens if I change my mind about our using your experiences?**

You can withdraw your consent from the study at any time. Just let us know in writing. You do not have to give a reason.

### **Who is running the project?**

The project is being undertaken by researchers at the Universities of Leeds (School of Healthcare) and Salford (the Health Care Practice R&D Unit). Professor Andrew Long at the University of Leeds (previously at Salford) is supervising the research. Other members of the research team are: Tony Bennett who has experienced the symptoms of Ménière's syndrome for over 15 years and has positive experience of using CAM; and from the University of Salford, Mei Xing, Lecturer in Acupuncture and Traditional Chinese Medicine, and Alison Brettell, Research Fellow (Information). The research is being funded by an internal grant within the University of Salford.

### **Can I get further information?**

If you would like any further information, please contact one of the research team.

## Appendix Two: Guidance Notes in Writing Your Personal Story

### Part One: Some Background Information

1. Please tell us who you are and how to contact you.

Name:

Address:

Tel no.

(if relevant): e-mail address:

2. Please give us some background information on you and your Ménière's syndrome.

What is your date of birth?

Are you male or female?

Approximately when were you first diagnosed with Ménière's syndrome?

3. Please can you give a brief description of your symptoms, their pattern over time and their severity.

What treatments were you advised to have by your ENT consultant? And, which ones did you have?

Were you advised to try any complementary or alternative medicine (CAM) therapies? If so, by whom, when and which ones?

Which CAM therapies have you tried, and for approximately how long?

### Part Two: Your Personal History

Feel free to write your personal history, or journey with Ménière's syndrome, in any way that you wish. You may find it helpful to think of it as a letter to a member of your family, or to a friend, with who you would like to share your experiences. Below we have listed some general pointers which you might find useful.

... *The effect Ménière's syndrome has had on your life.* The impact the symptoms have had on, for example, your family life, work, life-style and quality of life.

... *The different types of CAM treatments you have used.* Why did you try them? How did you hear about them – for example, through your GP, family, a friend, a magazine article, book or advertising

... *The complementary medications or therapies you think were beneficial to you.* The benefits experienced. The approximate length of time you have received the CAM therapies. If you are continuing with the CAM treatment. (You may have tried different treatments at different times and come back to them. Try and tell us about your whole journey.)

... A description of the difference that specific CAM treatments have had, or continue to have, on your condition.

... *Other effects that you think the CAM treatments may have had on your life in addition to the impact they have had on your Ménière's syndrome - for example, on life-style, attitudes, etc.*

... *Any recommendation or advice for others about using CAM for Ménière's syndrome.*

Many thanks for taking part in this research. We are very keen to find ways of relieving the severity and effects of the symptoms experienced by Ménière's sufferers. Your contribution is very valuable.

## Appendix Three: Project Consent Form

**Project Title:** A project to find out about the benefits of Complementary and Alternative Medicine in the treatment of Ménière's syndrome

I agree to take part in the above project which will be carried out by the Universities of Leeds and Salford.

My signature at the bottom of this forms shows that:

**Please tick the box**

I have read and understood the information sheet provided and have had the opportunity to ask questions.

I understand that my involvement will be CONFIDENTIAL and that my name will NOT be mentioned in any report.

I understand that my taking part in this project is voluntary and I can decide against being involved in the project at any time. I know I do not have to give any reasons.

I understand that quotes from my written account may be used anonymously in presentation and publications.

I understand that my written account may be edited and made available to others anonymously. But that this will happen only with my subsequent further consent.

Information has been given to me about what I should do if I need any further details.

Please sign below if you are willing to be involved:

Signature.....

Name.....

Date .....

Please return this signed form and your personal story to:

Professor Andrew Long, School of Healthcare, University of Leeds, Room 3.10, Baines Wing, Leeds, LS2 9UT, UK

## **Appendix Four: Advert in British Acupuncture News**

### **Research into Ménière's Syndrome**

#### **Patients' Personal Histories and Practitioner Case Reports**

Professor Andrew Long, from the University of Leeds, Mei Xing and Alison Brettle, from the University of Salford, and Tony Bennett, who has had long-term personal experience of the symptoms of Ménière's disease, are taking forward a research project looking at the value of complementary and alternative medicine (CAM) therapies in the treatment of Ménière's Syndrome. Whilst conventional treatment includes drugs, exercise and changes to diet, some people who suffer from this syndrome have explored CAM therapies to alleviate their symptoms. However, there is little published information on which CAM therapies might help those with Ménière's.

The research team is seeking your help.

Can you, as acupuncture or TCM practitioners, bring the project to the attention of any of your clients who have Ménière's Syndrome?

We are seeking to recruit people who have been diagnosed by an ENT consultant as having Ménière's Syndrome and who have been treated with acupuncture, and/or other complementary and alternative (CAM) therapies, to help with their condition.

Taking part in the study would entail the person writing in his/her own words about his/her use and experiences of acupuncture in the treatment of his/her Ménière's. Guidance is available to help to do this. Anything sent to the research team will be treated in confidence and all material will be stored safely and securely.

Currently we have personal narratives from 11 people in the UK and would like to hear from more.

Do you also have any case reports that you would be willing to share with us about your own success in treating persons with Ménière's? If so, we would be pleased to hear from you.

For more information about the project, please access the project's website or write to us at the address below. Thank you.

Web address: <http://www.fhsc.salford.ac.uk/hcprdu/projects/menieres.htm>

Postal address: Ménière's and CAM Research, Professor Andrew Long, School of Healthcare, Room 3.10, Baines Wing, University of Leeds, Leeds. LS2 9UT