

# What's that noise?

A profile of personal and professional experience of tinnitus in NI

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# Introduction

"It is my opinion that of all the bad things that can happen to people, tinnitus is the third worst. The most severe is intractable pain, the second is severe vertigo, and the third is severe and intractable tinnitus, for nothing robs a man of quality of life as tinnitus does." (Vernon, 1979)

RNID is the largest UK charity taking action on hearing loss. Our vision is of a world where deafness and hearing loss do not limit or determine opportunity and where people value their hearing. We work to ensure that people who are deaf, deafened and hard of hearing have the same rights and opportunities to lead a full and enriching life. We strive to break down stigma and create acceptance of deafness and hearing loss. We aim to promote hearing health, prevent hearing loss and cure deafness.

In 2009, RNID published its Strategic Plan 2009-2013, committing itself to ensure that older people with hearing loss/tinnitus have access to the information and services they need to manage their hearing loss/tinnitus effectively.

In order to support this commitment in Northern Ireland, RNID provides information, including leaflets and factsheets, for people with tinnitus and for health professionals, such as GPs, audiologists, ENT consultants and HSC Trust staff. We also publish *Solutions*, a catalogue of products for people who are deaf and hard of hearing which includes information on products that can provide relief for people with tinnitus.

In conjunction with information, RNID also organises public meetings across Northern Ireland for people with tinnitus and their families. Our 'listening ear' service is managed by a volunteer with tinnitus, who offers guidance on self-help and tinnitus management.



#### Context

Between April 2008 and March 2010, there was a 50% increase in the number of people who contacted the Communications and Information Officer at RNID Northern Ireland requesting information about tinnitus. In recent years, audiologists and HSC Trusts have also started to signpost people with tinnitus to RNID. Most people who contacted us directly or who were signposted to us were extremely distressed as a result of tinnitus. Their anecdotal evidence suggested that there was limited support available for people with tinnitus in Northern Ireland. This, coupled with an increased demand for tinnitus information from RNID, prompted us to explore the issue further.

## Aims and objectives

It was agreed that research should be undertaken to gain a better understanding of people's experience of living with tinnitus in Northern Ireland and to gain an overview of statutory and voluntary sector service provision.

With these aims in mind, we identified the following research objectives:

- To explore participants' experience of tinnitus; onset, reaction and age when they first began to hear tinnitus, their perceptions around causes and triggers, the length of time they have lived with tinnitus, their description of tinnitus, awareness of tinnitus and tinnitus duration and variation.
- To explore the impact of tinnitus on people's lives; relationships with family and friends, social life, everyday activities, work, concentration, sleep and mental health.
- To explore the coping strategies people use to manage tinnitus and the methods they use to find relief.
- To explore the length of time participants had to wait prior to seeking support for tinnitus and their experience of support received from GPs, audiologists, ENT consultants and HSC Trusts.
- To explore the role of tinnitus support groups in supporting people with tinnitus.
- To explore sources of tinnitus information.
- To explore people's perception of others' understanding and knowledge of tinnitus.

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# Section two: Research methodology



In this section, the research approach and methods of data collection used, the sample and procedure followed and the research ethics adhered to will be discussed.

In order to gather information about the unique experiences of people with tinnitus, a qualitative approach was used; namely, "one that focuses on participants' experience and/or assigning their behaviour to a given category."

In order to gather information about the support and services GPs, audiologists, ENT consultants and HSC Trusts provide

for people with tinnitus, a quantitative approach was used; namely, "one that focuses on measuring behaviour by assigning numbers to it."<sup>2</sup>

Following a review of research methods, it was decided to use interviews to collect data from people with tinnitus as they "enable participants to discuss their interpretations of the world in which they live and to express how they regard situations from their own point of view." In contrast interviews, however, are prone to subjectivity and bias on the part of the interviewer.

<sup>&</sup>lt;sup>1</sup> Eysenck (2005), *Psychology for AS level*, Psychology Press, Hove.

<sup>&</sup>lt;sup>2</sup> Ibid.

<sup>&</sup>lt;sup>3</sup> Cohan, L. Manion, L. & Morrison, K. (2000, 5th Edition) Research Methods in Education, Routledge/Falmer, London.

<sup>&</sup>lt;sup>4</sup> Ibid.



A structured interview schedule, where the sequence and wording of the questions are determined in advance, was designed. This type of interview schedule ensures greater consistency in the data gathered. However, it does limit generalisation. Standardised wording of questions may also constrain and limit the naturalness and relevance of questions and answers. All questions were open ended; participants could answer them in their own way and in their own words.

Following a review of research methods, it was decided to use questionnaires to collect data about the support and services GPs, audiologists, ENT consultants and HSC Trusts provide for people with tinnitus.

The advantages of questionnaires are:

- Participants can be questioned fairly quickly.
- They are less influenced from dynamics of interpersonal variables than is the case with interviews.
- There is less bias in analysing answers since questions are structured.<sup>5</sup>
- They tend to be more reliable, as they are anonymous, which therefore encourages greater honesty.
- They tend to be more economical than interviews in terms of time and money.<sup>6</sup>

However, questionnaires are only suitable for people who are literate and willing to spend the time filling them in.<sup>7</sup>

The interview schedule was piloted with an individual with tinnitus. The GP, audiologist, ENT consultant and HSC Trust questionnaires were piloted with relevant HSC professionals.

<sup>&</sup>lt;sup>5</sup> Ibid

<sup>&</sup>lt;sup>6</sup> Cohan, L. Manion, L. & Morrison, K. (2000, 5th Edition) *Research Methods in Education*, Routledge/Falmer, London.

<sup>&</sup>lt;sup>7</sup> Eysenck (2005), *Psychology for AS level*, Psychology Press, Hove.



#### Sample

People with tinnitus were recruited via the following methods:

- All staff working in RNID Northern Ireland were emailed to ask them if they or anyone they knew would be interested in participating in the research.
- Sensory support teams in each of the HSC Trusts were approached to request attendance at tinnitus support groups and to request that a letter be sent to people with tinnitus on Trust mailing lists.
- Tinnitus support group meetings in Ballymena, Newry and Portadown were attended.
- A press release was written for regional and local papers, in conjunction with RNID's media team.
- A letter was written to RNID members in Northern Ireland.
- An article was written for RNID's oneinseven members' magazine.

- An article was written for RNID Northern Ireland's Volunteer newsletter.
- Letters were included in information packs that were sent to individuals who had contacted RNID Northern Ireland requesting information about tinnitus.
- RNID Northern Ireland's Outreach and Information events in Belfast and Omagh were attended.

Using a volunteer sampling method, two staff members and four volunteers from RNID Northern Ireland, three members of HSC Trusts' tinnitus support groups, four members of HSC Trusts' lipreading classes and seven individuals were recruited via national and local press. In total, 20 self-identified and self-selected individuals participated in the research.





# **Profile of participants**

## **Table 1: Gender**

	Number of participants
Male	10
Female	10

# Table 2: Age

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	Number of participants
25-30	1
30-35	0
35-40	1
40-45	0
45-50	1
50-55	3
55-60	1
60-65	5
65-70	3
70-75	2
75-80	3





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## **Table 3: Residence**

	Number of participants
Belfast HSC Trust	2
Southern HSC Trust	2
South Eastern HSC Trust	5
Northern HSC Trust	3
Western HSC Trust	8

# **Table 4: Hearing status**

	Number of participants
Hearing impairment	16
No hearing impairment	2
Sign language users who are deaf	2







#### **Procedures**

#### **Interviews**

Interviews were carried out with participants during January and February 2010. The interviews lasted approximately 45 minutes. Fourteen participants chose to be interviewed in their own home, three chose to be interviewed in an HSC Trust premises, two chose to be interviewed in RNID and one chose to be interviewed in a premises occupied by a disability charity. All participants were given the option of being interviewed at a location and time convenient to themselves.

Standardised instructions, including assurances of confidentiality, were given to each participant and standardised procedures were followed. Participants were also informed that their interview would be recorded and translated verbatim and they could obtain access to their typed transcript and have the opportunity to comment on it and/or withdraw their data from the research if they so wished. None of the participants

asked to see their typed transcript and none of them withdrew their data.

In order to establish a non-threatening atmosphere for the interviews, an informal style of questioning was adopted. A conversational, non-confrontational and non-judgemental approach to the interviews was used to establish cooperation, trust and rapport with the participants.

For each interview, participants were asked exactly the same questions in exactly the same order. Interviews were kept moving forward by asking and clarifying questions, actively listening, responding to non-verbal cues, providing feedback and so on, while involving and motivating participants to discuss their thoughts, feelings and experiences. Efforts were also made to avoid evaluative cues, such as "behaviour inadvertently displayed by the researcher which might be interpreted as either disagreement or encouragement."8 At the end of each interview, participants were thanked for their participation.





#### **Questionnaires**

Questionnaires distributed	Questionnaires returned
GPs (1,154)	15% (174)
Heads of audiology (11)	91% (10)
ENT consultants (30)	33% (10)
Team leaders in sensory support (9)	56% (5)

Standardised instructions, including assurances of confidentiality, were included in each questionnaire that was distributed to GPs, audiologists, ENT consultants and team leaders within HSC Trusts.

#### **Ethics**

"Researchers have an obligation to protect people from being managed and manipulated in the interests of research." In order to adhere to the Social Research Association's (SRA) Ethical Guidelines, in conjunction with conducting research in a sensitive manner, the following ethical issues were considered.

#### Informed consent

All individual participants, GPs, audiologists, ENT consultants and team leaders within HSC Trusts were informed of:

- the purpose of the research
- the process in which they were to be engaged
- how their data would be used
- how and to whom their data would be made available
- how and why their data was being stored
- why their participation would be helpful.

Also, individual participants were informed of their rights; for example, privacy and confidentiality, voluntary participation, the right to withdraw from the research for any or no reason at any time, the right to access their personal data and to have it stored and destroyed appropriately.

<sup>&</sup>lt;sup>8</sup> Edwards, B. (2002), 'Deep insider research', *Qualitative Research Journal*, (2) 1, 71-84.



#### **Anonymity/confidentiality**

Individual participants, GPs, audiologists, ENT consultants and team leaders within HSC Trusts were reassured that their identity would remain confidential and that it would be protected in the context of the research report. Individual participant's anonymity was ensured using identification code: letters of the alphabet were used to identify participants' transcripts before saving them on computer. Identification codes and transcripts were password protected and saved separately. Hard copies were stored in a locked drawer in RNID. All data, including recorded interviews and questionnaires, are held on file for six months following completion of the research, then destroyed. No personal information about participants will be disclosed to others.

#### **Risks and benefits**

Interviewing participants may focus their attention on tinnitus and cause them distress. In order to overcome this risk and protect participants from psychological harm, a relaxed and flexible interview style was adopted, which allowed participants to pass on any interview question that they did not wish to answer and/or to terminate the interview at any stage. Contact details for RNID were provided and it was explained to individuals that they could contact the organisation if they required additional information or support.

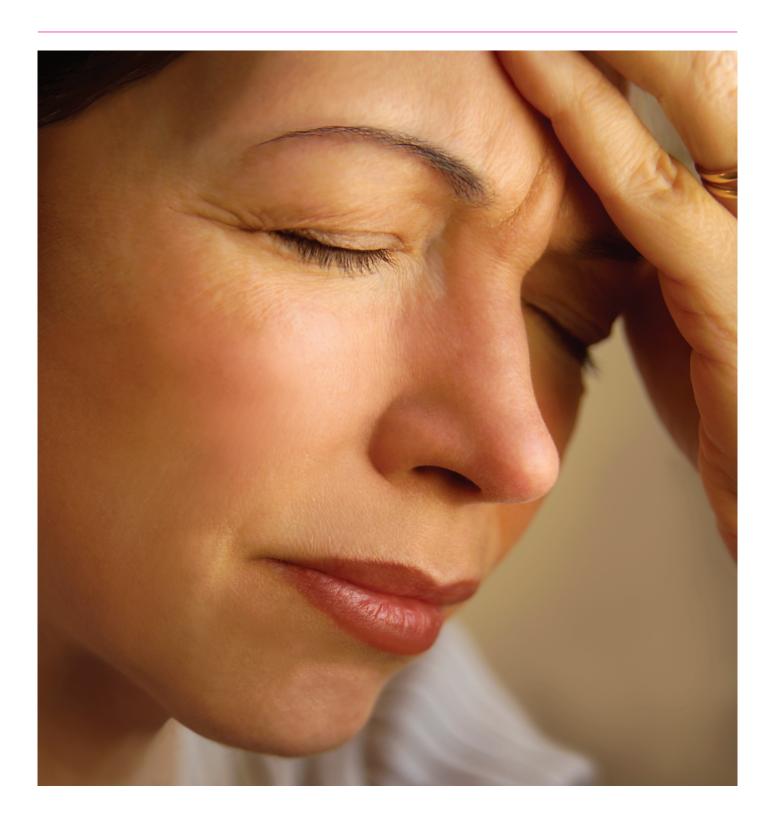
Hopefully the interviews benefited individual participants by providing them with an opportunity to share their experience of living with tinnitus and the questionnaires benefited HSC professionals by providing them with the opportunity to comment on the support and services they provide people with tinnitus.

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# Section three: Experiences of people with tinnitus







This section provides a framework for the participants' experiences which emerged from the data during analysis. Participants' experiences have been interpreted, set in theoretical context and presented systematically within themes throughout the section. The qualitative data collected from the interviews was analysed using thematic analysis. This involved the identification of general themes; namely, themes common to most or all of the interviews as well as individual variations unique to a single interview or minority of interviews. In the following section, short citations are provided to illustrate the data behind the themes and participants' descriptions are reflected in the form of quotations in findings.

#### **Definition of tinnitus**

Tinnitus, often described as 'ringing in the ears', is the perception of sound in the head or ears when no external sound is present. It may be acute or chronic. Acute tinnitus lasts days to weeks while chronic tinnitus is persistent, lasting for longer than six months.9 Tinnitus may be described as subjective or objective. Subjective tinnitus, heard only by the sufferer, is the most common, occurring in many forms and at different levels of severity. In contrast, objective tinnitus, accounting for less than 1% of cases can be heard by others and is most commonly associated with temporomandibular joint and vascular abnormalities, abnormal functioning of the central auditory system or muscular disorders. Tinnitus may be unilateral (heard in one ear) or bilateral (heard in both ears), pulsatile or nonpulsatile. Pulsatile tinnitus coincides with the heartbeat, suggesting a vascular source, whereas the more common non-pulsatile tinnitus is continuous and constant. 10

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<sup>&</sup>lt;sup>9</sup> Daugherty, J.A. (2007), 'The Latest buzz on Tinnitus', *The Nurse Practitioner*, (32) 10, 42–47.

<sup>&</sup>lt;sup>10</sup> Holmes, S. & Padgham, N. (2009), 'Review Paper: more than ringing in the ears: a review of tinnitus and its psychosocial impact', *Journal of Clinical Nursing*, 18, 2927-2937.



#### Prevalence of tinnitus

It is estimated that 10%-20% of the UK adult population complains of prolonged spontaneous tinnitus (PST) at any one time, where PST is defined as tinnitus which lasts for five minutes or more. 11 In June 2009, the estimated resident population of Northern Ireland was 1,789,000. 12 Based on this figure, we can estimate that there are approximately 178,900-357,800 people with tinnitus in Northern Ireland.

According to the British epidemiological investigation on the prevalence of tinnitus and its perceived severity, 0.5% of the general population regard tinnitus as a problem which severely affects their quality of life. <sup>13</sup> Based on the estimated resident population of Northern Ireland, we can estimate that tinnitus severely affects 8,945 people's quality of life in Northern Ireland.

According to Holmes & Padgham (2009), 1% of people under 45 experience tinnitus, 12% of people aged 60-69 develop it and those over 70 have a 25-30% risk of developing it.<sup>14</sup>

Thirteen (65%) of participants in this study were over the age of 60, reflecting the pattern of an increased incidence of tinnitus among the older population. The prevalence of tinnitus also increases with hearing impairment. Sixteen (80%) of participants in this study had a hearing impairment. Tinnitus can predate, coincide or develop after hearing impairment.

The average length of time that participants had tinnitus was 20 years and the average age at which participants first began to hear tinnitus was 42. Eight participants stated that tinnitus started suddenly, eight stated that it developed over time and two could not recall. Fifteen participants stated that tinnitus is constant; four stated that it is intermittent and one stated that it is constant in one ear and intermittent in the other. Fourteen participants stated that they experience some variation in the intensity, loudness and pitch of tinnitus, and six participants stated that they experienced no variation.

<sup>15</sup> Ibid.

<sup>&</sup>lt;sup>11</sup> El Refaie, A. E., Davis, A., Kayan, Baskill, A., Lovell, E., Owen, V. (2004), 'A questionnaire study of the quality of family life of individuals complaining of tinnitus pre- and post- attendance at a tinnitus clinic', *International Journal of Audiology*, 43, 410-416.

<sup>&</sup>lt;sup>12</sup> www.nisra.gov.uk

<sup>&</sup>lt;sup>13</sup> Erlandsson, S. I., & Hallberg, L. R-M. (2000), 'Prediction of quality of life in patients with tinnitus', *British Journal of Audiology*, 34, 11-20.

Holmes, S. & Padgham, N. (2009), 'Review Paper: more than ringing in the ears: a review of tinnitus and its psychosocial impact', *Journal of Clinical Nursing*, 18, 2927-2937.





#### **Description of tinnitus**

According to Holmes & Padgham (2009), tinnitus is commonly experienced as a high pitched noise with mechanical, electrical or musical qualities. 16 Participants in this study described tinnitus in a variety of ways: a hiss, a ring, a buzz, a beep, a hum, a roar, a pop, a squeak. Some described it as a high-pitched sound, similar to a whistle, a singing kettle or the sound heard at the end of televised submission. Others described it as being similar to an aeroplane, an engine, a drill, waves lapping against a shore, water boiling, the sound you hear when the phone is off the hook, when you dial a fax number, or when you are in the process of searching for a radio channel. Some participants with bilateral tinnitus stated that they heard similar sounds in both ears while others stated they heard different sounds in each ear.

# Participants' reaction when they first began to hear tinnitus noise

Participants' reaction to tinnitus when it first developed varied greatly. A couple of participants stated that, with the passing of years, they could not recall their reaction. Others who did not perceive their tinnitus as severe were not unduly bothered by it. However, the majority of participants stated that at onset they felt anxious and frightened. Some attributed their feelings to the fact that they were unable to identify their experience as tinnitus, while others thought that the noise they were hearing was a symptom of an underlying medical condition.

<sup>16</sup> Ibid.





- "I didn't really know what was happening. I wasn't sure what the problem was, something to do with the hearing, something to do with the brain." (N)
- "I thought I was taking a blood clot on the brain the first time I heard the noise." (T)

#### Cause of tinnitus

Though the underlying pathophysiology of tinnitus is unclear and it seems unlikely that there is a single underlying cause, most cases of tinnitus are related to ageing, hearing loss or noise exposure.<sup>17</sup> A small number of participants attributed tinnitus to these causes, but most were unable to identify a specific cause. Participants suggested that stressful life events, otitis media (glue ear), ear syringing, Ménière's disease, Legionnaire's disease, Temporomandibular Joint Disorder (TMJ), a bang to the head, feedback from a microphone, ear wax, infections and antibiotics may have caused their tinnitus. Many of these causes are cited in the academic literature.

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<sup>&</sup>lt;sup>17</sup> Ibid.



#### Awareness of tinnitus

Most participants, excluding those who had habituated to their tinnitus, were most aware of it at night when trying to sleep or when alone in a quiet environment.

"When I'm alone and in the house, it seems to be more intense." (I)

The distraction provided by daytime activities and the masking effect of ambient sounds are reduced or absent in quiet environments, which may make people more aware of tinnitus. In contrast, a small number of participants stated that noisy environments make them more aware.

# Factors that trigger tinnitus or make it worse

Factors that trigger tinnitus or make it worse vary for individuals. According to Kemp & George (1992), noise can exacerbate tinnitus severity. 18 Participants in this study stated that noise from mobile phones, computer games, traffic, machinery and power tools triggered their tinnitus or made it worse.

"I definitely think that if you're exposed to loud sounds, the tinnitus can be worse." (N)

Also, background noise in shops, cafés, bars, nightclubs and background noise on television were factors. Some participants stated that their mood triggered tinnitus or made it worse.

"I think when you're annoyed about something, when something is on your mind or when you're worried about something, you're more inclined to get it; louder, more irritating." (I)

Others stated that stress, eating chocolate, drinking coffee, thinking and talking about tinnitus and pain were all factors.

"When there's pain, the noise is more in your head; you know, with the pain going all the time, it's irritating, the noise starts to get more frequent." (A)

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<sup>&</sup>lt;sup>18</sup> Kemp, S., & George, R. N. (1992), 'Diaries of tinnitus suffers', British Journal of Audiology, 26, 381-386.



# The impact of tinnitus on people's lives

Similarities have been drawn between the experience of living with tinnitus and that of chronic pain. Both are intractable, subjective, constant and unpleasant, difficult to treat and significantly affect quality of life. As they cannot be seen and sufferers often adopt outwardly normal behaviour, their impact may be underestimated. 19

The impact of tinnitus on individuals varies and is dependent on a range of factors, such as severity, duration, preexisting psychological characteristics and so on. An individual's reaction to tinnitus may lead to a state of constant anxiety, directing attention to tinnitus and establishing a 'vicious circle' when tinnitus increases in direct proportion to anxiety.<sup>20</sup>

Most participants stated that tinnitus had significantly impacted on their lives, especially in the period following onset. One participant stated:

"It destroys everything you go to do, when you waken in the morning, it's there, when you go to sleep, it's the last thing you hear, no matter what you do or where you go, it's usually there, it spoils your life." (G)

#### **Relationships with others**

According to Holmes & Padgham (2009), 41% of individuals with tinnitus report negative effects on personal relationships.<sup>21</sup>

One participant stated:

"For the first six months, I was virtually impossible to live with." (P)

Others stated that tinnitus often dictated where they went and how long they stayed there for. Many participants avoided going to shops, cafes, restaurants, bars, nightclubs, cinemas, concerts and similar places on their own or with others, because they knew that the background noise in these venues would trigger their tinnitus or make it worse.

"Clinking cups and teaspoons and the noise of the coffee machine, you just want to stand and scream. You literally want to stand, put your hands over your ears and scream and scream. It's not going to do any good but that's how you feel because there's so much noise you just want to do something to shut it out." (F)

<sup>&</sup>lt;sup>19</sup> Holmes, S. & Padgham, N. (2009), 'Review Paper: more than ringing in the ears: a review of tinnitus and its psychosocial impact', *Journal of Clinical Nursing*, 18, 2927-2937.

<sup>&</sup>lt;sup>20</sup> Ibid.

<sup>&</sup>lt;sup>21</sup> Ibid.



A number of participants, especially those with a hearing loss, stated that they often made excuses to avoid meeting friends or attend family gatherings, such as weddings, funerals and so on, because they found it difficult to converse with others when background noise was present.

"If I was with a group of friends and everyone was talking, I feel I can't contribute because the noise is just too much; you feel a bit isolated." (J)

#### Mental health

A small number of participants in this study stated that at times they felt depressed; others stated that they had been diagnosed with clinical depression.

- "You get down days, you get depressing days, you get days when you don't want to get out of bed, you get days where you don't want to go on living." (F)
- "I don't think I would have depression at all only for the tinnitus." (E)

Tinnitus is associated with a higher occurrence of depression than in the general population.<sup>22</sup> According to Daugherty (2007), at least 40-60% of patients with tinnitus also have a major depressive disorder, which often worsens their perception of the condition.<sup>23</sup>

"It's just hard to keep going. I try to be positive but it's hard to be positive all the time."(E)

It is unclear whether tinnitus is a manifestation of a depressive disorder or a factor contributing to its development. In a study undertaken by Andersson et al (2005), tinnitus preceded the mood disorder in 23.5% of the sample and in 21% of cases these symptoms arose concurrently.<sup>24</sup>

Three participants stated that they had contemplated taking their life because they could no longer cope with living with tinnitus.

"One time I remember saying to myself, whenever it was very bad, 'How am I ever going to live with this noise in my head non-stop?' I was going to take an overdose." (R)

<sup>&</sup>lt;sup>22</sup> Ibid.

<sup>&</sup>lt;sup>23</sup> Daugherty, J.A. (2007), 'The Latest buzz on Tinnitus', *The Nurse Practitioner*, (32) 10, 42-47.

<sup>&</sup>lt;sup>24</sup> Holmes, S. & Padgham, N. (2009), 'Review Paper: more than ringing in the ears: a review of tinnitus and its psychosocial impact', *Journal of Clinical Nursing*, 18, 2927-2937.



"In the early stages, I felt that life isn't worth living like this. I felt suicidal, I was close to it, but I have a large family and wonderful grandchildren and I thought, I couldn't, you know, I could never do that to them." (J)

Two participants did take an overdose.

"It got to the stage that I couldn't take anymore; I took an overdose." (E)

According to Holmes and Padgham (2009), the causal link between suicide and tinnitus is tenuous and most cases are associated with co-morbid psychiatric disturbances.<sup>25</sup>

#### Sleep

Several studies have found that sleep difficulties are one of the most frequent complaints associated with tinnitus. Sleep disturbance is reported by about one half of those individuals who complain about tinnitus.<sup>26</sup> Almost all of the participants in this study stated that tinnitus had disrupted their sleep and, on occasion, their spouse/partner's sleep. Many feared

going to bed and had difficulty getting to sleep initially, getting back to sleep if they woke during the night and lying in. As a result they often felt tired the next day.

- "I couldn't sleep, it was dreadful, I might have been getting one hour, two hours maximum." (J)
- "By the end of the day, even by six o'clock, I was completely wrecked, totally drained and totally exhausted." (F)

A number of participants had been prescribed sleeping tablets by their GP in order to help them sleep. Some took these tablets, others did not.



<sup>&</sup>lt;sup>25</sup> Ibid

<sup>&</sup>lt;sup>26</sup> Henry, J. A., Dennis, K. C., & Schechter, M.A. (2005), 'General Review of Tinnitus: Prevalence, Mechanisms, Effects and Management', *Journal of Speech, Language, and Hearing Research*, (48), 5, 1204-1235



#### Inability to concentrate

According to Tyler and Baker (1983), 33% (n = 72) of their sample were unable to concentrate as a result of tinnitus.<sup>27</sup> A number of participants in this study stated that tinnitus reduced their attention and concentration span. One participant who could no longer read for extended periods of time due to tinnitus had to abandon her dream of starting a PhD. She described tinnitus as a

"thief of concentration." (J).

#### Work

Almost half (42%) of respondents to the RNID and British Tinnitus Association (BTA) survey (2006) reported that tinnitus interfered with their work.<sup>28</sup> In this study, one participant stated that he believed that he was pensioned off because of tinnitus. A second stated that she had to retire early because of tinnitus and others stated that they could no longer continue to carry out work they had previously been employed to do.



#### **Everyday activities**

Most participants had difficulty coping with everyday activities, such as listening to music, watching television, driving, playing sport and so on, because of tinnitus.

## **Coping strategies**

Over the years, some participants stated that they had developed coping strategies to manage tinnitus and it now impacted less on them than it did at onset. According to Tyler and Baker (1983), there is a large variation in human coping responses to tinnitus.<sup>29</sup>

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<sup>&</sup>lt;sup>27</sup> Tyler, R. S., & Baker, L. J. (1983), 'Difficulties Experienced By Tinnitus Sufferers', *Journal of Speech and Hearing Disorders*, 48, 150-154.

<sup>&</sup>lt;sup>28</sup> Holmes, S. & Padgham, N. (2009), 'Review Paper: more than ringing in the ears: a review of tinnitus and its psychosocial impact', *Journal of Clinical Nursing*, 18, 2927-2937.

<sup>&</sup>lt;sup>29</sup> Nondahl, M., et al (2007), 'The Impact of Tinnitus on Quality of Life in Older Adults', *Journal American Academy of Audiology*, 18, 257-266.



Andersson (2002), found that individual difference in coping ability is related to dispositional personality characteristics such as optimism.<sup>30</sup> For instance, those with tinnitus of high intensity may find it 'manageable' while others with very low intensity tinnitus may regard it unbearable.<sup>31</sup>

The majority of participants stated that when they were first diagnosed with tinnitus, they were very distressed. They found it difficult to accept that the noise they were hearing would never disappear, that there was no cure for it and that they would have to learn to live with it. In the first two to three years following onset, the majority of participants found it most difficult to live with tinnitus. It was only over the course of time and through a process of trial and error that they discovered coping strategies that worked for them. The success of participants' strategies centred on identifying what caused tinnitus to improve or worsen and their acceptance of the condition. Most participants developed strategies independently of others and, in most cases, in the absence of support services. Participants who had tinnitus longest were best able to cope.

"I've learnt to live with it. It becomes a way of life, you learn to live with a whole lot of things and you learn to live with tinnitus."(R)

The most frequently-used coping strategies that participants used were those that focused on creating a distraction. Many participants spoke about the importance of keeping mentally and physically occupied. Some found that working, looking after children and grandchildren, doing housework, shopping, reading, watching TV, walking and so on helped. Others found that being in company distracted them.

- "If I've company in the car my mind is focused on the conversation and not on the tinnitus." (O)
- "When you're with someone, it's probably better because you're talking and concentrating on something else." (L)

The majority of participants stated that it was best to try not to think or talk about tinnitus. Ignoring it was preferable to paying attention to it as focusing on it made it worse.

<sup>&</sup>lt;sup>30</sup> Naughton, P. (2004), 'The Quest for Quiet: People's Experience of Tinnitus in Ireland', Irish Tinnitus Association.

<sup>&</sup>lt;sup>31</sup> Holmes, S. & Padgham, N. (2009), 'Review Paper: more than ringing in the ears: a review of tinnitus and its psychosocial impact', *Journal of Clinical Nursing*, 18, 2927-2937.



- "I pay no heed to it anymore, it comes and goes and that's it." (T)
- "Whenever I leave it alone and don't think about it, it's not so bad, as soon as you start to mention it, to think about it, it becomes more pronounced." (A)

Many participants described their efforts to adjust their lifestyle to avoid or reduce trigger factors:

"I'm very careful to avoid situations which put me under additional stress or conflict." (P)

One participant used visualisation to cope:

"I think of somewhere that is special and sort of put myself into that ambience so that I try to put a pleasant connotation on everything." (J)

A number of participants stated that it was important for them to feel in control of tinnitus rather than allowing it to control them. Taking responsibility for their own welfare and exercising the power of positive thinking helped them cope better.

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- "I feel I am totally in control, it doesn't mean I don't have bad days and nights but I'm controlling it rather than it controlling me." (J)
- "I've gotten to the stage now where I can control my feeling in terms of tinnitus and control the impact it has on me." (B)
- "It doesn't stop me doing anything; I don't say I can't do anything because I've got tinnitus." (L)
- "You have to be cheerful no matter what, no point sitting in the corner moping." (A)

Others perceived tinnitus as a friend. If it became worse, it warned them that something was wrong or that they were under stress. This in turn prompted them to take action.

"You get to the stage where you hear it so much you get used to it. If you didn't hear it, you'd think something was wrong." (A)

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#### Relief from tinnitus

Given the significant impact that tinnitus can have on people's lives, it is understandable why many people expend considerable amounts of energy, and not a little financial outlay, on finding relief.

"If you have tinnitus, you'll grasp at straws." (P)

Most participants used a trial and error approach before they found relief. A small number were unaware that they could find relief and some participants, despite searching for years, had never found any relief.

"If you can think of anything to do with a cure for tinnitus, I've got the T-shirt. To no avail, nothing has worked." (G)

Participants stated that they found most relief when engaged in enjoyable activities that distracted them from tinnitus; for example, walking, cycling, fishing, flying, shopping, listening to music, reading, watching television, painting, completing Sudoku/crosswords and so on.

Some participants stated that wearing their hearing aid/s gave them some



relief. This may be because an increase in environmental sound may reduce the contrast between tinnitus and background noise, making it less intrusive.<sup>32</sup> The literature concerning hearing aids as produced mixed results. Johnson (1998), estimated that up to 90% of tinnitus patients may benefit from amplification.<sup>33</sup> However, Surr, Kolb, Cord & Garrus (1999), in contrast, found that hearing aids offer modest reduction in experienced tinnitus severity.<sup>34</sup>

Some participants stated that using sound generators, especially at night, helped provide relief. This finding is similar to that reported by Folmer & Carroll (2006), who

<sup>&</sup>lt;sup>32</sup> Holmes, S. & Padgham, N. (2009), 'Review Paper: more than ringing in the ears: a review of tinnitus and its psychosocial impact', *Journal of Clinical Nursing*, 18, 2927-2937.

Henry, J. A., Dennis, K. C., & Schechter, M.A. (2005), 'General Review of Tinnitus: Prevalence, Mechanisms, Effects and Management', Journal of Speech, Language, and Hearing Research, (48), 5, 1204-1235.



found that 76% of patients gained at least some relief from sound generator use.<sup>35</sup> One sign language user who is deaf highlighted that sound generators were of no benefit to people who are deaf as they are unable to hear the sounds produced.

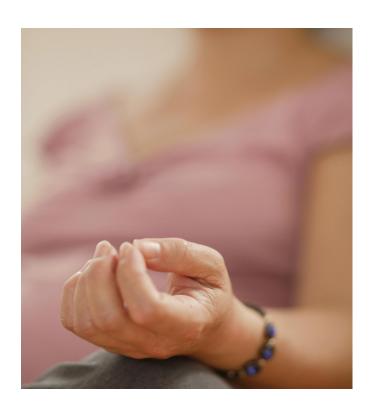
Some participants stated that having background noise, like the television or radio, provided them with relief while others avoided noisy environments.

"If I get peace and quiet for a while it goes away, a night's sleep would take it away." (A)

Others found that routine, especially at night, worked for them. In order to ensure a night's sleep, one participant described her bedtime routine. It was important for this participant to create a peaceful atmosphere in her bedroom, which she did using candles, music and aromatherapy. Ensuring that her bed was warm and comfortable and having a banana, oat cakes and a milky drink prior to sleep helped.

Approximately half of participants had tried complementary therapies. These included back, body, Indian head and head massage, acupuncture, reflexology, homeopathy and aromatherapy.

Others had tried yoga, the Alexander Technique, breathing exercises, nutritional supplements (magnesium, zinc, ginkgo biloba, B vitamins), faith healers and bone practitioners. Most of these participants found that complementary therapies offered them some temporary relief, but none of them offered permanent relief. According to Henry, Kyle & Schechter (2005), there is no convincing scientific evidence that complementary therapies are effective in providing relief for tinnitus. One participant raised concerns about the costs of complementary therapies and the lack of guarantee that they would work.



<sup>&</sup>lt;sup>34</sup> Noble, W. (2010), 'Treatments for Tinnitus', *Trends in Amplification*, 12, 236-241.

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<sup>&</sup>lt;sup>35</sup> Ibid.

<sup>&</sup>lt;sup>36</sup> Ibid.



Some participants stated that medication, namely medication to increase blood flow in the ears, and anti-depressants, gave them some relief:

"The anti-depressants help me cope at times to a certain extent." (E)

According to Holmes and Padgham (2009), drug therapy may help relieve symptoms associated with tinnitus such as depression and anxiety, making tinnitus more manageable. Some successes have been reported with tricyclic antidepressants: however, results of studies which used selective serotonin reuptake inhibitors (SSRIs) proved inconclusive.<sup>37</sup> According to Robinson et al (2004), there is no basis from the literature for a proposal that distressing tinnitus absent psychological problems such as depression and anxiety will be effectively managed by the use of antidepressants.38

Some participants stated that alcohol gave them relief, while others stated that reducing their caffeine, chocolate, sugar and salt intake helped. Putting pressure on the back of the ear, shaking off religion, reading Buddhist texts and listening to the hum from the fridge door were also cited as providing relief for some participants.

"I was opening the fridge door till the motor started and holding my head against it to get the hum and the hum was masking the tinnitus. I was glad of it at the time." (R)

## Length of time before seeking help for tinnitus

The prevalence of tinnitus is much higher than the number of people who seek treatment. Two participants stated that it was during a routine medical check at school that a problem with their hearing was identified and subsequent referrals to GPs resulted in tinnitus being diagnosed.

According to Henry, Dennis & Schechter (2005), the number of problems people associate with their tinnitus is greatest when tinnitus has been present for only a short period of time.<sup>39</sup> Individuals with more recent onset of tinnitus may experience more negative reactions to tinnitus than those who have experienced it for a longer period of time. This may explain why the majority of participants in this study who were initially troubled by tinnitus sought help within the first six months. Those who delayed seeking help or who never sought help were less troubled.

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<sup>&</sup>lt;sup>37</sup> Holmes, S. & Padgham, N. (2009), 'Review Paper: more than ringing in the ears: a review of tinnitus and its psychosocial impact', *Journal of Clinical Nursing*, 18, 2927-2937.

<sup>&</sup>lt;sup>38</sup> Noble, W. (2010), 'Treatments for Tinnitus', *Trends in Amplification*, 12, 236-241.

<sup>&</sup>lt;sup>39</sup> Henry, J. A., Dennis, K. C., & Schechter, M.A. (2005), 'General Review of Tinnitus: Prevalence, Mechanisms, Effects and Management', *Journal of Speech, Language, and Hearing Research*, (48), 5, 1204-1235.



According to Hallam (1987), habituation to tinnitus is the normal response.<sup>40</sup> Over time, tinnitus annoyance and intrusiveness decreases. The majority of people learn to accept tinnitus as 'part of their environment' within a year.<sup>41</sup>

"I've habituated to it in the same way you don't notice a clock ticking on the wall." (P)

However, there are those who find it difficult to habituate and continue to struggle.

**Support from GPs** 

The majority of participants in this study, some of whom had previously been diagnosed with Ménière's disease and/ or vertigo, initially sought support for tinnitus from their GP, a finding which corresponds to previous findings in the literature.<sup>42</sup> Some participants went to their GP with the expectation that they would be able to offer them a cure. Many were distressed to learn that there was no cure for tinnitus and found it difficult to accept that the noise they were hearing would never disappear. Others had gone with the expectation that their GP would be able to provide them with some relief

or would be able to support them to manage the condition.

Participants' experience of support from GPs varied. The majority stated that having a diagnosis and being able to give the noise a name was helpful. Some GPs prescribed participants with medication; for example, SERC, sleeping tablets, antidepressants, while some advised them about tinnitus management. Other GPs referred them to audiologists and/or ENT consultants. In some cases, participants stated that GPs were genuinely concerned for them but that they did not know how to support them.

"When there is no real cure, I think GPs feel at a loss that they can't really do anything for you." (F)

More than half of participants stated that their GP was unhelpful. Some participants were disappointed and, in some cases, angered by the response they received from their GP. Many felt that their GP was disinterested, unwilling to take the time to listen, unsympathetic, had limited understanding of tinnitus and insufficient knowledge of the condition. The majority stated that their GP did not offer them reassurance, information or advice about tinnitus management, nor did they refer

<sup>&</sup>lt;sup>40</sup> Nondahl, M., et al (2007), 'The Impact of Tinnitus on Quality of Life in Older Adults', Journal American Academy of Audiology, 18, 257-266.

<sup>&</sup>lt;sup>41</sup> Henry, J. A., Dennis, K. C., & Schechter, M.A. (2005), 'General Review of Tinnitus: Prevalence, Mechanisms, Effects and Management', *Journal of Speech, Language, and Hearing Research*, (48), 5, 1204-1235.

<sup>&</sup>lt;sup>42</sup> Naughton, P. (2004), 'The Quest for Quiet: People's Experience of Tinnitus in Ireland', Irish Tinnitus Association.



them to other professionals or signpost them to groups or organisations offering support. Many were told that there is no cure for tinnitus, nothing can be done and that they should just go home and live with it. This finding compares to RNID's study (2007) where (94%) of patients (n= 33) were told by their GP that nothing could be done.43

One participant stated:

"This is not what you want to hear when you are looking down the barrel of something you are having to come to terms with, you're not sleeping, you're distressed, you're suicidal." (J)

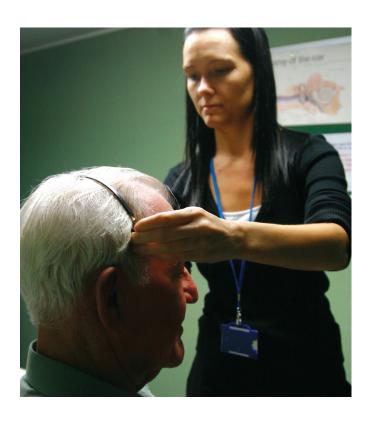
Participants stressed that a patient's first consultation with their GP is crucial. Their response to the patient can make a great difference.

"GPs can destroy people, any negative statement will impact badly on them." (P)

Participants recommended that GPs receive tinnitus training so that they have an understanding of the condition and the distress it causes. According to participants, GPs should treat patients in a sympathetic way and offer them

reassurance, encouragement and hope that they will find a way to cope. GPs should provide information to patients and discuss with them ways to manage the condition. They should be aware of referral options and should signpost patients to groups and organisations offering support so that they know they are not alone. The mere knowledge that help is available inspires hope for patients.

"It's important that people go away from the surgery with something happening for them, the fact that they know something is going to happen may reduce their tinnitus." (P)



<sup>&</sup>lt;sup>43</sup> Echalier, M. (2007), 'Managing Tinnitus', RNID London

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#### Support from audiologists

The majority of participants stated that they had attended an audiology clinic. Those who expressed satisfaction were fitted with a hearing aid and were given information and advice about tinnitus management.

Just over half of participants stated that they were disappointed with the service they received from audiology. Some stated that they had to wait a considerable period of time, following referral from their GP, to be seen by an audiologist. Some stated that audiologists tended to focus more on assessment and diagnosis of hearing-related issues rather than tinnitus, some stated that audiologists had limited knowledge and understanding of tinnitus and others stated that they had not received information or advice about tinnitus management nor were they referred to other professionals or signposted to other services for additional support.

"I think there is a gap in audiologists' knowledge. Now I don't know specifically, but my visits to the trainee audiologists or those early in their careers is that they haven't any major knowledge of tinnitus and how it affects people." (J)

#### **Support from ENT consultants**

Almost half of the participants stated that they had attended an ENT consultant. Some stated that the ENT consultant was sympathetic, knowledgeable and supportive and provided them with information and advice about tinnitus management. One participant stated that the ENT consultant had referred him to a hearing therapist and one participant stated that the ENT consultant had referred him to a tinnitus support group.

"The ENT consultant treated me with the most respect that anyone could be treated with from the word go and I told him that I found him to be a gentleman." (R)

Some participants were dissatisfied with the service they received from ENT consultants and stated that they were unsympathetic, had limited knowledge of tinnitus and did not provide them with information or advice about tinnitus management nor refer them to other professionals or signpost them to other services for additional support.

"I saw a consultant, I was in with him, I think, five minutes and he said 'You're the fifth person I've seen today, go away and learn

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to live with it, you've got tinnitus.'
I came home and I sat and cried.
I went to get some sort of help
and I didn't get it." (J)

This participant had spent £110 attending a private ENT consultant and recalled how angry she felt following the consultation.

#### Support from hearing therapists

Four participants had been referred by their GP or ENT consultant to a hearing therapist. All participants had to wait some time, following referral, before being seen. One participant stated that she had to wait eight months. All participants, bar one, stated that they benefited greatly from the support they received from the hearing therapist.

"A hearing therapist would be the best support you could have... [they] know what tinnitus is." (P)

# Support from mental health services

One participant stated that he had received psychiatric care, which he found beneficial.

#### **Support from HSC Trusts**

The majority of participants had accessed support from HSC Trusts. However, some participants were unaware that Trusts provided support for people with tinnitus and a small number were unaware of the existence of tinnitus support groups.

"I don't know if there are any support services, God knows how many people are out there in the same situation. They don't realise there is support." (A)

Most participants who had contacted Trusts were satisfied with the support they received. They stated that it was reassuring to know that they could turn to Trust staff if they needed support. Participants had received hearing-related products, such as flashing alarms, induction loops, pagers, personal listeners, phones and equipment to manage their hearing loss/tinnitus and some had been signposted to tinnitus support groups.



#### Tinnitus support groups

Three participants, who are members of a tinnitus support group, stated that they found the group beneficial as it afforded them the opportunity to vent their frustrations, share their feelings, concerns and experiences of living with tinnitus with others who understood. They stated that the group provided them with opportunities to access information and support about the condition and about tinnitus management. It also gave them a sense of perspective and helped them realise, in some cases, that their tinnitus was moderate when compared to others. Participants all stated that it was reassuring to know that they were not on their own and that there were people to whom they could turn and talk if they needed to.

"I reckon that group saved my life.
I wouldn't leave them for the world.
I would never miss a meeting.
You're with people who have the same problem. I get a lot of relief going to them. It's knowing that if you're in trouble, you can ring them, go over to them, knowing that there is someone there you can fall back on." (R)

Staff employed in sensory support teams within HSC Trusts generally signpost

people with tinnitus to tinnitus support groups. One participant stated that his GP had referred him to the Trust; another stated that he had discovered the group on the internet and approached the Trust himself. The majority of participants are longstanding group members. Membership is predominately made up of older people (60+); few young people attend. Given that the average age at which participants first began to hear tinnitus noise in this study was 42, Trusts could consider offering services to a younger cohort. Participants stated that tinnitus support groups tend to be on in the morning, which may not suit everyone, especially those who are working. All participants expressed concern regarding the sustainability of groups.

"The group does not get enough support. I think the government and people like that just want to brush tinnitus under the table, they don't seem to recognise it as an illness." (E)

One participant highlighted that there are no specific tinnitus support groups for sign language users who are deaf. According to this participant, people who are deaf think that tinnitus support groups are only for people who are hearing or hard of hearing.

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Another participant stated that she would find it difficult to function in a tinnitus support group because she was hard of hearing; however, she did think that a group would be beneficial for someone who only had tinnitus.

Some participants stated that they did not see the point of going to a tinnitus support group as they had found their own way to manage tinnitus. Some feared that going to a group would make their tinnitus worse as it would focus their attention on it.

- "I think people sitting around complaining about their tinnitus is not going to do me any good, I've got the kind of tinnitus I can live with. I can understand how people might get comfort out of it, if it is driving them mad, but it's just something I contend with." (O)
- "If I'm ever in an area where people are talking about it, that's something that can make it worse." (B)

Two participants stated that their tinnitus was not severe enough to seek support, but they did state that if it became worse they would consider going to a group or attending a course.



Some participants had attended a tenweek tinnitus course organised by HSC Trusts. These participants found the courses very beneficial.

"I couldn't emphasis that course enough. I went to every week of it; it was wonderful. The understanding I came away with was so much better, you know, than what I had before." (I)

At the time of the interviews, three participants stated they had been accepted onto a tinnitus course and were looking forward to learning from others about how they could better manage their tinnitus.



# Others' knowledge and understanding of tinnitus

Almost all of the participants thought that the general public had limited knowledge and understanding of tinnitus.

"It's easier to say 'I've got a migraine; I need to go and lie down.' If you've got a migraine, they leave you alone, if you've got tinnitus, they just don't understand it. "(F)

According to Tyler and Baker (1983), it is difficult for those without tinnitus to appreciate the devastating nature the condition can sometimes assume.44 The invisible nature of the condition and, in some cases, fear of ridicule, made it difficult for some participants to discuss tinnitus with family and friends. Lack of discussion contributed to lack of understanding which in turn resulted in family and friends being unsympathetic towards participants at times. One participant stated that it was only when his wife developed tinnitus that she fully understood what it was and consequently became more empathetic towards him. According to RNID and BTA (2006), lack of understanding from a partner may contribute to an individual's distress.45

A small number of participants stated that they had discussed tinnitus with their family and friends and felt that they were now more understanding. On occasion, participants had used tinnitus leaflets and magazine/newspaper articles to initiate discussion.

"You do need to be surrounded by people who love you and understand that you're going through a difficult time. It is a personal journey but it's better if you have support." (J)

## **Sourcing tinnitus information**

Participants obtained information about tinnitus from different sources. Websites are a major source of patient information; however, many are unreliable. Often the safety and efficacy of products which promote a cure are unknown, and professionals should caution against their use.<sup>46</sup>

Some participants stated that they had found information in their local library, in newspapers and magazines and in medical books. Those attending tinnitus support groups or in contact with HSC Trusts received information, which included information from RNID and the

<sup>&</sup>lt;sup>44</sup> Tyler, R. S., & Baker, L. J. (1983), 'Difficulties Experienced By Tinnitus Sufferers', *Journal of Speech and Hearing Disorders*, 48, 150-154.

<sup>&</sup>lt;sup>45</sup> Holmes, S. & Padgham, N. (2009), 'Review Paper: more than ringing in the ears: a review of tinnitus and its psychosocial impact', Journal of Clinical Nursing, 18, 2927-2937.

<sup>&</sup>lt;sup>46</sup> Ibid.



BTA. A number of participants stated that they had contacted RNID and the BTA directly for information. Others, though, had never heard of RNID or the BTA and were unaware that staff in these organisations could provide them with information.

In general, participants were of the opinion that there was a dearth of tinnitus information available. Sign language users who are deaf and have tinnitus stated that much of the information that is available is inaccessible as is not written in plain English.

"Unfortunately a lot of the information was in a written format that was actually quite detailed and technical and wasn't accessible." (B)





#### **Conclusions**

In general, members of the public have limited understanding and knowledge of tinnitus. In some cases, those who develop tinnitus may be unaware that the noise they are hearing is tinnitus. There is a need for a public information campaign to ensure that people who have tinnitus or who develop tinnitus know where to turn for support.

Tinnitus can impact significantly on people, leading to deterioration in their quality of life. Tinnitus causes most concern for people in the period following onset. Most people seek support from their GP within the first six months. Given that a number of people were dissatisfied with the support they received from GPs, audiologists and ENT consultants, we can conclude that there is a need for these professionals to be trained to support people with tinnitus.

A number of participants had to wait for extended periods of time, following referral from their GP, before being seen by an audiologist, ENT consultant or hearing therapist. Given that early intervention is essential to lessen the negative impact of tinnitus, we can conclude that there is a need to ensure that waiting times to be seen by professionals are reduced.

Participants were satisfied with the support they received from HSC Trusts.

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Trusts could continue to sustain, for example, tinnitus courses and tinnitus support groups, and work to develop additional services to meet the needs of their service users. The time that courses/groups are run, the age profile of people attending courses/groups and their degree of hearing loss should be considered. Given that support for people with tinnitus in each Trust area differs, there is a need for Trusts to work together to ensure that people can get support across Trust **boundaries.** A number of participants were unaware of the support Trusts offer people with tinnitus hence there is a need for Trusts to promote their work to the general public.

There is a lack of tinnitus information available. Websites do provide information, but many of them are often unreliable and people should be cautioned against their use. Some information may be inaccessible to sign language users who are deaf and may not be written in plain English. There is a need to ensure that people with tinnitus, including sign language users who are deaf, have access to tinnitus information.

Some participants had never heard of RNID or the BTA and were unaware that staff in these organisations could provide them with information. **There is a need for these organisations to promote their work to the general public.** 



### Section four: Professionals' experience of tinnitus

#### **GPs**

#### Number of patients presenting to GPs with tinnitus

Half (51%) (88) of GPs stated that they see between one to three patients a month with tinnitus. This finding compares to a survey commissioned by RNID in 2007 where 56% (284) (n=506) of GPs stated that they see between one to three patients a month with tinnitus.<sup>47</sup> Over two fifths (44%) (76) of GPs stated that they see fewer than one patient a month, 5% (9) stated that they see between four to five patients a month and 0.6% (1) stated that they see more than five patients a month.



#### **Medication GPs prescribe** patients with tinnitus

Over half (57%) (100) of GPs stated that they do not prescribe medication for patients with tinnitus, 43% (74) stated that they do. In some cases, GPs prescribe patients with medication if they present with tinnitus and an additional condition such as vertigo or Ménière's disease. Around one third (38%) (28) of GPs prescribe Betahistine, 23% (17) prescribe SERC and 19% (14) prescribe Stemetil (Prochlorperazine).

Other medications that are prescribed include:

- decongestants 8% (6)
- sleeping tablets 4% (3)
- antidepressants 3% (2)
- antihistamines 3% (2)
- Cinnarizine (Stugeron) 3% (2)
- Buccastem 1% (1)
- Diazepam 1% (1)

In 2007, RNID found that GPs who have received tinnitus training are less likely to prescribe medication.48

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<sup>&</sup>lt;sup>47</sup> Echalier, M. (2007), 'Managing Tinnitus', RNID London 48 Ibid.



### Actions GPs take when a patient presents with tinnitus

The majority 89% (154) of GPs take more than one action to support patients with tinnitus. Almost three quarters 72% (126) provide patients with advice about tinnitus management and just over half 54% (94) provide patients with tinnitus literature. 50 These findings compare with RNID's (2007) research, which found that 83% (420) of GPs provide patients with advice about tinnitus management and 61% (309) provide them with tinnitus literature. 49 RNID also found during this research in 2007 that GPs who had received tinnitus training were more likely to provide advice about tinnitus management and tinnitus literature than those who had not.

In this survey, the vast majority 81% (141) of GPs refer patients with tinnitus to an ENT consultant. In 2007, RNID found that 62% (314) of GPs refer patients with tinnitus to an ENT consultant; 19% (96) of these GPs had never received tinnitus training, 9% (46) had. Based on these findings, we can conclude that untrained GPs are more likely to refer patients to an ENT consultant rather than treating them in Primary care.

Just over one third 38% (63) of GPs refer patients to an audiology service. Only 2.3% (4) refer patients to a hearing therapist, compared to 47% in England.

Just 1.7% (3) refer patients to a counselling service, 1.1% (2) refer patients to a mental health service, 0.6% (1) signpost patients to HSC Trusts and 2.3% (4) signpost patients to tinnitus support groups.

None of the GPs surveyed signpost patients to community and voluntary organisations, including RNID and the BTA.

The findings above suggest that GPs may be unaware of the support other professionals can offer people with tinnitus and/or that they may be unaware that they can refer and/or signpost patients to community and voluntary organisations for support. Given the shortage of hearing therapists in Northern Ireland, GPs may not have the option of referring patients to them.

#### **Knowledge of tinnitus**

On a scale of 1-10, with 10 = most knowledgeable and 0 = least knowledgeable, almost half of GPs surveyed 47% (82) rated their knowledge of tinnitus as above average. Just over half 53% (91) rated their knowledge of tinnitus as average or below average.

<sup>49</sup> Ibid.

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#### **Training**

Over half of GPs surveyed 57% (99) stated that they had never received tinnitus training. Of those who had received training, 53% (40) had received training more than 10 years ago and 23% (17) had received training in the last five years. This compares with 29% (147) of GPs in England who had received training more than 10 years ago and 39% (197) who had received training in the last five years.<sup>50</sup> It is evident from these findings that GPs in England have received more recent tinnitus training than those in Northern Ireland.

The majority of GPs surveyed 77% (134) stated that they would like to receive tinnitus training. However, 82% (143) stated that they did not have opportunities to undertake CPD courses on tinnitus.

## What works well for GPs in supporting patients with tinnitus

GPs stated that it was important for them to initially establish a good relationship with their patients. This, they stated, could be achieved by adopting a caring attitude, displaying empathy, taking time to listen to patients, taking time to explain their condition to them, being clear about the diagnosis, suggesting ways to manage their condition and offering them

reassurance that their quality of life would improve over time.

GPs stated that having access to tinnitus information, either online or in hard copy, especially in relation to tinnitus management, worked well for them in supporting patients. Being able to promptly refer patients to ENT consultants and audiologists, especially in the case of newly diagnosed patients, being able to signpost them to tinnitus support groups and tinnitus websites, being able to leave information in waiting rooms and being able to prescribe medication also worked well for GPs in supporting patients.

### Specific challenges GPs face in supporting patients with tinnitus

GPs stated that the greatest challenge they face in supporting patients with tinnitus is the difficulty they have in treating them. GPs stated that patients often expect a cure and find it difficult to accept when told there is none. According to GPs, treatment options are limited. Supporting those who respond poorly to treatment or those who are not satisfied with treatment is a challenge. GPs stated that their limited knowledge of tinnitus, tinnitus management and lack of information regarding support groups/organisations and limited

<sup>50</sup> Ibid.

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resources, such as information leaflets, presented a challenge. Restrictions on their time present challenges in managing patients' distress, frustrations and sense of hopelessness, as well as managing co-existing symptoms, like depression, sleep disturbance, stress, and managing patients who re-attend expecting to be 'fixed'.

#### **Key findings**

- 51% (88) of GPs see between one to three patients a month with tinnitus.
- 53% (91) of GPs rated their knowledge of tinnitus as average or below average.
- 57% (99) of GPs have never received tinnitus training.
- 77% (58) of GPs who had received tinnitus training received it more than five years ago.
- 77% (134) of GPs would like to receive tinnitus training.
- 82% (143) of GPs did not have opportunities to undertake CPD courses on tinnitus.

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- 43% (74) of GPs prescribe medication for patients with tinnitus.
- 81% (141) of GPs refer patients with tinnitus to an ENT consultant and 37% (63) refer patients with tinnitus to an audiology clinic.
- 3% (5) of GPs refer patients to other services and no GP signposts patients to community and voluntary organisations, including RNID and BTA.

#### **Recommendations for GPs**

- As part of their undergraduate degree, medical students to receive tinnitus training.
- GPs to have opportunities to undertake tinnitus training as part of their CPD.
- Clear referral pathways to professional services; for example, ENT, audiology, counselling and mental health services to be established and made known to GPs. Patient waiting times for these services to be reduced to meet national standards.



#### **Audiologists**

GPs, audiologists, ENT consultants and hearing therapists can refer patients with tinnitus to audiology clinics. The number of patients referred annually to clinics ranges from 20-600 and is dependent on the size of the clinic and the number of audiologists employed. Patients generally wait between six to ten weeks to be seen by an audiologist, following a referral from a GP. However, if the GP refers them initially to an ENT consultant, they could wait longer before being seen.

Generally, audiologists treat all patients who are referred to them. The provision of hearing aids, tinnitus maskers and tinnitus information are the most common forms of treatment. Some audiologists also provide sound generators and a minority provide Tinnitus Retraining Therapy (TRT). TRT combines directive counselling with promoting habituation by the use of noise generators. Noise generators provide background sound at a level just below that of tinnitus, for 6-24 hours, including during sleep. Treatment with TRT usually requires one to two years to achieve the desired result.<sup>51</sup> The literature concerning tinnitus maskers has produced mixed results. Daugherty (2007), found that 76% of patients reported in-the-ear noise maskers helped their tinnitus at

least a moderate amount.<sup>52</sup> In contrast, Andersson et al (2005), found that tinnitus maskers are not effective for all patients and, for many, the effects are short-lived. For some, tinnitus increases after masking and for others tinnitus maskers may interfere with hearing and communication.<sup>53</sup>

Some audiologists refer patients with tinnitus to Craigavon Area Hospital where treatment options include TRT, Cognitive Behavioural Therapy (CBT) and stress management. According to Henry, Kyle, Schechter (2005), CBT is a type of counselling that identifies negative behaviours, beliefs and reactions and assists the patient in substituting appropriate and positive reactions. Professionals who wish to learn this method require general training in CBT techniques which they must adapt to the treatment of tinnitus. Henry and Wilson (2001), reviewed studies that have been conducted to evaluate the efficacy of (CBT) for tinnitus distress. They concluded that these studies offer 'considerable support' for using this form of treatment. The best results using CBT are achieved with at least eight sessions.54 Noble and Tyler (2007), suggest that flexible coalitions between clinical audiology and clinical psychology may be an optimal model for tinnitus treatment.55

<sup>&</sup>lt;sup>51</sup> Henry, J. A., Dennis, K. C., & Schechter, M.A. (2005), 'General Review of Tinnitus: Prevalence, Mechanisms , Effects and Management', *Journal of Speech, Language, and Hearing Research*, (48), 5, 1204-1235.

<sup>&</sup>lt;sup>52</sup> Daugherty, J.A. (2007), 'The Latest buzz on Tinnitus', *The Nurse Practitioner*, (32) 10, 42-47.

<sup>&</sup>lt;sup>53</sup> Holmes, S. & Padgham, N. (2009), 'Review Paper: more than ringing in the ears: a review of tinnitus and its psychosocial impact', *Journal of Clinical Nursing*, 18, 2927-2937.



The majority of audiologists state that they continue to treat patients after their initial visit, especially if they wear a hearing aid or tinnitus masker.

Nine audiologists stated that they refer patients to sensory support teams within HSC Trusts. Six signpost patients to lipreading classes and five signpost patients to tinnitus support groups facilitated by Trust staff. Seven audiologists stated that they refer patients to a hearing therapist, two refer patients to a counselling service, two refer patients to a mental health service and three refer patients to a speech and language therapist. Six audiologists stated that they signpost patients to RNID, five signpost patients to the BTA and four signpost patients to community and voluntary organisations, which may include RNID and BTA.

#### **Knowledge of tinnitus**

On a scale of 1-10, audiologists rated their knowledge of tinnitus on average as a 7, with 10 = most knowledgeable and 0 = least knowledgeable. All rated their knowledge of tinnitus as above average. The highest rated score was 8 and the lowest rated score was 5.

# Audiologists' views on undertaking additional training in psychological approaches to tinnitus management

All audiologists stated that undertaking additional training in psychological approaches to tinnitus management would be beneficial. Some stated, however, that they would need time off work to undertake additional training which would require the employment of additional audiologists to cover. Three audiologists stated that they do have opportunities to undertake CPD courses on tinnitus, while seven stated that they do not; the main reason being lack of funding.

## What works well for audiologists in supporting patients with tinnitus

Audiologists stated that offering reassurance to patients and providing them with hearing aids, white noise generators and tinnitus information works well for them in supporting patients. Also, being able to refer patients for specialist support, such as the tinnitus rehabilitation manager at Craigavon Area Hospital and being able to refer them to other professionals worked well. Continuity of service, review of patients' condition and acting on patient feedback were also highlighted as working well.

<sup>&</sup>lt;sup>54</sup> Henry, J. A., Dennis, K. C., & Schechter, M.A. (2005), 'General Review of Tinnitus: Prevalence, Mechanisms , Effects and Management', *Journal of Speech, Language, and Hearing Research*, (48), 5, 1204-1235.

<sup>&</sup>lt;sup>55</sup> Noble, W. (2010), 'Treatments for Tinnitus', Trends in Amplification, 12, 236-241.



# Specific challenges audiologists face in supporting patients with tinnitus

The majority of audiologists (7) stated that they do not have sufficient resources to provide an effective tinnitus service. Lack of funding, lack of staff, lack of time with patients, lack of accommodation onsite and lack of training opportunities present challenges for them. Professional delays in referring patients to audiologists and the reduction in hearing therapists means that audiologists have fewer referral options.

#### **Key findings**

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- All audiologists rated their knowledge of tinnitus as above average.
- Three audiologists stated that they do not have opportunities to undertake CPD courses on tinnitus.
- All audiologists stated that undertaking additional training in psychological approaches to tinnitus management would be beneficial.
- Audiologists are most aware of the additional support that sensory support teams, hearing therapists and community and voluntary organisations can offer people with tinnitus and less aware of the support that counselling, mental health and speech and language therapists can offer.
- Seven audiologists stated that they do not have sufficient resources to provide an effective tinnitus service.

## Recommendations for audiologists

- Additional audiologists to be trained to support patients with hearing loss and patients with tinnitus in Northern Ireland.
- As part of their undergraduate degree, audiology students to receive tinnitus training.
- Resources to be secured to ensure that audiologists have opportunities to undertake tinnitus training as part of their CPD.
- Audiologists to have opportunities to undertake training in TRT, CBT and stress management to support patients with tinnitus.
- One audiologist in each clinic to be trained to provide specialist support to patients with tinnitus.
- Clear referral pathways to professional services, such as counselling, mental health, speech and language therapy to be established and made known to audiologists. Patient waiting times for these services to be reduced to meet national standards.
- Waiting times to be seen by an audiologist to be reduced and standardised across all hospitals.
- Audiologists to review patients with tinnitus and invite them for an annual check up.
- Audiologists to provide patients with tinnitus opportunities to feedback on the service they receive.
- Hearing therapists to be attached to audiology clinics.



#### **ENT** consultants

ENT consultants receive most referrals from GPs. Less common referrals come from other consultants, audiologists, paediatricians, hearing therapists, integrated clinical assessment and treatment services (ICATS), private patients and NHS patients. The number of patients referred annually to ENT consultants ranges from 10 to 500 and is dependent on the size of the clinic and the number of ENT consultants employed. Patients generally wait between 4-17 weeks to be seen by an ENT consultant following referral.

Generally, ENT consultants treat all patients who are referred to them; however, this is not always the case. One ENT consultant stated that 100 of the 250 (40%) of patients referred are treated while another stated that 80 of the 120 (67%) of patients referred are treated. All ENT consultants stated that they provide patients with tinnitus information and advice about tinnitus management. Four prescribe medication; SERC, Betahistine, Amitriptyline being the most common, and one uses MRI (Magnetic Resonance Imaging) scans to rule out specific pathology.

All ENT consultants stated that they refer patients to audiology clinics and to hearing therapists. Two stated that they

refer patients to sensory support services within HSC Trusts. None refer patients to a speech and language therapist. Three ENT consultants stated that they signpost patients to community and voluntary organisations and four signpost patients to RNID.

The number of patients requesting a second appointment varied between 10%-25%. Severity of symptoms and difficulty coping were cited as the main reason for requesting a second appointment.

#### **Knowledge of tinnitus**

On a scale of 1-10, ENT consultants rated their knowledge of tinnitus on average as a 7, with 10 = most knowledgeable and 0 = least knowledgeable. The highest-rated score was 10 and the lowest rated score was 3. Seven ENT consultants stated that they had received tinnitus training, three stated that they had not. Of those who had received training, five had received it in the last five years and two had received it between 5-10 years ago. Three did not answer this question. Six ENT consultants stated that they would like to receive training, four stated that they would not. Eight stated that they did have opportunities to undertake CPD courses on tinnitus and two stated that they did not.





### What works well for ENT consultants in supporting patients with tinnitus

Three ENT consultants stated that good audiological and hearing therapy support worked well in helping them to support patients with tinnitus. Spending time with patients, taking consideration of their medical history, explaining the condition to them, offering them reassurance and providing them with well written tinnitus literature, including literature from RNID helped. Undertaking a full investigation, such as an MRI scan to rule out specific pathology, also helped.

# Specific challenges ENT consultants face in supporting patients with tinnitus

The majority of ENT consultants stated that time limitations, and two ENT consultants stated that resource limitations, presented challenges for them in supporting patients with tinnitus. One ENT consultant stated that it was a challenge to treat patients with psychiatric disorders and to treat patients who had been prescribed multiple medications. Other challenges included lengthy waiting times, difficulty explaining potential causes, lack of understanding within the medical professional and the shortage of hearing therapists to refer patients to.

#### **Key findings**

- Seven ENT consultants had received tinnitus training.
- Five ENT consultants had received tinnitus training within the last five years.
- Two ENT consultants do not have opportunities to undertake CPD courses on tinnitus.
- Six ENT consultants would like to receive tinnitus training.
- Waiting times to be seen by an ENT consultant differ across hospitals in Northern Ireland.
- ENT consultants are most aware of the referral routes and support services audiologists and hearing therapists provide people with tinnitus. They are less aware of the referral routes and support services HSC Trusts, speech and language therapists and community and voluntary organisations can offer.

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## Recommendations for ENT consultants

- As part of their undergraduate degree, medical students to receive tinnitus training.
- ENT consultants to have opportunities to undertake tinnitus training as part of their CPD.
- Waiting time to be seen by an ENT consultant to be reduced and standardised across all hospitals in Northern Ireland.
- Clear referral pathways to professional services, such as counselling, mental health, speech and language therapy and so on to be established and made known to ENT consultants. Patient waiting times for these services to be reduced to meet national standards.





#### **HSC Trusts**

### Tinnitus support groups in Northern Ireland

#### **Belfast HSC Trust**

The former South and East Belfast HSC Trust does not have a tinnitus support group. However, it did fund a 10-week tinnitus course which began at the end of January 2010. The former North and West Belfast HSC Trust does not have a tinnitus support group.

#### **South Eastern HSC Trust**

There are presently no tinnitus support groups in the South Eastern HSC Trust. The Trust plans to establish a tinnitus course in October 2010.

#### **Southern HSC Trust**

Staff members from sensory support teams within the Southern HSC Trust facilitates tinnitus support groups in Newry, Moy and Portadown.

#### **Western HSC Trust**

There are presently no tinnitus support groups in the Western HSC Trust. Two hearing therapists provide one-to-one support for people with tinnitus in a hospital setting and are employed by the Trust on a sessional basis.

#### **Northern HSC Trust**

Staff members from the sensory support team facilitate a tinnitus support within the Northern HSC Trust in Ballymena.

### Services HSC Trusts offer service users with tinnitus

HSC Trusts receive most referrals from GPs, audiologists and ENT consultants. Individuals can refer themselves if they have been diagnosed with tinnitus and relatives may also refer them if there is a tinnitus diagnosis. On occasion, RNID signposts people to HSC Trusts. Trusts estimate that between 100+ and 200+ service users with tinnitus are referred to them annually and that between 10-50% of service users who are deaf and hard of hearing have tinnitus. Trusts find it difficult to estimate the number of service users with tinnitus because the SOSCARE (Social Services Client Administration and Retrieval Environment) system that they use does not allow for the accurate recording of numbers.

All HSC Trusts stated that they provide service users with tinnitus information, advice about tinnitus management and equipment and products. Two Trusts stated that they facilitate tinnitus support groups and four Trusts stated that they, on occasion, facilitate tinnitus courses.



Three Trusts stated that they refer services users for stress management: one of these Trusts stated that stress management was accessed via the health promotion team within the Trust. One Trust stated that they refer service users for TRT. None of the Trusts have staff in their teams who are trained to provide TRT, counselling or CBT. According to Daugherty (2007), individual counselling with a psychologist or therapist can improve the patient's ability to cope and help reduce the impact of tinnitus distress. 56 One Trust employs a staff member who provides stress management and one Trust is supporting a member of the sensory support team to undertake CBT training. Another has identified a member of staff who is willing to undertake CBT training.

Four Trusts stated that they refer service users to mental health services; two Trusts stated that they refer service users to counselling services and three stated that they refer service users to a hearing therapist. One Trust stated that the hearing therapist in their area had recently retired hence referring service users to them is no longer an option. None of the Trusts refer service users to speech and language therapists.

All Trusts stated that they signpost service users to RNID and two Trusts stated that they signpost service users to the BTA.

#### **Tinnitus budget**

Four Trusts stated that they do not have a specific budget to deliver a Tinnitus service. One Trust stated that they do. None of the Trusts provide funding for transport to enable service users with tinnitus to access their services. This means that some people, especially older people and those living in rural areas, are not receiving the support they need.

#### Partnership work

All of the Trusts stated that opportunities exist for them to work in partnership with RNID to provide services for people with tinnitus. Trusts suggested that partnership work could involve the establishment and maintenance of tinnitus support groups, the organisation of tinnitus training for staff and conferences for professionals. Partnership work could also involve the identification of funding for service delivery.

#### Knowledge of tinnitus

On a scale of 1-10, sensory support team leaders rated their knowledge of tinnitus on average as 8, with 10 = most knowledgeable and 0 = least knowledgeable. The highest rated score was 8 and the lowest rated score was 6. One Trust did not answer this question.

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<sup>&</sup>lt;sup>56</sup> Daugherty, J.A. (2007), 'The Latest buzz on Tinnitus', *The Nurse Practitioner*, (32) 10, 42-47



#### **Training**

All of the Trusts stated that they do have opportunities to undertake CPD courses on tinnitus and had received training within the last five years. Trusts highlighted that training should contribute to PQ (Post Qualifying) Awards and be recognised by the Northern Ireland Social Care Council. Four of the Trusts stated that they would like to receive additional training. One Trust did not answer this question.

# What works well for (HSC) Trusts in supporting service users with tinnitus

Trusts stated that being able to spend more time with service users, offering one-to-one support, being able to refer service users to hearing therapists, tinnitus support groups and courses worked well for them. They also stated that employing additional staff and training existing staff to facilitate therapeutic groups and provide CBT would benefit them.

#### Specific challenges faced by HSC Trusts in supporting service users with tinnitus

Resourcing pressures, such as the ability to free up staff to provide one-to-one support and the lack of staff with specific tinnitus expertise, presents challenges. Limited resources and identifying people with tinnitus is also problematic.





#### **Key findings**

- The Department of Health Social Services and Public Safety (DHSSPS) does not record the number of people with tinnitus that present to HSC Trusts in Northern Ireland.
- The SOSCARE (Social Services Client Administration and Retrieval Environment) system that Trusts use to record service user information does not allow for the accurate recording of service users with tinnitus. As a result, identifying evidence of need becomes problematic.
- All Trusts stated that they do have opportunities to undertake CPD courses on tinnitus and all stated that they had received tinnitus training within the last five years.
- Currently, staff employed in sensory support teams within HSC Trusts are not trained to provide TRT, counselling or CBT for service users with tinnitus.

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- Given the shortage of hearing therapists in Northern Ireland, there is less of an option for Trusts to refer service users to them for support. Presently there are only two hearing therapists working full time in Northern Ireland. There are no opportunities for people to train to become hearing therapists in Northern Ireland. Those interested in pursuing a career in hearing therapy have to take opportunities elsewhere in the UK. If additional hearing therapists are not recruited in Northern Ireland, the gap in service provision will increase further, thus impacting significantly on service users, which includes people with tinnitus. Failure to recruit hearing therapists will mean that GPs, audiologists, ENT consultants and HSC Trusts will no longer have the option of referring people with tinnitus to these professionals for support.
- All Trusts stated that opportunities exist for them to work in partnership with RNID to provide services for people with tinnitus. All Trusts are currently signposting service users with tinnitus to RNID.

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## Recommendations for HSC Trusts

- The Department of Health, Social Services and Public Safety (DHSSPS) and HSC Trusts to develop systems to accurately record the number of service users with tinnitus.
- The Regional Sensory Impairment
   Training Strategy Group, responsible
   for designing a pathway for training
   staff in sensory support services, to
   ensure that pathways are developed
   which provide opportunities for
   sensory support staff employed in
   Trusts to develop expertise in tinnitus.
- Trusts to support staff, including social workers, rehabilitation officers and technical officers to develop tinnitus expertise. Staff to be supported to undertake TRT, counselling or CBT courses as part of their CPD.
- CPD courses to contribute to PQ (Post Qualifying) Awards and be recognised by the Northern Ireland Social Care Council.

- All Trusts to continue to sustain, for example current tinnitus support groups and tinnitus courses and to develop additional services to meet the needs of their service users.
- All Trusts to work in partnership with each other to consider best practice in supporting service users with tinnitus, including service users who are deaf. Different approaches may be required to support people in different stages of coping with tinnitus, such as one-to-one help, therapeutic support, group education sessions and so on.
- Rehabilitation for people with tinnitus to be standardised across all HSC Trusts.
- Trusts to make their tinnitus services known to GPs, audiologists, ENT consultants and members of the general public.
- Trusts to liaise with RNID to explore partnership opportunities in relation to supporting people with tinnitus.
- Additional hearing therapists to be trained to support patients with tinnitus in Northern Ireland.



#### Section five: Conclusions

Given the increase in people's life expectancy and the link between repeated exposure to loud noise and tinnitus, we can expect the number of adults and young people with tinnitus in Northern Ireland to increase. These factors, combined with a better educated public, suggest that there will also be an accompanying increase in demand for tinnitus services. It is therefore essential that a range of services are developed to meet this demand. Health and social care professionals could potentially work in partnership with each other and with community and voluntary sector providers to maintain existing tinnitus services and develop new services. In order to do this, the prevalence of people with

tinnitus needs to be accurately recorded to ensure that service providers have the evidence they need to plan services and prepare a sufficiently-trained workforce. This research indicates that HSC professionals are aware that they need to improve their knowledge and understanding of tinnitus. Many are keen to undertake CPD courses on tinnitus. It is therefore imperative that they are provided with opportunities to learn more about tinnitus and to develop specialism in this area.

The full copy of this report is available in hard copy. It can also be accessed online at **www.rnid.org.uk** 





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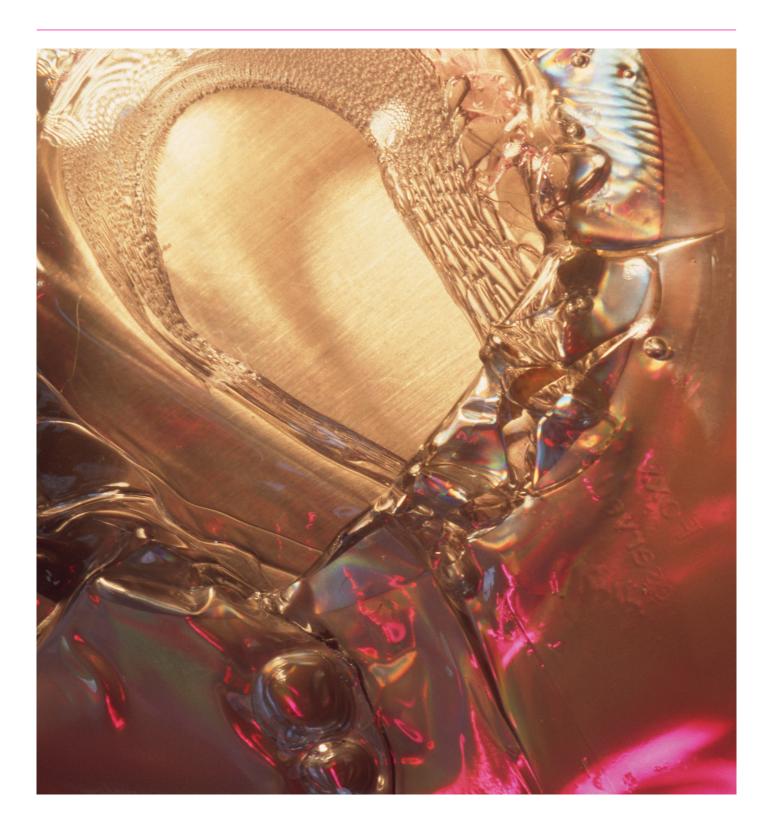
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