

# THE QUEST FOR QUIET

PEOPLE'S EXPERIENCE  
OF TINNITUS IN IRELAND

*A research study for the  
Irish Tinnitus Association*

*Funded by the  
National Disability Authority*

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Funded by the National Disability Authority  
under the NDA Research Promotion Scheme (2004)

*Information on support services for people with tinnitus is available from the  
Irish Tinnitus Association, 35 North Frederick Street, Dublin 1 (Tel. 01 872 3800).*

*Website: [www.nadi.ie](http://www.nadi.ie)*

*or from Cork Tinnitus Support Service, at 5 McCurtain Street, Cork (Tel. 021 450 5994).*

*Price: € 6 (incl. p. & p.)*

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*The views and comments expressed in this work are those of the author and do not necessarily represent the views of the National Disability Authority*

## EXECUTIVE SUMMARY

Tinnitus is a common condition whereby the affected person hears sounds in the ears or head that do not have an external cause. Research studies suggest that about one per cent of the population is seriously affected by the condition. Severe tinnitus can be disabling on the person, with anxiety, insomnia, and depression among its effects. The incidence of tinnitus increases with advancing age, but affects many in early middle age, and even children. Attributed causes include impairment due to noise damage; the natural decline in hearing that occurs with ageing; head and neck injury; infections; and the use of certain medications. While the precise mechanism involved in tinnitus generation is not yet fully understood, it is believed to involve the brain's processing of impaired auditory signals from the cochlea. There is no medical or pharmacological cure, and consequently, therapy aims at successful management of the condition. Worldwide research into possible treatments is ongoing, but currently, the most effective approaches largely consist of psychological interventions, utilising forms of counselling therapies, sometimes combined with sound enrichment techniques.

The Irish Tinnitus Association (ITA), founded in 1996, runs a number of support groups throughout the country, and provides information, as well as a telephone advice service to people affected. Up to recently, the country had no services dedicated to people with tinnitus; the first tinnitus clinic was recently established as a pilot project in Cork. There has been no published data on the incidence of tinnitus in Ireland, nor on the nature of people's experiences of the condition. In 2003, the ITA was awarded funding by the National Disability Authority to conduct research into Irish people's experience of tinnitus. This resulting study records the experiences of 73 people with tinnitus. The sample (39 males, 34 females) is drawn from the membership database of the Irish Tinnitus Association. Telephone interviews were conducted with the sample during March, April and May 2003. The data collected is partly quantitative, but largely qualitative, and is presented and discussed thematically.

The principal themes to emerge from the data may be summarised thus:

- The general patterns of incidence, age profile, co-symptoms, and reported course of the condition are broadly similar to those reported in international studies. People's experience of tinnitus ranges from very mild to very severe. The most disabling effects are largely psychological in nature.
- For most people, the early months or years are the most disabling phase, with a gradual lessening of distress as people come to 'live with' the noise, either through resigned acceptance, or true habituation. While about one fifth of people are only slightly affected, about twice as many continue to struggle with the condition, with considerable negative effects upon their daily lives.
- People affected with tinnitus consult a wide range of medical and other opinion in their pursuit of a cure, or at least relief. The picture emerges of many healthcare professionals that tend not to acknowledge the sometimes traumatic effects of tinnitus upon the person, that seem to have limited awareness of developments in the therapeutic field in relation to tinnitus, and that provide those consulting them with little – in terms of management techniques or of information - that would encourage and aid them in managing the condition.
- The invisibility of tinnitus means that it elicits little empathy or support from the general public. Most people with tinnitus do not talk to others about their condition, and believe that people generally do not understand it.

- People with tinnitus mostly rely upon the advice and support of other sufferers, and upon their own self-help strategies in their management of the condition. Information is gleaned from the newsletters of tinnitus associations and the Internet. A wide range of self-help strategies is employed, to varying effect.

The study concludes that a range of therapeutic and support services are urgently required to aid people with tinnitus. A considerable challenge exists in integrating these services into the healthcare system, yet many of the elements of such services appear to be already present. Complementary relationships should also be established between professionals and voluntary support services. A priority should be to identify practical needs through research, and establish diagnostic and therapeutic protocols to meet these needs. Much could be learned from best practice in other countries in structuring support services. Given the reported experiences of people with tinnitus in accessing health services, and in the response of others to their condition, the study concludes that a parallel education campaign targeted at professionals and the public is also required.

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*This research is funded under the NDA Research Promotion Scheme. This scheme was established to facilitate disability groups and community & voluntary organisations working on disability issues to undertake research. The scheme aims to build the research capacity of such groups; to broaden and deepen knowledge of specific disability issues; and to inform policy makers and service deliverers of disability needs and issues. The NDA is committed to research using participatory methodologies and within the framework of a social model of disability.*

## INTRODUCTION

### Eoin's Story

I became gradually aware of my tinnitus some 20 years ago. It followed exposure to a very loud noise. It is in both ears, and has fluctuated in quality and loudness over the years. It can be low and bearable or very loud and distressing, sometimes accompanied by another rattling sound. When it began, it was low and did not bother me. I believed it would go or could be easily treated. But it worsened, and I experienced much distress.

I was constantly aware of the noise, I was anxious, and had trouble sleeping. I couldn't concentrate; I lost interest in work, and avoided social situations. I became despairing and suicidal. My doctor put me on anti-depressants which did make me feel better. He was the first person to listen to what I had to say about tinnitus, and his sympathy was very helpful to me at that time. He also sourced leaflets on tinnitus for me. I went to an ENT specialist who told me I would get used to it in time, but to present yourself to a professional at a time of great distress and to be told to put on a fan in the background to help you sleep is not help.

At a time of desperation, I purchased the *Therapak* as advertised in *Quiet*. I believe there was some benefit because I was doing something positive about the problem. I should probably have given up my work or changed jobs at the time, but instead I struggled through. I did have to make some changes. I had always been hard of hearing but the tinnitus made that problem worse.

I think it must have been about three years after first getting it that I felt I was managing it better. It was a combination of things: I suppose habituation was taking place. I joined the BTA and received *Quiet*, which was a huge help. I also took up hobbies to take my mind off it. Now, it is usually at its worst in the morning, receding somewhat with the day's activities. Having the radio and television on helps. So does relaxation by any means. I know that stress, lack of sleep and any loud noise can make it worse. My relatives have seen the depths of despair that tinnitus has driven me to. They have heard me complain all too often, but their words of comfort and sympathy have helped me through the bad times.

I have read everything about tinnitus I could lay my hands on. I have kept every copy of *Quiet* I ever got. At this stage I could write a book on it myself. I don't attend support groups or public meetings, but I find the newsletters helpful. I'm not sure about TRT. After 20 years of coping on my own, I would welcome any help at this stage. I am always fearful of it getting worse, but I hope I can continue to have some control over it by using the ways I've mentioned.



## Chapter 1      Review of the Literature

The subject of tinnitus is both an old and a new phenomenon. References to tinnitus are to be found since ancient times, but the modern era has seen a dramatic growth in interest in the subject. This interest partly derives from the more general growth in research into a variety of chronic and disabling conditions, but it is also due to puzzlement among researchers and others at the paradoxical nature of the tinnitus problem. As a condition, it is extremely common worldwide, yet its precise nature defies definition, leading to diverse research directions. However, the growth of internet sites recording tinnitus research activities and their outcomes has greatly opened up the knowledge field to the general public, and has allowed new understandings of the condition to be disseminated quickly among professionals and wider audiences.

The range of tinnitus literature extends from locally- and nationally-produced newsletters to self-help guides and leaflets, to reports of clinical research in the journals of the field. Even within the latter, the range of disciplines is wide, as tinnitus engages the interest of audiologists, psychologists, biochemists, otolaryngologists, neurologists, and others. The diverse aetiology of tinnitus has as consequence this span of interested parties. The discussion that follows reflects the diversity of the literature, and attempts to draw together the medical, biological, social and psychological dimensions of tinnitus. The disabling effects of tinnitus are discussed, as are the treatment approaches commonly employed. The review concludes by highlighting the dearth of research in Ireland, and the need for further research internationally. The research question is then formulated.

### **The nature of tinnitus**

Tinnitus is the experience of sound in the ears or head in the absence of any appropriate external stimulus. Definitions vary, but the key features are similar. A person is aware of a sound or sounds that are not being caused by a source outside of the person; the sound often is sensed as being within the ears, or may be sensed as located somewhere in the head or neck. Sometimes only one ear is affected (unilateral) but more commonly it's bilateral. The sound is experienced *subjectively*, i.e. not audible to anyone else. There is also a rare *objective* tinnitus that can be heard by others, or may be measured by sensitive instruments.

The sounds are variously described by tinnitus sufferers as ringing, whistling, rushing, whining, hissing, grinding, rumbling, etc. A common perception is that of bells jangling. (The term 'tinnitus' derives from the Latin verb *tinnire*, 'to ring'). For others, the sound is likened to that of industrial machinery, a domestic vacuum cleaner, or a jet engine. Many people experience a number of noises simultaneously. The loudness of the noises can vary from day to day, as can their pitch and quality. Henry and Wilson (2001) record that Ludwig von Beethoven suffered greatly from tinnitus as well as his more publicised deafness.

The onset of tinnitus may be sudden, or it may develop over some considerable time, so that the person's initial awareness of the noises may not coincide with their onset. Other features may be present along with the noises – these are discussed below. Occasionally, the noise is temporary and disappears spontaneously. What was once termed 'disco tinnitus' - nowadays perhaps 'club tinnitus' - is the experience of temporary tinnitus after exposure to loud music. This usually disappears within a day, although

repeated exposure to very loud music or other noise can result in tinnitus that does not recede. Temporary tinnitus is occasionally resolved by the removal of hardened earwax. However, most cases of persisting tinnitus are likely to be permanent.

People with tinnitus commonly report that it is most noticeable in quiet environments, when the noise is not 'masked' by external sounds. Hence, the tinnitus sounds are generally reported as being more intrusive at night. Tinnitus is also commonly reported as being louder earlier in the morning or upon waking. Some sufferers believe that their tinnitus wakens them, but this may not be the case (Folmer and Griest, 2000).

### **A diverse aetiology**

One of the remarkable aspects of tinnitus is the wide variety of conditions that it accompanies.

Tinnitus is known to occur as a concomitant of almost all the dysfunctions that involve the human auditory system (Andersson, 2002).

However, tinnitus is also reported by people who have no other apparent physical or psychological disorders. It is now accepted that tinnitus is not an illness in itself, but is a *symptom* of some form of dysfunction in the auditory system. Authorities have long differed about the location of the generation of tinnitus, i.e. at a *central* or *peripheral* site, the former being within the cortical (brain) regions related to auditory processing, the latter within the auditory pathways, especially the cochlea (inner ear) (Simpson and Davies, 1999). While majority opinion seems to agree that some kind of damage to the mechanisms of the inner ear is the initial generator, the subsequent persistence of it as a sensation, and especially as a troubling sensation, is now believed to involve some kind of neural / cortical reprocessing of the impaired auditory signal (Cacace, 2002; Rauschecker, 1999), and the involvement of the *limbic system*, which attaches emotional significance to human sensations.

While the majority of cases [of tinnitus] probably start with some disorder in the ear, such as infection, noise damage or ageing effects, the most important thing thereafter is what the brain does with the abnormal signals resulting in the hearing nerve coming from the ear (Coles, 2001)

Recent advances in medical diagnostic scanning technology (e.g. positron emission tomography), and its application to brain functioning, have shown that changes in neural activity are detectable in those with tinnitus (Johnsrude, Giraud and Frackowiak, 2002). Simpson and Davies (1999) say that these changes

could be likened to those found in phantom limb pain, where reorganisation of neural circuits leads not only to the generation of pain, but where it also changes the site of the processing of the sensory information received from remaining parts of the body (p.13)

Allowing that differentiation may be made between the *onset* and *persistence* of tinnitus, the most common 'initiating' causes of tinnitus have been reported as:

- Noise-induced hearing loss
- Age-related hearing loss (presbycusis)
- Head and neck injuries, including falls or 'whiplash'
- Consequent on ear infection, colds, flu
- As side-effect of certain medications, or in withdrawal from them

- Consequent on surgery
- Abnormalities in the vascular system, sometimes giving rise to a particular form of the condition known as 'pulsatile tinnitus'.

Very rarely, tinnitus is due to the presence of an acoustic neuroma (tumour) on the auditory nerve. Although rare, this needs to be ruled out through scanning, especially if the tinnitus is unilateral (Fahy, Nikolopoulos, and O'Donoghue, 2002). Simpson and Davies (1999) also note that "several non-otological conditions such as allergy, diabetes and thyroid dysfunction have also been attributed as causes of the condition" (p.12).

Reading through the personal accounts of tinnitus that appear in newsletters and similar publications gives some idea of the variety of actions and events that people with tinnitus believe to be the source of their problem. (The letters page of the British Tinnitus Association's quarterly *Quiet* - Winter 2002 - is a good example). Many of these beliefs cannot be proven. For example, some people believe that their tinnitus was caused by syringing of their ears. However, according to Buffin (1999), there is no reason why competent careful syringing should cause tinnitus. Similar attributions of blame are made about a range of medications and drugs, and while some are known to be ototoxic, most have not been proven to cause tinnitus. Simpson and Davies (1999), suggest that "particular culprits are barbiturates, benzodiazepines and histamine receptor antagonists". Allergies may also be blamed, but a recent study has claimed that there is no evidence of a link between allergies and chronic tinnitus (Weichbold, Schmidt and Zorowka, 2003).

A wide range of factors are reported as aggravating pre-existing tinnitus, among these being caffeine, alcohol, various dietary ingredients, tiredness, emotional upset, anger and stress. However, the effects of these on each individual may vary considerably. For example, some find that exercise exacerbates the condition while others benefit from it; similarly contradictory opinions are expressed about alcohol intake. Changes in the weather, especially involving barometric pressure changes, are frequently reported as leading to changes in the quality of the tinnitus noise. Changes are also attributed to adopting certain bodily postures, or in response to eye or facial movements. Idiosyncratic variations in these reports cannot be casually dismissed, while the origins and the very nature of the condition remain disputed. Indeed, the fact that in the majority of cases of tinnitus, no definite cause can be identified, leaves the field open to speculation and conjecture.

### **Related conditions / symptoms**

The great majority of people with tinnitus also experience some degree of hearing loss. It is speculated, but remains uncertain, that tinnitus may be the result of the auditory system compensating in some way for the (often high-frequency) hearing loss. Because hearing loss can develop gradually, it may well be the emergence of the tinnitus that first alerts the person to the existence of a hearing impairment.

Another common condition that can accompany tinnitus is *hyperacusis*, a heightened sensitivity to certain sounds, which can cause considerable discomfort. This condition has many common features with tinnitus, and requires similar therapeutic strategies [See [www.tinnitus.org](http://www.tinnitus.org)].

*Ménière's Disease* is a condition characterised by vertigo, hearing loss and often tinnitus. In this condition, treatments for the vertigo may also relieve the tinnitus (Havia, Kentala and Pyykkö, 2002). Additionally, people with tinnitus may complain of other forms of discomfort, such as dizziness, or a sensation of 'fullness' in the ear.

### The effects of tinnitus

The tinnitus condition can lead to many negative consequences for the affected person. According to Henry and Wilson (2001), such difficulties can include

. . . high levels of emotional distress such as depression; anxiety; irritability and anger; sleep difficulties; concentration problems; and disruptions to occupational, social, recreational, and interpersonal activities (p.xiii)

Where performance at work is adversely affected, absenteeism increases and occasionally, the tinnitus sufferer feels unable to continue in his or her career. In rare cases, suicide has occurred, although there is usually pre-existing depression or other aggravating factors (Lewis, Stephens and McKenna, 1994). Obviously, one of the factors that can lead to high anxiety in people is the fear that the tinnitus is the symptom of a serious illness. While this is very rarely the case (e.g. the presence of an acoustic neuroma), it is initially a real fear for many, and requires prompt attention and possibly some testing to allay such fears. For others, the intrusiveness of the tinnitus noise may seem unbearable, a burden that is frequently increased by medical and other opinion that advises the person that “there is no cure”, “you will always have this noise”, or “you must learn to live with it”. Fears about the ability to continue in one’s employment, about the risk of going deaf, or of mentally breaking down are also reported.

Clearly, the most significant effects of tinnitus are of a psychological nature. This has led some to speculate that tinnitus is itself a psychological illness, or is of a psychosomatic character. However, the research literature fails to confirm this interpretation, acknowledging that tinnitus is “both an audiological and psychological phenomenon” (Henry and Wilson, 2001: xiii). Andersson (2002) says that “there is little evidence that psychiatric disturbance is a direct cause of tinnitus”. In many respects, tinnitus is likened to chronic pain in its effects upon sufferers, with similar therapeutic approaches recommended (Tonndorf, 1987).

A considerable literature exists on the psychological profile of people with tinnitus (e.g. Budd and Pugh, 1995; Halford and Anderson, 1991; Stouffer and Tyler, 1992). Some of this literature analyses the psychological features of tinnitus sufferers, attempting to determine whether certain individuals are predisposed to developing tinnitus, or to be more distressed by it. The findings of such research fail to confirm that any predisposition towards *developing* tinnitus exists. However, it also suggests that people of a particular disposition are more likely to be *troubled* by tinnitus, once it occurs. Thus, a person of a habitually anxious nature, or someone who has been prone to depression may be more troubled by the emergence of tinnitus, than the person of a more optimistic or stress-tolerant personality. The sense of being at the mercy of the tinnitus noise creates distress for many; conversely, the sense of gaining some measure of control over the condition, or *over one’s reaction to it*, is an important step towards the lessening of distress. Andersson (2002), referring to his own small-scale 1996 study, suggests that “individual differences in coping ability are related to dispositional personality characteristics such as optimism” [emphasis added].

In other words, the reaction and attitude of the person who develops tinnitus are significant factors in determining the course of the condition. This is related to the emotional significance attached to the onset of tinnitus by the person affected (Jastreboff and Hazell, 1993; Jastreboff, Gray and Gold, 1996; Hallam, 1989). The *neurophysiological* model of tinnitus generation, which has in recent years led to the evolution of *Tinnitus Retraining Therapy* (TRT) (Jastreboff and Jastreboff, 2000), derives from the strong

association between sensation and emotion, in this case negative emotions such as anxiety, fear and anger. (TRT is discussed further below).

### **The experience of tinnitus as annoyance**

Allowing for the wide variation in the quality and nature of the tinnitus sounds, probably the most significant feature in the perception of tinnitus by the individual sufferer is the extent to which it is experienced as annoying or intrusive. McKenna and Andersson (1998) remark that "severe tinnitus is often distinguished by subjective reports of intrusiveness and irritation because of the sounds". Many assume that it is the loudness of the tinnitus or its particular quality that will determine the level of annoyance. However, research shows that this is not necessarily the case (e.g. Jakes et al., 1985; Harrop-Griffiths, et al., 1987). Thus, a person whose tinnitus loudness level has been matched and measured as very loud may not regard it as greatly troubling, while another may be extremely distressed by the sensation of a relatively quiet tinnitus. While this supports the contention that it is the reaction of the person that is of most significance, it is also suggested that tinnitus "is almost always found to be very loud at the very highest levels of distress" (Henry and Wilson, 2002: 23, quoting their 1995 study).

However, the extent to which tinnitus is perceived as troubling can vary considerably in the same person over time. Most people with tinnitus report that the quality of the sounds, as well as their pitch and loudness, vary from time to time. Such changes are generally unpredictable, but can cause renewed distress if they are perceived as threatening, in the sense that they presage a deterioration in the condition, that the new noise will be impossible to endure, or that hearing or other health aspects may be negatively affected.

Efforts have been made to construct scales of tinnitus severity, through the psychometric assessment of tinnitus problems, by use of various types of questionnaire. The most commonly used examples are listed by Henry and Wilson (2001: 37):

- *The Tinnitus Reaction Questionnaire* (TRQ) (Wilson, Henry, Bowen and Haralambous, 1991)
- *Tinnitus Handicap Questionnaire* (THQ) (Kuk, et al., 1990)
- *Tinnitus Questionnaire* (TQ) (Hallam, 1996; Hallam, Jakes and Hinchcliffe, 1988)

Also listed are other kinds of questionnaires that measure some aspects of tinnitus distress:

- *Tinnitus Cognitions Questionnaire* (TCQ) (Wilson and Henry, 1998)
- *Tinnitus Coping Strategies Questionnaire* (TCSQ) (Budd and Pugh, 1996b)

### **The experience of tinnitus as disabling**

When tinnitus is perceived as unrelenting and severe, it has the potential to render the affected person seriously disabled. As outlined above, negative effects upon most areas of social, personal and occupational functioning may be noted. Writers on the subject note that while this group is a minority of tinnitus sufferers, a significantly larger group may be subject to regular if intermittent distress and disability. The American Tinnitus Association notes that tinnitus has a major negative impact on the lives of several million citizens of the US. Assuming similar patterns of incidence in Ireland, there may be as many as 20,000 people suffering some degree of disability due to tinnitus in this country. It may reasonably be argued that with even a modest therapeutic programme, much of this disability could be minimised. The absence of even the most rudimentary supports allows the condition to exert a much more disabling effect upon the individual than might otherwise be the case.

### **The general path of the condition**

Despite the seemingly intractable nature of tinnitus, it is the case that for most people affected, the condition follows a predictable enough pattern. The initial acute phase, which might last weeks or months, tends to be followed by a gradual *habituation* to the noise, as hope for a cure is replaced by a grudging acceptance that the noise is now unlikely to go away. For each person the duration of these stages or phases varies, and is dependent upon the level of support and reassurance available, as well as on the person's own attitude towards the condition.

Many people with tinnitus expend considerable amounts of energy - and not a little financial outlay - on initially frantic attempts to find 'the cure'. The dawning realisation that there might not be one, can be the start of a greater acceptance and tolerance of the noise. In the meantime, much anguish and torment can be endured. Medical advice may be sought from several sources, with little learned that is new. Relief from depression may require medication, tranquillisers may be necessary, and in addition, some need sleeping medication. Many also are sent through the medical testing routines, some of which are necessary to rule out any serious underlying condition. While these tests rarely uncover new information, they can serve a reassuring, if expensive function at this stage.

Research suggests that for the great majority of people, the annoyance and intrusiveness of tinnitus decreases over time (Hallam, 1989). For them, their tinnitus is an irritation, an annoyance which reduces the quality of life, but is tolerated as something unavoidable. For others, the battle with tinnitus goes on unrelentingly, and quality of life is seriously affected. Such people often feel at the mercy of the tinnitus, finding it difficult to distract their attention from it. They may report that the noises have become louder over time, but in the absence of accurate objective measures, subjective descriptions and perceptions are difficult to assess.

Reducing the elements of fear and anxiety should be a significant aim of the early therapeutic approach, as it speeds up the process of habituation. Counselling, employing cognitive therapy, is likely to be helpful at this stage (Henry and Wilson, 2001). Habituation will be further accelerated by the provision of a systematic approach to the problem, as may be seen in the operation of multi-disciplinary clinics in several countries (BTA, 1999). However, even structured support such as *Tinnitus Retraining Therapy* embodies, can take from six to twenty-four months to be effective.

In the absence of this kind of support, the person with tinnitus may move into an ongoing cycle of recovery and relapse as the noises vary and change over time, resulting in greater and lesser levels of distress. Many fear that they will be overwhelmed by the noises, and lack the strategies to deal with such fears. Some reach for spiritual consolation, others seek relief through the pursuit of complementary treatments, and alternatives to traditional medicine. Sometimes, the only support is provided by an organised meeting of 'fellow sufferers', variously termed 'mutual help groups', 'self-help groups' or 'support groups'.

### **Epidemiology**

As has been mentioned already above, the incidence of tinnitus seems to be relatively consistent worldwide. The incidence of persistent tinnitus, troubling enough to lead the person to consult medical opinion, seems to affect about 10% of the population. Perhaps one in three of these are regularly affected by their tinnitus, to the point that it has a negative effect on their quality of life. Of those with persistent tinnitus, it appears that one in ten are severely affected, with serious deterioration of their quality of life, i.e. one person

in 100 of the general population. Applying similar incidence to Ireland would suggest that at any one time, 15,000 to 20,000 people may be in this category. Figures obtained from a large ENT clinic in the south of Ireland showed that some 12% of the 2,800 attending in 2002 complained of tinnitus. Details of the age profile of these patients were not available.

*Age* All statistics show that while tinnitus is reported by people of all ages, including children (Baguley and McFerran, 1999), its incidence increases dramatically with the advance of age. The association between *presbycusis* and tinnitus contributes to the misconception that tinnitus is exclusively a complaint of the elderly. In fact, many people develop tinnitus in their early middle age, and younger.

*Gender / Occupation* It appears that the incidence of tinnitus is similar for men and women. The greater employment of men in noisy employment environments such as construction, engineering, and the military might suggest the likelihood of a greater incidence of tinnitus among the male population. On the other hand, women have a tradition of employment in noisy textile and other manufacturing industries. The reporting patterns of men and women about health problems generally may distort the actual incidence of the condition, as appears to happen with some medical complaints. Hallam says that “women seem to be more bothered by tinnitus than are their male counterparts”, and mentions insomnia as one area about which women with tinnitus complain more than men (1989, p.20). Yet, Andersson (2002) says that “there are no clear indications that tinnitus should be experienced differently by men and women” (p.978). Some occupational groups are at higher risk of a range of hearing impairments including tinnitus. These include musicians, divers, and those working in noisy environments as mentioned above. Stressful working environments may also be implicated, e.g. teachers (Hillert, Maasche and Kretschmer, 1999), and air-traffic controllers (Vogt and Kastner, 2002).

*Class* United Kingdom (1981) figures found tinnitus to be twice as common among people engaged in manual occupations as among those in professional positions. It may be speculated that the level of exposure to occupational noise could explain this variation. However, more general health patterns across socio-economic groups could be significant here. Slater and Terry (1987) say that “people who reported long-standing illness, disability or infirmity were twice as likely to have tinnitus as those who reported no such long-standing sickness” (p.94). If a higher incidence of ill-health generally is reported by people in the manual occupational groups, a higher incidence of tinnitus would not be surprising.

It is not clear whether the incidence of tinnitus is increasing. Some hold that modern factors such as a noisier environment, especially in clubs, and the use of overly-loud personal headsets, will result in more cases of tinnitus. The modern-day stressful lifestyle may also be seen as a villain. Higher rates of consultation with medical opinion could also result from greater public awareness of the condition, as well as the greater unwillingness of people to tolerate chronic health conditions. If, as some fear, increasing numbers of younger people are affected, a lowering of the age profile of tinnitus sufferers seems probable. When this is combined with the forecast growth in the retired population in Ireland over coming decades, tinnitus will assume an increasing profile in the health services here.

### **Approaches to the problem – internationally**

Increased interest in the tinnitus condition has resulted in a greater range of available treatments, especially over the past 20 years. It has to be stressed however, that none of these yet offers a cure. What is now suggested is that tinnitus need not be a disabling

condition, as each person should benefit to a greater or lesser degree from some of the recommended approaches. Nevertheless, the non-availability of many of these management resources, the lack of informed health professionals, and the scarcity of skilled therapists, means that most people with tinnitus are neither reached nor helped.

A range of treatments / management approaches to tinnitus is depicted in Table 1. The categorisation is an attempt to range various approaches along a continuum, from professional interventions to personal self-help and group support. In addition, some approaches are more frequently employed and practised, others less so. (Not included here are many other anecdotal reports of varying degrees of success with particular methods of treatment, many of them unusual, and some bizarre. Details of these may be read from the many websites dedicated to such reports). I do not intend to present detailed analysis or evaluation of the many popular approaches here. A brief explanation of the treatment and its rationale is presented.

### **Medical / surgical / pharmacological**

It is probably best to begin with the medical approaches to tinnitus, not because these are many or effective, but because most frequently, it is to medical professionals that the person affected by tinnitus first turns. Commonly, the initial approach is to the general practitioner. The GP may be able to remove hardened earwax and alleviate the tinnitus, if that is the simple cause. The tinnitus might also disappear after antibiotic treatment of an ear infection. Where tinnitus is a symptom of Ménière's Disease, *betahistine dihydrochloride* (e.g. Serc) may alleviate the noise.

More often however, the patient needs reassurance and information. Where there is already a significant degree of distress, the doctor might prescribe tranquillisers or sleeping medication. Anti-depressant medication may be considered if the tinnitus is accompanied by, or is causing, depression. Research suggests that such medications do not have a direct effect upon the tinnitus itself, but can bring about an increased tolerance of the noise as mood lifts and anxiety subsides. Henry and Wilson (2001) report a significant association between high levels of anxiety and depression, and tinnitus, and recommend the clinician, where necessary, "to consider utilizing specific interventions to reduce the level of depression" (p.25).

Many are ever-hopeful of the pharmacological breakthrough that will provide "the pill for tinnitus". Recent advances in the pharmacological treatment of tinnitus are reviewed by Simpson and Davies (1999). They point out that few drugs have been found to directly alter tinnitus. Lidocaine, administered intravenously, has been found to have the most success, but has serious side-effects that would not allow ongoing use. The point is made however, that whatever the action of the drug, it shows that tinnitus can be silenced by a pharmacological agent, however short-lived the relief, giving hope to those who believe that 'a pill for tinnitus' will eventually be available. Studies have trialled other agents such as zinc (Yetiser, et al., 2002), with inconclusive results.

Only in very rare cases is there likely to be successful surgical treatment for tinnitus. If the noise is being generated in the cochlea, then severing the auditory nerve might be expected to silence the tinnitus. The evidence is that this procedure does not guarantee success, as other sites may be involved in the tinnitus generation. Thus, while hearing will be lost in the ear concerned, the tinnitus may continue, or worsen. As might be expected, this radical option is rarely considered. People with severe hearing loss who undergo surgery for a cochlear implant frequently also have tinnitus, but Miyamoto and Bichey

Table 1: SUMMARY OF TREATMENTS / APPROACHES TO MANAGEMENT OF TINNITUS

MEDICAL / SURGICAL	AUDIOLOGICAL	PHARMACOLOGICAL	PSYCHOLOGICAL	COMPLEMENTARY THERAPIES	SELF-HELP	MUTUAL HELP
Removal of ear wax	Fitting of hearing aid	Antidepressants	Counselling: individual and / or group	Ginkgo biloba	Relaxation	Support groups
Cochlear implantation	Masker / Wearable Noise Generator	Tranquillisers	Cognitive-behavioural therapy	Hypnosis	Exercise	Personal stories
Surgical removal of acoustic neuroma	Combination instrument (masker + hearing aid)	Sleeping medication	Tinnitus Retraining Therapy	Acupuncture	Distraction / active ignoring	Newsletters, publications of tinnitus associations
	Hearing Therapy	Intravenous Lignocaine (Lidocaine)	Internet-based counselling	Osteopathy / cranio-sacral therapy	Imaging	Tinnitus internet websites
		Bethahistine dihydrochloride (e.g. Serc)	Stress management	Yoga	Prayer / Meditation	Telephone helplines
		Zinc supplements		Bio-feedback	Dietary adjustments	
				Application of electromagnetic impulses	Sound enrichment therapy	
					Diary	
					Information / understanding	

Compilation: Naughton, 2004

(2003) report that “a large percentage of patients do report some degree of tinnitus suppression postoperatively”.

Some success in temporarily relieving tinnitus is claimed for the application of electrical impulses to the head (Konopka et al., 2001); the researchers report that electrical stimulation to relieve tinnitus has been used for nearly 200 years, in different forms. Also researched is ‘transcranial magnetic stimulation’ (Plewnia, Bartels and Gerloff, 2003), again claiming transient success. In addition, Swedish researchers report that “bone-conducted sound has the potential to relieve tinnitus in the same way as air-conducted sound” (Holgers and Hakansson, 2002).

### **Audiological**

Many people affected by tinnitus are referred to an audiologist, especially if there is evidence of a hearing impairment in conjunction with the tinnitus. Hearing aids may be recommended, following audiometric assessment. It is sometimes the case that the resulting improvement in hearing leads to a reduction in awareness of the tinnitus. In recent years, various forms of sound therapy have been devised, each aiming to *desensitise* the hearing of the person with tinnitus, so that gradually, less attention is paid to the tinnitus sounds. Earlier practices of seeking to ‘mask’ the tinnitus with a louder sound by means of a *masker* or *noise generator* were found to be ineffective in the long term, as the internal and external sounds competed with each other. It is now believed that habituation to the tinnitus can only occur if the tinnitus can actually be heard. Consequently, the *wearable noise generator* (WNG) will be set at a level just below the tinnitus, and must be worn for certain minimum durations of time daily. This kind of sound therapy is an integral component of TRT. Some people report that extended listening to *white noise* – similar to the hissing sound of a radio tuned off the station - subdues loud tinnitus.

### **Psychological**

Each person who is distressed by tinnitus requires immediate reassurance and encouragement – this can be provided by counselling psychologists, but it may effectively be provided by audiologists or trained peer counsellors. Some people with tinnitus will require at least a short intensive spell of individual counselling. Counselling for the distressing effects of tinnitus may take different forms, and can depend on the particular approach of the individual counsellor, as well as the needs of the client. Some may practice *cognitive therapy*, or *cognitive behavioural therapy* (often referred to as CBT), aiming to help the person change their beliefs about and attitudes towards tinnitus (Henry, 2002). Others take the view that counselling on broader personal issues will have benefit for the handling of tinnitus as an indirect effect. Counselling may also be provided in group sessions where tinnitus management skills are taught and practiced. Recent research, in addition, has looked at the potential of internet-based counselling for tinnitus, with encouraging conclusions (Andersson, et al., 2002).

## Tinnitus Retraining Therapy

This is perhaps the most widely known approach to tinnitus management over the past decade. Deriving from the work of Jastreboff and others, it interprets tinnitus through a neurophysiological model (Jastreboff and Hazell, 1993; Jastreboff, Gray and Gold, 1996). This interpretation – which it has to be said is not universally accepted – sees tinnitus as a problem because of the reaction of the person to it. In fact, tinnitus is not considered to be an illness, but a normal activity of the audiological and neural system.

The critical difference between this model and most of its predecessors is the emphasis it places on the central nervous system as the main factor governing whether or not the tinnitus causes distress (BTA Working Group, 1999a: 1)

Therefore, TRT aims to reduce the distressing reaction a person experiences, to the point where the noise no longer causes upset or negative feelings. In time, this is claimed to lead to less and less attention being paid to the tinnitus, in some cases leading to its disappearance. TRT proponents do not set out to eliminate perception of the tinnitus itself, but claim that this is often the indirect outcome of the therapy's approaches. The use of sound therapy (such as WNGs as outlined above) is an integral part of the therapy. Improvement rates in excess of 80% are reported (Jastreboff, Gray and Gold, 1996; Jastreboff and Jastreboff, 2003).

The specific elements of the approach to tinnitus management contained within TRT are very defined. The BTA Clinical Guidelines Working Group (1999a) refers to the “unjustifiably dogmatic strictures and considerable expense of present-day TRT”, and urges audiologists and others to adopt the elements of TRT in combination with other approaches, including a range of counselling strategies. This arises in part because it is not clear from research findings which elements of TRT are having the positive effect. While the supporters of TRT present very encouraging research results for the application of their methods over the past decade, not everyone is wholly convinced that TRT is the only way, or indeed the most effective way to treat tinnitus problems. Writers such as Henry and Wilson (2001) – proponents for a *cognitive behavioural* approach to tinnitus – and Kroener-Herwig et al., (2000) are among those who critique the claims for the success of TRT, arguing that the research studies claiming success have methodological weaknesses. Nevertheless, as the BTA Working Group state

... the general concepts of the neurophysiological model are very plausible, ... [and] offer the therapist, doctor or counsellor a more rationalised, systematised and constructive basis for management of patients with tinnitus than generally seems to be applied in the NHS or elsewhere (BTA Working Group, 1999a: 8)

It is not easy to identify and categorise the various approaches to tinnitus management. Therapists may find that the best solution is to fit the therapy to the individual patient. One would have to conclude that a combination of therapeutic approaches seems to offer the best way forward. Research evidence will undoubtedly accumulate over the coming years, clarifying which treatments or combinations of approaches are most effective for individual tinnitus cases.

### **Alternative therapies**

Inevitably, there is significant interest in alternative therapies among those who have met with professionals proclaiming their powerlessness to deal with tinnitus. It is probably the common pattern when a person is faced with the prospect of a chronic condition that all possible avenues are explored in the search for a cure, or at least a palliative. Among the options explored are known to be: herbalism, homeopathy, aromatherapy, massage, osteopathy (including cranio-sacral therapy), acupuncture, biofeedback, hypnosis, yoga, prayer, meditation and imaging. In the case of each of these treatments, anecdotal evidence can be gathered that both supports their efficacy and discounts it. Inconclusive reports are also available for the efficacy of a particular herb *Ginkgo Biloba* (BTA, 1999b; Morgenstern and Biermann, 2002). Hopes that this might prove the answer to tinnitus have not been fulfilled, even though many therapeutic effects are attributed to Ginkgo.

### **Mutual support / Self help**

During the latter half of the 20th century, there was a dramatic growth in the number and variety of self-help and mutual-help groups (Powell, 1994; Stone, 2001). This phenomenon is a consequence of the dissatisfaction of many people, who, with chronic physical and mental conditions, have found the mainstream medical / health services limited in their capacity to respond therapeutically. At national and international level, tinnitus associations have been established, representing the views of their members and acting as advocates for improved treatments and services, and more research. At local level, subsidiary support groups try to provide personal support and information services (Cohen, Underwood, et al., 2000).

The teaching of self-help techniques is frequently a priority for such groups. However, while there is a significant international literature on the workings of mutual help groups and organisations, it proved impossible to locate any such studies specific to tinnitus groups. Some tinnitus support groups have been termed “phobic training camps” (‘The Tinnitus and Hyperacusis Site’ [www.tinnitus.org](http://www.tinnitus.org)). While it is likely that what people hear at a support group may occasionally have the effect of increasing fears or anxieties around tinnitus, the foregoing is unfair comment on the many committed volunteers who, starved of professional support and with minimal funding, do the best they can for each other. Nevertheless, the application of principles for effective groups to tinnitus support groups is an urgent priority, in this researcher’s view. Publications of the tinnitus associations, such as quarterly newsletters, keep the membership informed of research developments and allow members to tell their stories and share experiences. These are important channels for those members who are not attracted to group gatherings, or cannot avail of them due to geographical isolation or disability.

## Chapter 2 Research Methodology

### The research question

While there is now a considerable body of tinnitus research internationally, Ireland is a 'data desert' when it comes to tinnitus. Neither will public attitudes have been helped by the adverse publicity surrounding the Irish army 'deafness claims' controversy in the late 1990s, when many claimants reported having tinnitus as well as hearing impairment. The dearth of data on the incidence of tinnitus in this country makes it necessary to apply the patterns observed elsewhere to the Irish context. There is no reason to believe that the experience of tinnitus in Ireland is any different from that reported worldwide. In these circumstances, it should be apparent that the tinnitus problem cannot be ignored. While we may wait for the international research community to make the breakthrough that will be universally beneficial, we need at the very least to gather data on the experience of tinnitus in Ireland.

As a start in that direction, the research question for the present study has been formulated thus: *"to determine the therapeutic and other support needs of tinnitus sufferers, and to influence public policy towards improved provision of services to meet these needs"*.

### Methodology

The methodology chosen for this project was a qualitative survey of the experiences of people with tinnitus in Ireland. The survey was undertaken by means of personal interviews with a representative sample of the membership of the Irish Tinnitus Association, a sample size projected at between 70 and 80 members. In the event, structured telephone interviews were conducted between March and May 2003 with 66 members, while 7 others requested the opportunity to respond by means of written questionnaire rather than be interviewed over the telephone – the reason in each case was difficulty using the telephone due to hearing impairment. The format of the structured interview was adapted closely to a questionnaire format for this purpose. The total sample therefore was 73. Statistical details of the samples approached for participation are provided on the attached summary.

**Table 1: Sample details and response rates**

Number in mailed sample	Total replies received	Positive respondents	(Number of these completing questionnaire)	Number of respondents declining	Total completing interview or questionnaire
112	92	81	(7)	11	73

*Note 1:* Two declining respondents indicated that they were members of the ITA out of interest, but did not have tinnitus

*Note 2:* Interviews did not take place with 8 positive respondents, due to subsequent problems making contact, or respondents being unavailable to interview for other reasons, including illness.

## Sampling

The quota sample was selected by identifying every fourth name on the ITA membership database, ensuring a minimum sample of 85. Following the response to initial mailing, the same process was extended until a total mailing of 112 members eventuated in a sample of 73 respondents. That sample of 73 represented some 21% of the Association's membership; 39 were male, 34 female. The sample can be considered representative of the Association's membership, being distributed across 21 counties of Ireland. The rate of response must be considered unusually high, but may be explained as evidence of the enthusiasm of the association's membership for research into their condition. It might be added that the interviewer was told by a significant number of respondents that this was the first occasion on which they had been given time to talk about their tinnitus to an interested party. It may well be that for some, the interview served a quasi-therapeutic purpose.

The sampling method chosen had the distinct advantage that all respondents were already members of a tinnitus association, and would consequently be a more willing group; conversely, the sample might over-represent those who have already become involved in self-help and mutual help action. Such a group might be considered not to represent the general section of the population affected by tinnitus. (Indeed it was noted by this researcher during the interview process that professional persons appeared to be over-represented in the sample). However, it may equally be argued that because the more socially active and more motivated persons may be over-represented in the membership of an activist group, the non-members are likely to be more passive in managing their condition, less informed about treatment options, less able to afford alternative therapies, and consequently more in need of support.

## Why this approach?

The interview approach to data collection has its strengths and weaknesses. The surveying of a geographically widespread population with the relatively limited funding available restricted the research options. In cost terms, the telephone proved a relatively inexpensive medium. The interview was considered more likely to produce a holistic picture of the respondents' experience than the questionnaire was. The researcher considers that his own experience of tinnitus enabled him to elicit fuller responses from interviewees. The average duration of the interviews was 35 minutes, somewhat longer than the average 25 minutes envisaged.

However, actually recording the interview data was not without challenges. Tape-recording of the interviews was considered cumbersome and somewhat invasive, so written recording of data was used instead, utilising a pre-structured interview template. All interviewees were contacted initially several days before the interview to arrange dates and times – this also helped to establish interviewee trust.

## Structure of the Interview / Questionnaire

The interview consisted of 5 main sections: *Personal Data; Onset of Tinnitus; Initial Effects of Tinnitus; Looking for Help; Present Situation; Outlook*. This structure was decided upon in order to collect the kinds of data considered to answer the research question, i.e. how is tinnitus experienced by people; how do they cope with it, initially, and as time passes; what kinds of help are sought by people and how does that help aid or fail to aid them; can we provide a snapshot of how people stand at present; and finally, what services do they consider necessary, and what are the people's hopes and fears about their own tinnitus as they ponder the future.

## Chapter 3 Findings

In this chapter, the results of the survey are provided under the following main section headings

- Personal Data
- Onset of Tinnitus
- Initial Effects of Tinnitus
- Looking for Help
- Present Situation
- Outlook.

(Figures / percentages refer to the total responding sample of 73, unless otherwise stated).

### Personal Data

*Age:* Only one respondent was aged under 30; eleven (15%) were in the 30-50 years age bracket, while 84% of respondents were aged over 50; two were over 80 years. The average age of respondents was over 60 years, reflecting the common pattern of an increased incidence of tinnitus among the older population. A similar age profile is seen in the membership of tinnitus support groups. In some countries, special efforts are made to involve younger people in tinnitus help groups, acknowledging that the wide age spread of members may lessen the attractiveness of the groups to younger people. However, the preponderance of older persons presenting with tinnitus reflects a worldwide pattern.

*Gender:* The random sample selection in this survey produced a 55:45 male / female ratio. However, analysis of the 2002 / 2003 membership database of the Irish Tinnitus Association, from which this sample was drawn, shows an exact 50:50 male-to-female ratio. Most studies suggest little difference in the incidence of tinnitus among men and women.

*Duration:* Over half of the respondents had their tinnitus condition for more than 10 years, nearly one-fifth for in excess of 20 years. Two people reported that they had had tinnitus for over 40 years, one of these having had tinnitus since childhood. The figures suggest that those who are members of the tinnitus association are mainly those with long-term tinnitus.

*Contact:* Some one-fifth of respondents live alone. It might be surmised that isolation would be a negative influence on coping with tinnitus. However, not one of the respondents raised this as an issue. Many who lived alone had active social lives and good familial and other contacts. The role of others in one's management of tinnitus is an issue we shall revisit later in this report.

### Onset of Tinnitus

*Nature of onset:* There is an almost even divide among those who reported that their tinnitus began suddenly (52%) as against a gradual onset (48%). However, initial awareness of the noise might not necessarily coincide with the actual onset of the noise. Since many report that their tinnitus became gradually more noticeable with time, it is possible that the initially quiet onset may have escaped notice. Yet quite a few respondents were able to identify the actual beginning of their tinnitus, especially when

they could attribute the cause to a particular event or circumstance. Among such attributed 'definite' causes were:

- ear surgery
- occupational noise exposure (mainly construction work, use of firearms, farm or factory machinery)
- being in the vicinity of an explosion (included one man who lived through the Blitz in London)
- road-accident injury (usually whiplash, or head or neck injury)
- other head injury (e.g. a fall; an assault)
- exposure to sudden loud noise
- acoustic neuroma
- viral infections (including the common cold)
- medications
- ear syringing
- stroke

*Possible causes:* When asked to comment on the likely or possible causes of their tinnitus, the majority of people said they simply did not know what had triggered it. They speculated on the causes, while acknowledging that they were guessing, and could not prove their beliefs. Among such 'speculated' causes were:

- occupational noise damage
- use of antiarthritic medication
- genetic cause
- extreme stress
- a heavy cold
- a glandular disorder
- rupture of a blood vessel
- sinusitis
- poking in ear as child
- loudspeakers at a party
- dental surgery under anaesthetic

*Accompanying factors:* Some people had additional factors accompanying the onset of their tinnitus but could not be sure if they were implicated. Stressful situations at work or at home were suspected by some; potentially stressful situations were also mentioned, e.g., a woman who had just returned from Australia; a man who had just retired; a woman who was sitting examinations; a woman who had recently had a baby; a woman whose sister was terminally ill at the time. Obviously, the onset of tinnitus during periods of stress is a significant feature here. In all, some 34% of respondents reported that some kind of 'life stresses' accompanied the onset of their tinnitus.

There were also a number of people who suffered from some degree of ill-health prior to the onset of tinnitus, but they were unable to say what the connection might be with their tinnitus, if indeed there was any. A few suspected that treatment for a pre-existing condition could have brought on the tinnitus.

*Co-symptoms:* Hearing impairment frequently accompanies tinnitus. Seventy per cent of respondents here said that they had some degree of hearing impairment. Most described this as a "high-frequency hearing loss". In some cases the impairment pre-dated the tinnitus; others believed that it coincided with the onset of the tinnitus; a few said that the hearing loss developed some time after the tinnitus began. The relationship between hearing loss and tinnitus is the subject of ongoing debate worldwide. Other audiological

and non-audiological symptoms mentioned by respondents included: fullness in the ears; balance disorders (in 6 respondents this was associated with diagnosed Ménière's Disease); hyperacusis; pain and discomfort in the head or face; persistent sinusitis; compacted earwax; temporomandibular joint (TMJ) problems; and trigeminal neuralgia.

*Location of noise:* Asked about the location of their tinnitus noise, roughly similar proportions reported that the sound was in either their right (21%) or left ear (23%). However, both ears were affected for 41% of the sample, while 15% reported their tinnitus as being "somewhere within the head".

*Quality of the noise:* The tinnitus sounds are variously described as: hissing, whistling, ringing, whining, rumbling, buzzing, humming, ticking, roaring, etc. Some use metaphors to describe the noise: 'a tinny high-pitched sound', 'air escaping from a pump', 'tractor engines', 'a swarm of bees', 'concrete blocks tumbling', etc. A minority of people are unable to find a word to describe the noise. Where both ears are affected, there may be different noises in each ear.

*Previous knowledge:* Just 15% of respondents had some knowledge of tinnitus before their tinnitus began. A few had heard of it, but knew little more; some had had a parent who suffered from the condition.

## **Initial Effects of Tinnitus**

The way a person reacts to tinnitus at its onset can determine the progress of the condition for some time afterwards. In the present survey, 73% of respondents said that they were troubled to a greater or lesser extent by the onset of the noise. Some 26% said that they were 'not unduly bothered' at the onset; one person couldn't recall the onset due to the passing of years. As will be discussed later in this report, many people who were initially troubled came to some level of acceptance of the noise; however, some who began untroubled, later developed problems when their condition worsened.

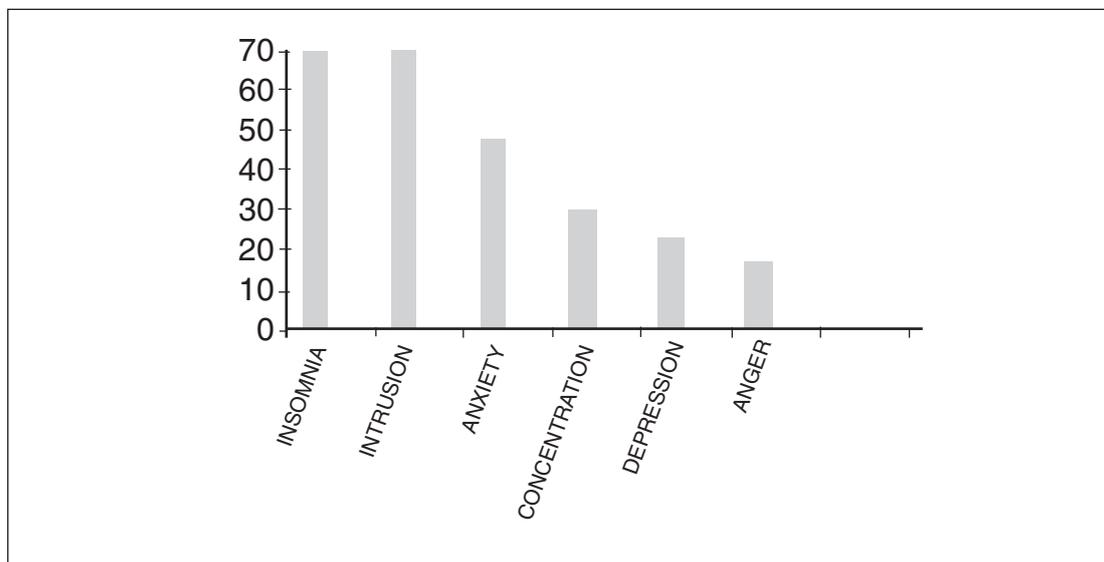
### **Effects of tinnitus at early stages**

International research on the effects of tinnitus on the person shows that having one's attention persistently drawn to the noise is one of the principal negative effects, especially in the early stages. In this survey (see Figure 1 below), 70% of respondents said that this was the case for them, i.e. that they found it very difficult to ignore the tinnitus noise. Some said that they could not divert their attention from it. The debilitating nature of this situation is self-evident, exacerbated by accompanying fear and anxiety. Nearly half of all respondents (47%) described themselves as 'fearful' and 'anxious' during these early weeks and months. The ability to concentrate was affected in 29% of cases, often becoming evident in the inability to sustain reading or studying.

Sleep disorders are often reported as a result of troublesome tinnitus – here, 70% said their sleep was disrupted; for some, insomnia became a major problem, requiring medical intervention. Similar intervention was also required for those who became depressed by their situation (22% of people in this survey). Being restricted in their social lives was an issue for just 12% of respondents – for most people, the problem arose, not from the tinnitus itself, but from the negative effects on their tinnitus of being in noisy environments such as pubs and clubs.

Sixteen per cent of people said that they were angry about the medical treatment they received, believing that such treatment either contributed to their tinnitus, or failed to deal in any effective manner with their symptoms or concerns.

**Figure 1: Percentage of respondents reporting initial effects of Tinnitus**



*Gender differences:* Women were more likely to report anxiety and depressive symptoms in the early stages of tinnitus; men were more likely to report concentration difficulties. There were no significant gender differences in the reporting of insomnia, attending to the noise, or anger at treatment.

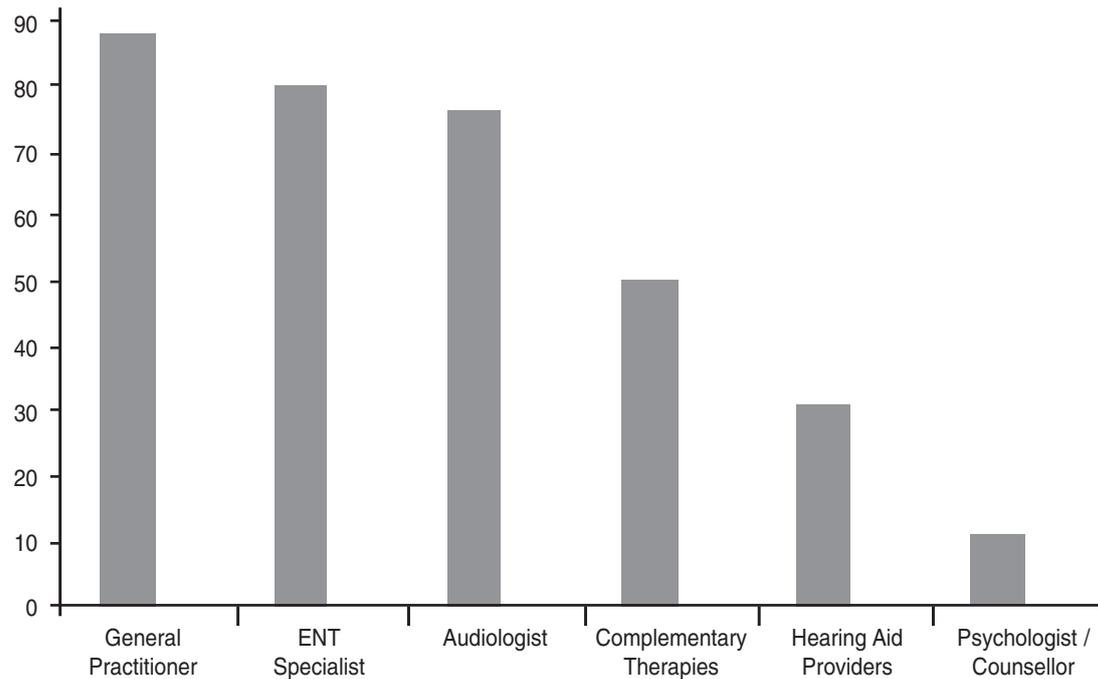
### Looking for Help

Respondents were asked to tell which medical or other professionals they consulted for their tinnitus condition, and which kinds of treatments they sought and received. In addition, they were invited to comment on their level of satisfaction with the response they received, and with any subsequent treatments.

#### Who did you consult with your tinnitus?

- 89% of respondents attended their GP at least once.
- 81% consulted an Ear, Nose and Throat specialist
- 77% consulted an audiologist
- 51% tried alternative / complementary treatments
- 32% consulted a hearing aid clinic or salesperson
- 12% attended a psychologist / counsellor / psychiatrist

The usual pattern of consultations with medical and other professionals is reflected in the above figures. The general practitioner is almost always the first professional attended. The figures for attendance with an ENT consultant or audiologist suggest that the vast majority of people are referred onwards by their GP for further investigations. These figures in turn arise from the GP's lack of options in treating tinnitus, coupled with the demands of patients for some kind of action. In addition, the GP may wish to ensure that no sinister underlying condition is giving rise to the tinnitus. Attendance at the other professionals is commented on further below.

**Figure 2: Percentage of respondents consulting various opinions****Satisfaction with GPs' responses and treatments:**

Almost nine out of ten people with tinnitus went first to their GP for advice or treatment. Roughly one third of those who attended a GP declared themselves satisfied with their GP's response; most qualified this by saying that they believed he / she had done all they could do. Another third said they were not satisfied with the response / treatment they received, while a third again did not express an opinion.

Interviewees commented, some with approval, some with criticism, on the response they received from GPs. Critical comments referred to doctors' lack of knowledge of the tinnitus condition, or insensitivity to the burden of dealing with it. The following is a representative sample of comments:

- My GP knew little about tinnitus - said "You'll have to put up with it"
- The doctor said I was just imagining the noise
- He listened attentively and was quite interested
- He was a great help and support, and sourced leaflets for me
- My doctor had tinnitus himself, and was a good example of someone living with it
- He said "We must accept things like this as part of ageing"
- I got no explanation, no advice
- I knew more about tinnitus than the doctor did
- I got no sympathy from the medics
- She was supportive but powerless to help

**Satisfaction with audiologists' responses and treatments:**

Seventy-seven per cent of the sample consulted an audiologist. One quarter of these said they were satisfied with the response they received concerning their tinnitus; some 15% of them were not satisfied; 60% did not express an opinion either way. Comments made by respondents suggest that audiologists generally confined themselves to audiometric assessments and diagnosis of hearing problems, but gave little or no advice or comment on the tinnitus. Some people were fitted with hearing aids or maskers, but few reported success with these.

Among the comments made were:

- She didn't know much about tinnitus but liaised with the ENT
- He just said 'try to ignore it, but he did care'
- She used sound therapy with me; made good efforts with the tinnitus
- Said I had industrial deafness but made no comment on tinnitus
- I went to two [audiologists] but got no answers
- She was very interested; sent me for an MRI
- Said my hearing loss was normal for my age, but made no comment on the tinnitus
- She said 'You've got tinnitus – it's not going to go away'

### **Satisfaction with the responses and treatments of hearing aid providers:**

When people with tinnitus consider availing of hearing aids, it is often because of an accompanying hearing loss. It can happen that the improvement in hearing resulting from the aid serves to subdue the tinnitus. Hearing aid providers (some of whom may be audiologists) may also fit 'maskers' to control the tinnitus. In the present survey, about one third of the respondents had either been recommended to wear a hearing aid or aids, or had had them fitted. Of the 23 who did seek a hearing aid or a 'masker', 5 declared that they were satisfied with their treatment, 7 declared themselves dissatisfied, and the remainder did not express an opinion.

Some of the comments made here included:

- The hearing aid made the tinnitus worse
- The audiologist supplied me with hearing aids and has been very facilitating
- My hearing aids made no difference [to tinnitus]
- I didn't go for it - the salesman was too pushy
- The aid at least enabled me to hear my own voice
- I use two maskers – they give me some sense of control over the tinnitus
- I don't really use the hearing aid regularly

### **Satisfaction with responses and treatments from ENT specialists:**

Four out of five people in the present survey sought the opinion of an ENT specialist. While one fifth of those consulting said they were satisfied with their treatment, more than twice as many declared themselves dissatisfied with the response they received.

Comments made by respondents include the following:

- He said 'I'm busy; I don't have time to listen to your tinnitus story' – his manner was quite offensive
- He offered reassurance and said that I would live with it
- He said 'go away and get used to it'
- He told me to put on a fan, and I would get used to it – this is an unacceptable way to deal with someone who has tinnitus
- I was happy enough with him
- He said 'pretend it's not there' and told me to go to the ITA
- He told me not to worry about it – but he didn't even explain what it was or what I could do
- He did everything he could and sent me for X-rays
- He said 'You're getting old; put up with it, it won't do you any harm' [to a woman aged 55]
- He treated me for an infection but he had no interest in tinnitus
- He gave me the usual line but did refer me to the ITA

### **Satisfaction with psychologists' responses and treatments:**

Twelve per cent of the sample sought help from a psychologist, psychiatrist or counsellor. This figure might be considered surprisingly low, given that the thrust of international efforts in developing tinnitus therapies is largely in the area of counselling and in *Tinnitus Retraining Therapy*. However, given the virtual absence of tinnitus treatments in Ireland to date, this figure should not surprise. Four of the 9 respondents who sought psychological help said that they were satisfied with their treatment; 1 was not. Four others did not express an opinion either way.

The comments here included:

- I found his advice helpful
- He gave me tapes and helped me with cognitive therapy
- He gave me good references for tinnitus on the web

One respondent was not happy because his counsellor "had no interest in tinnitus; it made no difference". A few others had a different take on counselling. One man explained that his GP was effectively his counsellor because he took a great interest in his tinnitus and gave him a lot of advice. Another said, "I don't need a counsellor – I have a good one in my wife".

### **Satisfaction with responses and treatments of alternative / complementary practitioners:**

Given the chronic character of tinnitus, it is not surprising, in the absence of any structured medical treatments, that many people seek out alternative / complementary therapies. Just half (51%) of the sample here consulted some kind of complementary therapist, with acupuncture being by far the most common treatment. Other therapies tried included reflexology, yoga, herbalism, aromatherapy, homeopathy, Reiki, head massage, and osteopathy (mostly cranio-sacral therapy). A number of respondents took Ginkgo Biloba extract; several also sought help from 'healers'. The common evaluation of these therapeutic approaches was that they had little or no beneficial effect on the tinnitus. Many respondents did claim that they felt better or felt more relaxed after treatments, but where there was any benefit for tinnitus, it was indirect.

The recommendation that people affected by tinnitus be medically assessed in order that serious underlying conditions be ruled out, leads to a high level of diagnostic testing. In the present survey, 41% reported that they had had medical tests of various kinds for their tinnitus. Most commonly, these were scans, such as MRI or CAT scans, or X-rays – the overwhelming majority of these detected no abnormality. Just one detected an acoustic neuroma, for which the person had surgery. Somewhat surprisingly, only two respondents said that they had consulted with a neurologist, yet most people who had scans are likely to also have had them seen by a neurologist.

## **Present Situation**

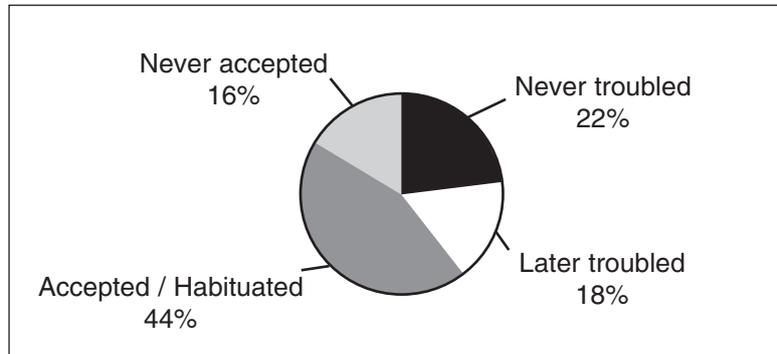
### **Years to acceptance and / or habituation**

It is commonly reported that the majority of people who are affected by the tinnitus condition come to terms with it in time. This process involves elements such as acceptance, and a gradual reduction in the amount of attention given to the noise. This 'getting used to' tinnitus is termed *habituation*, a natural psychological characteristic of people. It enables us to ignore or tune out from sensory features once we have registered them as unimportant and as not meriting our continued attention. Tinnitus continues to be a problem for those people who, for whatever reason, are unable to achieve this habituation.

In terms of adapting to or habituating to tinnitus, the present survey found that there were four main groups:

1. Those who had never been very troubled by their tinnitus
2. Those who initially were not troubled, but later became distressed
3. Those who initially were troubled, but eventually accepted and / or habituated
4. Those who have never accepted it, and continue to struggle against it

**Figure 3: Status of attitude towards one's tinnitus**



The first group above constituted 22% of the sample. These people said that their tinnitus was never very troublesome. Some said that they made a decision right from the start of it that they would not allow it to become a problem:

“I was busy. I didn’t even have time to attend to it”

“I accepted it from the start – I didn’t fight it because you can’t win”

“It wasn’t really distressing so I decided to leave well enough alone”

“My tinnitus was not so bad – I realised that others had it much worse”.

Most of the second group above were those whose tinnitus worsened over time (18%). It can happen that a tinnitus condition that emerges when one is in a strong position to manage it, can become more difficult to handle later on due to a decline in personal health or other circumstances. Deteriorating hearing levels are also blamed by some for an increased foregrounding of the noise, i.e. the tinnitus is less masked by external sounds. “The noise became more troublesome as the years went by”; “The tinnitus has been worsening as my hearing has been worsening”.

Looking at the third group above (44% of sample), the time taken to achieve some measure of acceptance and / or habituation varied from a few months to over ten years; the typical experience was 2 to 3 years. A distinction should perhaps be drawn between *habituation* and *acceptance*: the former group have learned to largely ignore the noise – it’s no longer a problem to them; the latter group may have *accepted* that there is little that can be done for their condition, but continue to struggle with it periodically, perhaps at a lower level. Some commented that it was only when they accepted it that they began to habituate to it. In these cases, ‘acceptance’ seems to mean that a decision is made to stop ‘fighting it’.

“I live with it – it hasn’t changed much over the [five] years”

“I just worked at reducing my attention to it”

“It had been gradually improving anyway, but going to the support group made a great difference”

“Joining the ITA completed my journey to acceptance”

“I suppose I gradually accepted it while I was running around looking for a cure”

"I turned the corner when I began to talk with people at the group".

Other things that people said were of help to them in coming to terms with their tinnitus included: listening to certain kinds of music (*Lyric FM* was given credit by a few); reading a lot, and simply coming to understand the condition; avoiding silence, and / or using sound therapy; keeping social contact; investing time in hobbies and recreation.

A number of respondents (16%) said that they had not habituated to the tinnitus: "I've quested everywhere for a cure; I've gone everywhere in the hope of relief"; "I've been fighting it for years, especially since 1996 when it worsened"; "It has persisted as a problem over many years"; "I still feel disorientated when the tinnitus is severe".

This 'battling' group, it should be pointed out, includes more recent 'entrants' to the situation, some of whom could be expected to come to terms with the noise in time.

Also important is the group whose hearing impairment, vertigo or other health difficulties have become more of a concern than the tinnitus. This category of respondents includes people from each of the above categories. For some of these people, it is not necessarily that the tinnitus has improved, but rather it has been eclipsed by a more difficult condition, which may serve to distract attention from the tinnitus.

### Patterns in the tinnitus

When asked to identify patterns in the 'behaviour' of their tinnitus, some clear patterns emerged. A majority reported that there was a day / night contrast, most commonly quieter, or at least less noticeable tinnitus by day, becoming more intrusive in the evenings, and more so again at night. This pattern is to be expected, given the distraction provided by daytime activities, and the masking effect of ambient sounds; both effects are reduced or absent in the evenings and night.

- I am very aware at night; OK by day
- It's loud on waking but OK after a few hours
- I'm distracted by day but at night it's a monster that won't let me go
- I'm occupied by day but at night it eventually wakes me

A significant number of respondents said that their tinnitus was more or less constant – for some that meant that it was mild and never very troubling; for others it meant that the noise was constantly loud and intrusive:

- It's very loud most of the time but OK when I'm busy
- It's constant, but most of the time I don't bother about it
- I have no day / night difference – it's never very severe
- It's always there; audible even over loud sounds

Patterns over longer periods than the day / night contrast were also noted:

- I get a good week, then a horrendous week
- It's quite difficult about every two weeks
- It's louder in the mornings, and worse in spring and autumn
- I get a few bad days, then better days

Some comments related to other factors that produced temporary worsening of the noise. These included: 'after being in a noisy place', 'when my ears are blocked', 'when I have a cold', 'after exercise', 'when I remove my hearing aids'.

### **Management strategies**

The most common strategies employed by respondents in trying to manage their tinnitus were as follows (listed in descending frequency of mention):

- Sound enrichment (most commonly having a radio, music system, television or other ‘sound producer’ on around the home by day; by night some use headphones, others have pillow speakers; a few use ‘maskers’)
- Keeping busy, at work, at hobbies or socially
- Actively ignoring it – one referred to “exercising discipline over my attention to it”
- Work at relaxation and avoidance of stress
- Keeping contact with people
- Avoidance of noise and potentially noisy situations
- Taking of sedative medication such as sleeping tablets
- Taking of alcohol
- Driving or riding in a car

### **What makes it worse?**

A wide variety of situations and activities were claimed to influence the tinnitus for the worse. While a minority of respondents said that they could not identify any particular ‘villains’, most people were able to name some negative influences. Among them were the following, again listed in descending order of frequency of mention:

- Stressful situations; hassle
- Noisy environments
- Hurrying; fretting
- Being anxious about things
- Being tired
- Feeling low; feeling down
- Changes in weather
- Alcohol
- Headcolds and congestion
- Getting annoyed or angry
- Body movements (including closing of eyes) or body positions (such as lying down or crouching)

The above list holds few surprises, but leaves interesting unanswered questions. For example, why is it that for some people, alcohol exacerbates the noise, while others, as we saw earlier, use alcohol as a means of relaxation? What are the body mechanisms that allow bodily movements to change the tinnitus noise? How do changes in weather alter tinnitus? This latter question was raised by a number of respondents, some of whom speculated that barometric pressure might have an influence on bodily states.

There are obviously strong links between psychological states and the ‘troublesomeness’ of tinnitus - this is well borne out by research internationally. Similarly, we cannot be surprised to see emotional factors playing a part. The fact that tinnitus is worsened by heightened nervous states is commonly reported.

### **Talking and learning about tinnitus**

*“What are people’s reactions when you talk to them about your tinnitus?”* – this was a question posed to interviewees. A few prominent themes emerged. It is apparent that the majority of people with tinnitus do not talk much to others about their condition; quite a few said that they never talk to people about it. Quite common was a statement such as: “At the start, I would tell people about it; but now I hardly ever mention it, and then only when someone asks about it”. Most respondents said they felt that people didn’t understand tinnitus, because it was ‘invisible’. A few even felt that talking about noises in one’s head

left one open to ridicule or even suspicion. People were also reported as 'not wanting to know about it', because they found the prospect of it so alarming.

Many respondents said they felt that tinnitus was not taken seriously by society generally. However, it was also frequently remarked that people were genuinely concerned about it, and that they were sympathetic. Sometimes they might not want to ask about it as this would make the person more aware of it. It seems that the private suffering of tinnitus is compounded by the fact that there is a widespread ignorance of the condition. Those with tinnitus have internalised the belief that people don't want to know about it, and so they have largely stopped talking about it. Obviously, a balance needs to be struck between hiding the distress of the condition by remaining silent, and annoying those around through excessive complaining.

A sample of comments:

"Most people haven't heard of it and don't understand it"

"I get sympathetic comments – 'that must be awful', and the like"

"I found that people I spoke to were terrified of it"

"People don't understand what they can't see or hear"

"Those who listen and understand are those who have it themselves"

"The words of comfort from my family have helped me through the bad times"

"People can't really know what it's like having noises all the time"

"My friends got tired of listening to me, so I say little now"

Here too there can be a role for the counsellor who could help the person with tinnitus to distinguish between 'tinnitus problems' and 'non-tinnitus problems', particularly as they affect interpersonal relationships. The possibility of a person adopting the 'sick role' in a family because of tinnitus may also need to be explored through counselling.

### **Learning about tinnitus**

*Would you like to know more about tinnitus?* In response to this question put to interviewees, 79% said they would like to know more about it; the opinion of many here was that the more one knew, the better one could understand it, and consequently manage it more effectively. However, 21% said they would 'prefer to forget about it', or that they knew enough to manage at present. The figure for those keen to learn more is perhaps surprisingly high, as one might expect many with tinnitus to avoid thinking or talking about the condition, lest this increase one's attention to it. It should also be read as an encouraging figure, evidence of people's desire to better understand the condition.

*Asked what their sources of information on tinnitus were:*

- 97% said they got information from tinnitus association newsletters – Irish, UK and US
- 20% of respondents in addition used the internet
- 18% also said they learned about tinnitus by reading books and articles in newspapers, and by talking to people

*Asked how helpful they found the newsletters,*

- 84% rated the newsletters as 'very helpful' or 'helpful'
- 14% said the newsletters were 'not very helpful'
- 2% did not read the newsletters

### **Public meetings and support groups**

In Ireland, an important means by which people gain information about tinnitus is through public meetings organised by the Irish Tinnitus Association. The Association organises at

least two such meetings annually in Dublin, Belfast and other regional centres. Cross-Border meetings and links have also been a feature of recent developments. Leading international figures in the fields of tinnitus research and treatment are invited to speak to such gatherings. Two-thirds of respondents in the present survey had attended at least one such meeting. Comments on the meetings were largely positive, with the speakers considered to be 'interesting'.

### **Support Groups**

The Irish Tinnitus Association has also set up a number of support groups over recent years. Most are in major cities. A few meet monthly; most meet less frequently. The present survey found that only a minority of respondents (40%) currently attend or have at some stage attended support group meetings. At first glance, this might seem surprising, given that the sample here were all members of the association. However, comments from respondents suggest that the support group setting and / or format are not attractive to everyone. The comment "I'm not really a support group person" might well encapsulate the feeling of quite a few.

For some, the nature of the encounter at the group, or the nature of the encounter they expect, is what puts them off. Others referred to the content of the groups as 'negative' and occasionally upsetting. Some cited issues such as timing, location and accessibility as reasons they had never attended. Others felt they could manage their condition well enough by themselves, with help from literature. Others again said that they were geographically remote from any centre where support groups met, and that the larger (and perhaps more anonymous) public meeting was their only option. It would also seem that many members attend support groups for a relatively short time, perhaps three or four meetings, before deciding that they no longer need what the group offers. A few said they found the group meetings repetitive, that in the absence of a cure, the same points were being made at each gathering.

Some representative critical comments:

"I think the meetings would draw more attention to my tinnitus"

"I'd like to go, but meetings are too far away"

"I'd probably go if my tinnitus got worse"

"I don't think that support group meetings are generally helpful"

"There's not a lot to them – people don't know what the answers are"

"I found the meetings to be negative and repetitive"

"It's good to know they're there, but I don't think I need them"

However, seemingly bearing out the point that some people are "support group persons" - and some are not - this survey also found that the reasons given by people for attending the support groups were quite similar to those cited above for not attending. For these people, the personal encounters at the meetings were important and valuable; simply being with and talking with others who had tinnitus provided enough motivation for attending the meetings. Some expressly said that they wished to assist and support others, and could do this through the solidarity of the group. The meetings were also considered to be a social event and an antidote to isolation.

Some representative supportive comments:

"It's good to be able to share our experiences of managing the tinnitus"

"I find people in the \_\_\_\_\_ group do listen and want to hear what I have to say"

"It makes me feel better to be able to talk about it"

"I like being able to reassure new people"

"The \_\_\_\_\_ group is very professionally run"

"I like the mutual help idea"

“We can show new members that we have learned to cope”  
 “It was at the support group that I learned about relaxation”  
 “The group is a social outing for me”

## Outlook

### Needed services?

In the final part of the survey, interviewees were asked about the kinds of services they felt were needed to aid people with tinnitus. The following were suggested:

- A clinic where diagnostic and treatment options would be available (19%)
- Mutual support of various kinds (19%)
- A medical person interested in tinnitus to be available for consultation (12%)
- A counselling service, especially for those with distressing tinnitus (11%)

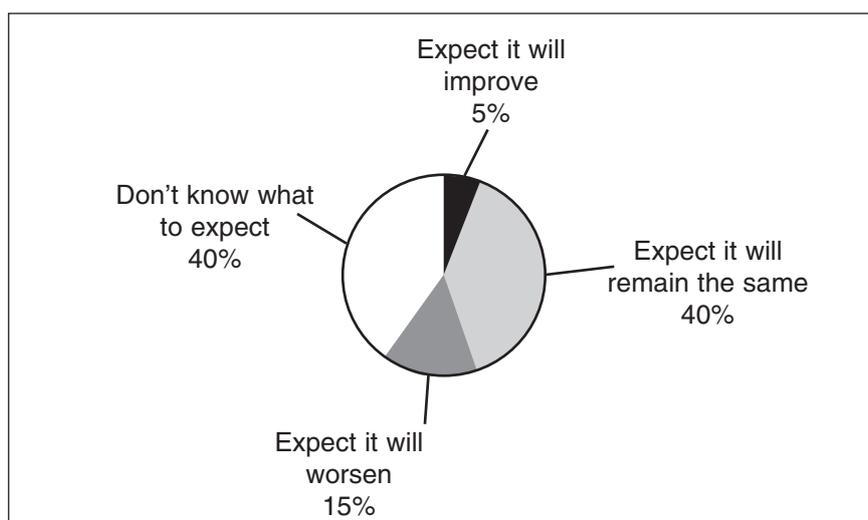
In addition, five per cent said they didn't know what services were available or could help, while nineteen per cent did not express a view.

On the assumption that most people with tinnitus would have heard of *Tinnitus Retraining Therapy* (TRT), interviewees were asked whether they would avail of TRT if it could be provided:

- 52% said 'yes'
- 18% said 'no'
- 15% were undecided
- 15% weren't familiar with TRT

The final question asked of interviewees explored their expectations for their tinnitus in the future. Some 15% expected it to worsen, especially if their hearing continued to deteriorate, but 40% believed it would stay the same; 40% of respondents said they didn't know what to expect, as it had been so unpredictable up to now. Only a small minority (5%) expected it to improve.

**Figure 4: Expectations for one's own tinnitus condition**



Other than those who expected it to improve, virtually all others expressed the hope that it would not get any worse.

Some comments to end:

“I don't believe it will change – I hope it won't”

“I’ll be happy if it stays the way it is”

“It’s not getting easier as I get older; I sometimes despair”

“Since I’ve lived with it and come to terms with it, I expect I’ll continue to cope”

“I worry about the second ear becoming affected”

“I fear it will get worse if my hearing worsens”

“I worry about it getting so bad I wouldn’t be able to cope”

“Barring a medical cure, I expect I’ll always have it”

“Probably it will remain the same; I’m not going to sit around worrying about it”

## Chapter 4 Discussion

This chapter discusses the data collected in the present survey in terms of the research question, which was “to determine the therapeutic and other support needs of tinnitus sufferers, and to influence public policy towards improved provision of services to meet these needs”. Therefore the discussion analyses the information collected in relation to the following elements:

*Firstly, what is the typical experience of the person with tinnitus in Ireland?*

- what is the profile of the average person with tinnitus?
- how has tinnitus manifested itself in the person's life?
- how has it affected their quality of life?

*Secondly, how have they managed the condition?*

- what treatments / therapies / supports did they receive?; what is their evaluation / opinion of those treatments?
- what forms of self-help or mutual help have they availed of?
- what has been the typical course of the condition?

*Thirdly, what other views do they give about tinnitus, that might help in the structuring of therapeutic services for those with the condition?*

The discussion ends by identifying relevant patterns in the data as a basis for the conclusions and recommendations of the present study.

### **The experience of people with tinnitus in Ireland**

The variety and range of data provided by respondents makes it difficult to construct a profile of a ‘typical’ person with tinnitus. However, it can be said at the outset that, in accordance with international statistics, that person is equally likely to be a man or woman, and he or she is of later middle age, in the middle or later 60s. He or she will most likely be retired, and / or on pension. The ‘average person’ has had tinnitus for about 12 years, and lives in company with spouse or family. This general profile, however, cloaks a wide range in the statistics. For example, many people with tinnitus are still engaged in their working life; reported duration of tinnitus ranges from just a few months to over 40 years.

People's personal experience of tinnitus is also quite diverse. The onset of the noise is as likely to have been sudden as gradual. Frequently, the person was under some form of physical or mental stress at the time of onset of the condition. The range of causes (or suspected or speculated causes) of the tinnitus accords with other research findings. However, it is noteworthy that only a minority of people attribute their tinnitus to noise damage, either occupational or otherwise. Some of the possible causes seem totally random, in that there seems no way they could have been predicted or prevented. Even the common cold is implicated by some. However, it remains the case that for the majority of people, the cause of their tinnitus is unknown. The implication for prevention programmes seems to be that only a proportion of tinnitus cases could effectively be prevented.

For many, the onset of tinnitus is accompanied by other symptoms, most commonly hearing impairment. But even here it is important not to make simple links between hearing impairment and tinnitus. Certainly, a majority of respondents also had hearing difficulties, but about one in three did not. Therefore it is sometimes necessary to provide therapies for tinnitus alone. From the present survey data, it also seems that many with tinnitus suffer from at least one other condition of ill-health. This should hardly surprise, taking the age profile into account, but it does tell us that holistic therapeutic approaches

may be advised, in which cases tinnitus may be ameliorated indirectly through the treatment of other disorders.

### **Troubling tinnitus**

Descriptions of the quality of the tinnitus noise and its location are typical of other research findings, but about three out of four people who developed tinnitus found it to be quite troublesome from the outset. The nature of these effects is predominantly as intrusions on daily routines and functioning. Over two thirds of people found it difficult to ignore the noise, while a similar proportion suffered sleep disruption, some requiring medication. Nearly a third reported difficulties with concentration, while half of respondents were fearful, some describing the fear as 'terror'. One fifth experienced depression, which required medical intervention. One in six people were angry about their treatment, or lack of it. Respondents frequently referred to the burden that their tinnitus imposed upon their spouses and families. Few respondents reported disruption of their occupation, although short-term absence from work was mentioned by a few. Again, figures have to be interpreted in the light of the age profile of people affected, and the significant number of women who were working at home when their tinnitus emerged.

The pattern of responses reflects that often reported worldwide, with psychological effects predominating. When the nature of tinnitus is considered, none of this is surprising. The loss of silence, the often-unpleasant quality of the noise itself, the sense of being overwhelmed by the condition, and anxiety about one's future health and about the future – all these add up to a major personal challenge for the affected person. It is indeed remarkable that most people find the resources and strength to cope and get through the initial stage, eventually reaching some kind of accommodation with the noise. However, one of the key findings of this survey is that that 'accommodation' – while allowing 'normal' life to continue – represents a significantly reduced quality of life for many people with tinnitus. The range of activities enjoyed has become restricted, rest and sleep are constantly under threat, while some are on ongoing medication. There are indirect effects on their families. Below and behind the visible effects of tinnitus, there is a persistent battle to get on with life, and to not allow the condition to impose limitations.

### **'Non-troubling' tinnitus**

It has been shown too that a significant minority – about a quarter – of those with tinnitus reported that it didn't present them with any major distress when it began. This is evidence of the standard reported fact that the reaction of people to tinnitus when it first develops varies greatly. It is not possible to say from the present survey data why certain people were severely distressed by the noise, while others could virtually ignore it. Answering that question would require psychological profiling and the administration of standardised tinnitus reaction questionnaires. One must also allow that for some people, the noise actually *is* very loud, and perhaps unpleasant in addition, justifying their adverse reaction. Conversely, people who say they were not, or are not, troubled by the noise, often report that it is usually fairly quiet. It is the case too that some of the initially 'untroubled' people experienced distress later, when, for one of a variety of reasons, their condition worsened. However, more commonly, people in this group have never been seriously affected by their tinnitus. For these people, minimal supports are required and then only for the short term.

Such variation on the reporting patterns of tinnitus need to be taken into account when planning for services is undertaken - it could inform the construction and design of intervention programmes and support services. For example, directing the supports

exclusively towards those aged over 65 might perhaps reach more than half of those affected, but would fail to help a substantial minority. Research to accurately quantify the Irish 'tinnitus population' is a pre-requisite to service planning. At the very least, we need data on incidence in the population at large, on sufferers' age-profile, and employment status, as well as on the degree of disability that tinnitus causes for people affected. Not everyone will require long-term support or therapy – many will require nothing more than encouragement and reassurance.

### **Looking for help**

The data presented in the previous chapter illustrates the pattern of people's quest for help when tinnitus begins. Consultation with the general practitioner marks the start of that quest for nine out of ten people. The great majority are then referred onward to specialised consultations with otolaryngologists (ENT specialists), audiologists, and sometimes neurologists. Half of all sufferers tried out alternative / complementary treatments; one in three considered or tried out hearing aids and / or maskers. Just one in eight sought help in the psychological area.

It is evident that large amounts of time, energy and money are spent on this quest. People are prepared to spend as much as they can afford in the search for answers, or at least relief. Considerable amounts of public resources are also expended, most of this resulting in very little progress for the person with tinnitus. This survey did not interview medical professionals for their views, but considerable anecdotal evidence suggests that most feel ill-equipped to assist the person presenting with tinnitus. While some say as much to the person, others may leave it to the next professional consulted. How that particular message is delivered to the person with tinnitus is important. The evidence from this survey suggests that many medical professionals could do better in this regard. Being better informed about the choices / options available to the patient would enable them to take a more constructive and tactful approach.

One could distinguish here between *response* and *treatment*. Doctors may feel they have no 'treatments' to offer, but their 'response' to the person with tinnitus can make a great difference. This becomes more apparent when people consulted the specialist areas such as the ENT surgeon or the audiologist. The former is frequently the end of the line of consultation for the tinnitus patient, but with an orientation largely towards surgical intervention, can offer little specialist treatment. In its absence, the manner in which the tinnitus story is listened to, and remarked on, is of great importance, and encouragement and advice become crucial. The same can apply to the audiological area, yet few respondents were given specific advice on tinnitus by their audiologist.

However, in the main, interviewees in the present survey were not strongly critical of the professionals they had consulted. Even when dissatisfaction with response or treatment was expressed, many excused the doctor because he or she 'did all they could'. People with tinnitus often accepted the statement that there was 'nothing to be done', and that they 'would have to live with it'. It is only fair to note that similar responses are received by people with tinnitus in other countries, despite considerable development of knowledge about tinnitus management in those same countries.

Nevertheless, there are evidently considerable problems around the way people with tinnitus are dealt with. These problems could be summarised thus:

- Medical professionals who come across as unsympathetic, or who trivialise or discount the distress caused by the condition; a person can even be made to feel guilty for bringing their condition to the surgery

- Those who tell the patient little or nothing about the tinnitus; some interviewees believed that the doctors knew little about it, or just were not interested; some probably felt they could not afford the time to talk or listen
- Those who gave the patient little encouragement or hope, merely saying there was nothing to be done; people are often told to 'learn to live with it', but are given no suggestions on how that is to be done

A few doctors were praised by respondents for sourcing information for them. A number of others felt that their doctor was genuinely concerned but acknowledged a lack of options. At least here, the patient's plight is being taken seriously. A number of respondents told of moving from their doctor to get another opinion, usually getting a better response there. But far more commonly, the person with tinnitus feels unaided.

It has to be assumed that a widespread belief that there really is nothing to be done for tinnitus is behind these responses. The most regrettable aspect of all this is that people with tinnitus are not being told that a wide range of helps and supports has been emerging over recent years. Some respondents told of being referred by their doctor to the Irish Tinnitus Association, but other doctors seemed not to be aware of its existence. Information could be given about relevant literature, about telephone help lines, about informative websites. People need to be told of developments such as *cognitive therapy* or *tinnitus retraining therapy*, and while these are not widely available in Ireland, the mere knowledge that some possibilities of help are in existence would be heartening to many. Even a few simple suggestions about relaxation and stress would give some feeling of control back to the patient. The dissemination of this kind of information to the relevant professionals is an urgent task for those with the resources to undertake it.

Psychologists with appropriate training can offer effective help to people with troublesome tinnitus. However, very few respondents in the present survey availed of any kind of counselling. There are a few likely reasons for this. One is a severe underdevelopment of tinnitus-specific counselling skills among psychologists in this country. (The Irish Tinnitus Association and the National Association for Deaf People have funded limited basic training in tinnitus management for a few audiologists and psychologists in recent years, but much more needs to be done to augment the pool of expertise). It would also seem that counselling is not commonly seen as an effective means of dealing with tinnitus distress; consequently, few people are referred in that direction. Yet the international evidence all points to the beneficial effects of various types of psychological help for tinnitus. A reluctance among people with tinnitus to seek psychological help may also account for the low take-up of such services. Misunderstandings about what 'counselling' means in this context may play a part. People with tinnitus themselves need to be told that while tinnitus is not a psychological condition, it does affect people emotionally and psychologically. Counselling helps people to manage their thinking, feelings and reactions to tinnitus, often leading to a significant reduction in distress.

As detailed in the previous chapter, alternative and complementary therapies were sought by every second person with tinnitus. Again, considerable resources of time and money are expended for little direct effect on tinnitus. However, indirect benefits are widely reported. The high rates of consultation in these areas bear testimony to the 'chase after a cure' that tinnitus distress engenders. One respondent said "I'd go anywhere, and spend thousands to get rid of this noise". This survey did not encounter reports of any 'alternative' practitioner that claimed to have a 'cure' for tinnitus; none ever promised more than the 'possibility' of getting some relief through their particular therapy. Despite the

practice of some support groups of having such practitioners speak to their meetings, members are regularly advised that each person has to make his or her own decisions about the value of any one therapy – no recommendations can be made.

The supply, fitting and maintenance of hearing aids seem to cause concern among people with tinnitus. There appears to be little regulation of the market in these products, other than of health service provided aids. Some respondents said they felt pressured by visiting salespersons to purchase a hearing aid, at significant cost. Obviously elderly people can be a particularly vulnerable population in this context. Unsatisfactory follow-up service for aids that fail to live up to promised performance is an additional area of concern. It seems that more hearing aids sit in junk drawers than in ear canals.

### **The course of tinnitus**

The present survey attempted to find out from people how they have fared with the condition over a number of years. As outlined in the data chapter, respondents could be categorised into four groups. The first of these groups is the one in five for whom tinnitus was not a serious problem at its onset, and for whom it has continued to be not more than a minor irritant. The attitude that some of these people reported adopting towards their tinnitus may have been significant in determining that it would not become a major problem for them. This simultaneously points to the fact that attitude is important, and that helping people to adopt the right attitude may be an important means of reducing the distress of tinnitus. Thus, for many, information, reassurance, encouragement and the provision of basic cognitive strategies may be sufficient.

### **When tinnitus worsens . . .**

Different therapeutic approaches may be required to aid people in different stages of coping with tinnitus. The second group previously identified may be an example. These people were not initially troubled by their noise, but became distressed later on when it worsened. The key question here is: *what caused the tinnitus to worsen?* It is likely that quite a number of people were experiencing deterioration in their hearing, which can serve to make the tinnitus more noticeable. Effective audiological investigations and treatments are required here, with the possible dual effect of maintaining optimum hearing and consequent masking of the tinnitus. Counselling must also play a role, so that the person is made aware of what is going on in the auditory system, and is helped to understand why the tinnitus seems worse. Worries about losing hearing or worse events can generate great fear, with tinnitus being exacerbated as a result. Other reasons why the tinnitus has worsened would need investigation. Emotional and psychological factors linked to stresses or traumas in one's personal life could also be considered.

### **Acceptance or habituation?**

Nearly half of respondents in the present survey made up the third group, i.e. those who came to terms with their tinnitus through some degree of acceptance or habituation. Some were able to achieve this in months, but for most it took two to three years. It has been speculated earlier that true habituation may not have been attained by many of these people. Instead they have resigned themselves to the likely persistence of the noise, and have stopped fighting it. A sense of relief could follow a decision to "lay down arms". Although this might be termed acceptance, it is not habituation in the real sense. Were it so, people are likely to report that for most of the time, their tinnitus is hardly noticeable – not many reported that.

Interestingly, the great majority of people attributed their success at acceptance or habituation either to their own efforts or to those of people they met at support groups; in

addition, two respondents said that they were greatly helped by counselling. What is notable here is the virtual absence of structured helps and supports from the health services or from individual medical professionals. Almost all progress had been achieved outside the mainstream services, through self-help, mutual help and voluntary supports. This state of affairs could be read as an indictment of the services, or as a tribute to the work of voluntary support group organisers and members. It probably is both, and underlines the important complementary role that lay support groups play in the web of service provision.

More obviously in need of therapeutic interventions are those in the final category identified, i.e. people who are still battling with tinnitus - some after many years - and who have never been able to find effective relief. The real 'tinnitus sufferers' include people in this category, many of whom have quested far and wide for a cure, or at least relief. They should be targeted as priority by any therapeutic services that emerge in the near future.

### **How do people 'manage' their tinnitus?**

In the absence of therapeutic services, the majority of people with tinnitus have to manage their condition as best they can. It can be helpful when a pattern is noted in the behaviour of the noise, as this may aid better management strategies. Commonly, tinnitus is more noticeable in the evenings and at night. Therefore, maintaining a sound-rich environment at such times is reported as being helpful. For people whose tinnitus is exacerbated by loud noise, avoidance of such situations is essential. Controlling one's attention to the tinnitus is another recommended strategy, but is a considerable challenge – some find that keeping busy and occupied is helpful; others try to actively ignore the noise. A helpful strategy for one may be an irritant to another. For example, a man reports that exercise makes his tinnitus worse, another that it is a help towards relaxation. A few also take alcohol as a relaxant, but others avoid it.

The success of a person's management strategies largely centres around identifying what causes the tinnitus to improve or worsen. When these factors are apparent, people can help themselves to some extent, through appropriate action. However, many factors are implicated by people as having effects on tinnitus, some of which are unavoidable. Who can always avoid stressful situations? How can someone avoid contracting the common cold? When there is no pattern to the tinnitus, people do whatever they can to cope with its vagaries. When it is distressing and apparently unmanageable, sedative medication may be the person's only relief, and even that is likely to be partial and temporary. Yet a sense of having some control over the noise is crucial to overcoming the distress that results from it.

### **The role of self-help and mutual help**

The data from this survey shows clearly that people deal with their tinnitus almost totally through self help and mutual help. Most of the management strategies referred to in people's accounts are forms of self help. Learning about what works may be a process of trial and error, but information gained from reading and research helps also. Four out of five respondents wanted to learn more about tinnitus. Most people sought to learn more through reading the regular newsletters of the tinnitus associations, while one in five also searched the internet. Talking to others about tinnitus was also considered to be an important means of learning about it. Yet there are limits to self help. The difficulty of being able to objectively assess one's own tinnitus; inconsistency in applying one's self to management tasks; trying out approaches based on incorrect self-diagnosis; such problems mean that self-help strategies can be 'hit and miss', or on occasion may do more harm than good. All this points to the urgency of having available a professional diagnostic and therapeutic service to aid people with tinnitus.

A surprisingly low proportion of respondents to the present survey were regular attendees at support group meetings. Reported reasons - and suggested reasons - for this are detailed in the previous chapter. What this amounts to is that the support group has appeal to some and not to others, and where people do attend, their involvement tends to be temporary. The literature on the workings and effectiveness of support groups internationally shows that, when they have well-structured programmes, are competently led, and where real help is given, such groups can have huge beneficial effects, as a complement to professional services. In Ireland, the national tinnitus association is in relative infancy (just 7 years in existence). A few committed voluntary people (all of whom have tinnitus) attempt to develop the association's services. Despite Trojan efforts, the network of support groups remains underdeveloped, with just a few strong groups. The association needs leadership training and other supports to develop the support groups specifically for people with tinnitus. Professionals who regularly urge people to contact the association have themselves a responsibility to promote and support the development of its services.

### **Talking about tinnitus**

Interesting data emerged from the present survey concerning the way people with tinnitus present themselves to others. The most commonly reported fact was that people generally did not talk about their condition, even within their own family. Many said they had spoken of it initially, but learned that there was no point in continuing to do so. A few did not want to burden spouse or children with their concerns. All this has to do with both public and private attitudes towards chronic 'invisible' conditions like tinnitus. Where visible physical disabilities elicit sympathy and some measure of concern, tinnitus is almost 'suspect' in the eyes of many. When such public attitudes are internalised, they produce private silence. The compounding of the burden of tinnitus through having to bear it without public concern or support, even to remaining silent about it, must be challenged in any public education programme.

### **What services do people want for themselves and others?**

In this survey's interviews, it was found that few people had a clear idea of what services would be of assistance to those with tinnitus. Just one in five mentioned a wish for a clinic dedicated to tinnitus therapies, including counselling services. A similar number of people felt that more mutual help was desirable. One in eight talked of the need for at least one professional person to become interested in tinnitus and its treatment. More than half of respondents would avail of TRT if it were offered to them, one in five declining, saying that they were managing well enough. Thirty per cent of respondents knew only a little, or nothing at all about TRT, and were non-committal.

Given the virtual absence of dedicated therapeutic services for tinnitus, most interviewees qualified their wishes for services with statements that they did not expect anything of significance to materialise. One speculated that perhaps if an ENT specialist were stricken with severe tinnitus, he or she might become the champion of those who were heretofore ignored and dismissed! It is indeed remarkable that no such crusader (even one unafflicted) has yet emerged in this country, given the contrasting level of activity in the tinnitus field in Ireland's nearest neighbour. International developments would lend support to the services suggested above: a comprehensive clinic provision presupposes an interested specialist in the field, and counselling options are also an essential component of the services required. The fact is however, that most lay people don't really know how tinnitus treatment services might be organised, nor what therapeutic options there might be. It is difficult to conceive of desert flowers blooming when all one sees until now is the arid sand.

In this context, the establishing of a pilot tinnitus clinic in Cork in late 2002 heralds change. Such a clinic was proposed in a submission to the *Consultation Process on the Health Strategy* by the Cork Tinnitus Support Group in 2001 (Department of Health and Children, 2001, p.101), and has been actively promoted by the ITA and the National Association for Deaf People. At time of writing, the clinic is underway for one year and its operation is currently being evaluated. At the clinic, funded by the Southern Health Board (SHB) for people in Cork and Kerry, the person with tinnitus is provided with an audiological assessment, and with the rudiments of tinnitus management, as well as information about the available supports of the local ITA group, and the services of the Cork Association for the Deaf (CAD). The clinic is currently being developed through the planned training of voluntary advisers / counsellors, and the expansion of the support group, 'help line' and other backup services; links with otolaryngological services are also under consideration. Relevant medical professionals in the SHB area have been informed of the clinic's service. This is the first clinic dedicated to tinnitus management in the country. (A clinic has been in operation in Belfast for some years - some people reported that they had attended it, at their own expense). If evaluations recommend its continuation and development, the Cork clinic could become a comprehensive tinnitus service, possibly serving as a model for similar regional provision.

### **What people expect**

The final part of the present survey asked people what they expected of their tinnitus in the future. Although only one in twenty expected their condition to improve, just 15% expected it to worsen. The great majority did not know what to expect, or were unwilling to speculate. The final comments quoted in the previous chapter clearly represent a blend of hopes and fears. It seems that most people would be pleased enough if they reached a stage of coping where the noise remained the same, i.e. 'manageable'. The fear of matters worsening might well be alleviated if people knew that help would be at hand in that event. Many in addition expressed the hope of a cure sometime in the future, and hoped it would be within their own lifetime.

## **Chapter 5            Conclusions and Recommendations**

This study explored the experiences of people with tinnitus in Ireland, through in-depth interviews with a sample of members of the Irish Tinnitus Association. What has the survey told us about their experiences?

- People in Ireland report the experience of tinnitus that is similar to that of people in other countries, in terms of patterns of incidence, age at onset, presumed causes, negative effects, co-symptoms, and the reported course of the condition
- For a significant proportion of people with tinnitus, the condition has an ongoing negative influence on their quality of life; many who 'cope' just about manage
- Most medical professionals believe that they have little to offer patients with tinnitus; those with tinnitus understand that there is as yet no cure, but believe that medical professionals could be more helpful in their response
- The majority of people with tinnitus receive little or no therapeutic help from the health services, but receive most support from others with the condition, and from their association
- People with tinnitus believe that they have to help themselves to a large degree; they employ a wide range of self-help and mutual-help strategies
- Four out of five people want to know more about tinnitus, and most want to learn to manage the condition better
- Most people were unclear about available options for tinnitus management

### **What are people's needs? How can they be met?**

As well as recording the experience of tinnitus, the survey set out to determine "the therapeutic and other support needs of people with tinnitus". Although they were well able to describe the effects of tinnitus on them, it was found that most people were unable to articulate their needs in terms of services that would help them. This state of affairs partly derives from the fact that heretofore, people in Ireland have had no services dedicated to the relief and treatment of tinnitus, and partly from the general acceptance of the widespread belief that "nothing can be done for tinnitus". Nevertheless, the needs were clearly expressed, and the appropriate services or approaches to treatment will be readily apparent to those working in the area.

- The first need of people with tinnitus is to have the distressing nature of their condition acknowledged. They deserve compassion, and they should not be made to feel apologetic for making an issue of their tinnitus.
- People need someone to listen, and hear them express their fears.
- People need to be given hope: they don't need the added burden of believing that they are destined to be tormented by the noise for the remainder of their lives.
- They need information and education: they are entitled to know the up-to-date position in relation to research findings and treatment options.
- They need to know that some kind of practical help is available, in whatever form it is presented.
- They need advice about longer-term management of the condition, and they need access to informal complementary support services.

### **Structuring interventions and supports**

The patterns of tinnitus experience emerging from the present survey data should be of use when health service providers are considering the type of treatments and supports that are needed. Also of value is the fact that the experience of tinnitus in Ireland is found to be little different from that reported in other countries. Thus, while larger-scale and more

focused research will be required to clarify the precise range of needs, it will be essentially a search for statistics. The nature of people's experience is not likely to be different from that reported here. Models of support services in other countries should also be informative in relation to best practice.

Each person who comes through the referral system with troublesome tinnitus needs to be assessed for an individual programme of therapeutic options. Some will need minimal counselling, while others will require longer-term supports. The level of distress caused by the tinnitus will determine immediate treatment needs, and co-symptoms will also need evaluation. For example, the most intensive intervention is often justified at the early stages, when distress is at its peak. However, many people require ongoing support, albeit at a lower level and frequency. [Examples of how a tinnitus service might be structured are to be found in the *Clinical Guidelines Working Group* document from the BTA (1999a)]. It hardly needs to be stressed that, starting from the present situation where tinnitus services are virtually non-existent, even a minimal provision would provide hope.

## Recommendations

The study concludes that a range of therapeutic and support services are urgently required to aid people with tinnitus.

***Clinics should be established at a number of regional centres, such clinics dedicated to the diagnostic and therapeutic needs of tinnitus patients***

At these clinics, the range of possible therapeutic options could include:

- Medical evaluation, including a line of referral to specialist services where appropriate
- Audiological assessment
- Access to hearing aids, maskers and other audiological appliances
- Provision of information on the nature of tinnitus, possible causes, and the likely progress of the condition
- Counselling for tinnitus management, possibly extending to the elements of Tinnitus Retraining Therapy
- Counselling, if necessary, for the management of accompanying hearing impairment

A priority should be to identify through research the practical needs of people with tinnitus, and establish diagnostic and therapeutic protocols to meet these needs. Research will be required to collect data on the incidence of tinnitus in Ireland, and in particular of troublesome tinnitus. It is necessary to know how people's lives are affected, and what tinnitus costs people, personally and financially. In addition, the effective cost of present diagnostic and related services needs to be assessed, when cost projections for proposed services are being made. It could be that a co-ordination and integration of existing resources, guided by interested professionals, would go a long way towards meeting the needs of those with tinnitus. The ongoing evaluation of the current tinnitus clinic pilot project in the Southern Health Board area may be significant in this regard.

Given the reported experiences of people with tinnitus in consulting with health professionals, and in the response of others to their condition, the study concludes that ignorance of the nature of tinnitus and its effects is widespread.

***At a system level and societal level, there is an urgent need for a programme of public information and education about tinnitus.***

Such a programme should aim to counter popular misconceptions about tinnitus, and should extend to the professionals who deal with people with tinnitus. This could entail making up-to-date research findings available to relevant professionals. The public also needs to be told that reasonable precautions should be taken to prevent tinnitus, through appropriate care of the ears, and protection of hearing against noise damage. Young adults and those employed in high-risk noisy environments might be targeted as a priority.

***Voluntary support services and their associations should be promoted and strengthened***

Such voluntary services have, until now, been the main source of ongoing support for many with tinnitus. They are likely to continue to play an important role even where structured services are available. People with tinnitus should be able to:

- Become members of a tinnitus association, and gain access to information by means of public meetings, newsletters, etc.
- Attend at a support group
- Have access to supportive contact via a telephone 'helpline'

***Complementary relationships should be established between professionals and voluntary support services.***

Links between professionals and lay support personnel could be beneficial in structuring effective services, provided they clearly define appropriate relationships, boundaries and responsibilities.

A considerable challenge exists in integrating these services into the healthcare system, yet many of the elements of such services appear to be already present. Much could be learned from best practice in other countries in structuring support services. Finally, in the provision of services for those with tinnitus, much could be achieved with three not-very-expensive ingredients: knowledge, compassion and will.

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