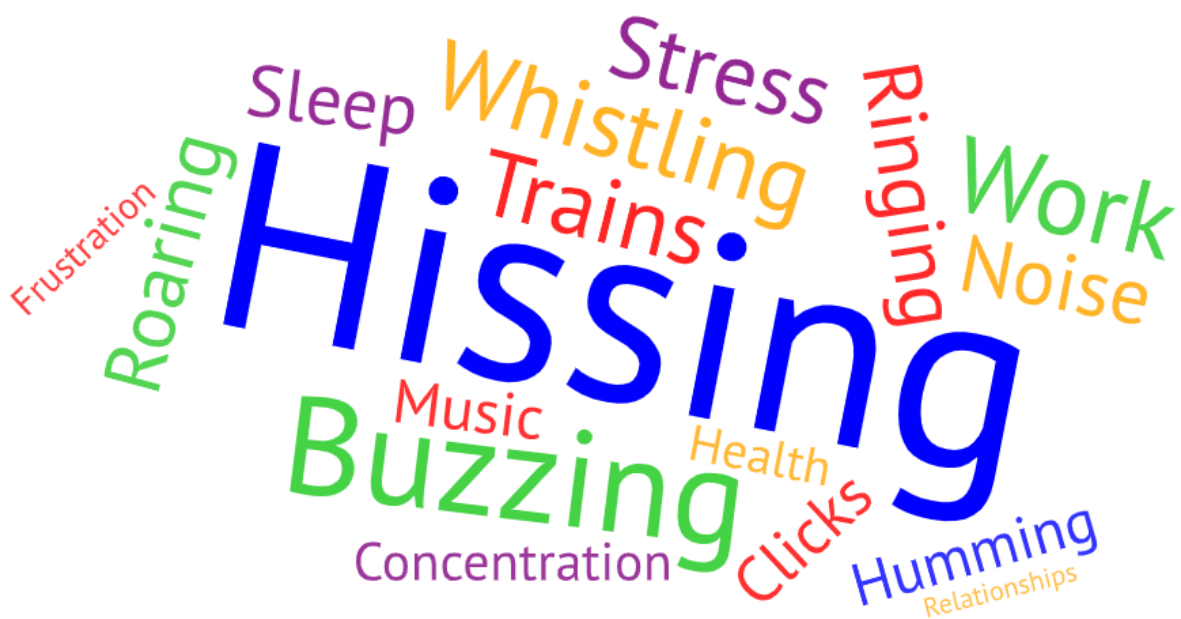


Tuning out tinnitus



The experiences of people in Scotland seeking information and support to reduce the impact of tinnitus in everyday life

December 2019

Contents

| | |
|---|----|
| • Foreword | 4 |
| • Survey design, methodology and recruitment of participants..... | 5 |
| • Details about research participants..... | 6 |
| • Research participants' experiences of tinnitus..... | 7 |
| • Accessing support from GPs..... | 9 |
| • Accessing support from audiology services..... | 11 |
| • Accessing support from Ear, Nose and Throat (ENT)..... | 13 |
| • Accessing support from counsellors..... | 15 |
| • Accessing support from other services..... | 17 |
| • Recommendations..... | 19 |

Foreword

Persistent severe forms of tinnitus can significantly impact on sleep, concentration, stress levels and mental health so it is vital that, when people seek information and support, they are provided with tools to help limit the condition's effects.

Whilst there is currently no cure for tinnitus, good work is being done by NICE (National Institute for Health and Care Excellence) who published draft guidelines in September 2019 and the Scottish Tinnitus Advisory Group's tinnitus protocols, drafted in February 2017, which set out proposed minimum standards of practice when a patient with the condition is referred to health care professionals.

In undertaking the research which informs this short report, we reached out to 459 people across Scotland and asked them to share details about how they are affected by tinnitus and steps they took in seeking information or support, so that we could get a sense of 'on the ground' views and experiences, and identify barriers to potential coping options.

We believe that our report is a significant starting point in highlighting those barriers as well as offering suggestions about potential improvements.

Going forward, we would like GPs to have increased awareness about tinnitus and the range of support that it is available; quicker access for people whose condition is associated with hearing loss to secure NHS hearing aids; immediate referrals for individuals who need psychological support to cope with their tinnitus and more peer support groups.

We look forward to taking opportunities to work in collaboration with the British Tinnitus Association (BTA), GPs and other healthcare professionals to help ensure people with tinnitus throughout Scotland are more informed, supported and empowered to reduce the impact of the condition in everyday life.



***Teri Devine, Director
Action on Hearing Loss Scotland***

Research design, methodology and recruitment of participants

Action on Hearing Loss's research and policy team designed a survey comprising of questions about each participant's age range, gender, location and regional health board, as well as their experiences of accessing information, treatment and support to help them to cope with tinnitus in everyday life.

When completing the survey between February 2018 and November 2018, participants provided their informed consent to use their data in this research project. They had the option to withdraw their responses at any time and could choose to remain anonymous. All responses were confidential and stored in a secure location.

The survey was available online and paper copies were supplied to people attending third sector community-based services, tinnitus support groups as well as via local groups whose members may have worked in loud environments when hearing protection was not legally required. Regional and local newspaper coverage as well as social media engagement generated responses from across Scotland.

The survey focused on three aspects of the patients' experience: their first point of contact, the outcome of that initial appointment and whether they were made aware of any support in a local setting. Participants were also able to set out their views on what helps them and the types of support they would like to see provided.

When the survey was finished, our researcher coded all paper copies of survey responses and entered the data, in electronic form, via SurveyMonkey. Data cleaning was carried out using Microsoft Excel. Please note that responses to every question does not always add up to 100% as people doing the survey were given the opportunity to provide more than one answer to some questions.

Details about research participants

459 people from 13 of Scotland's 14 regional NHS health board areas responded to the survey and, as shown in Table 1, more than half of the respondents were from Ayrshire & Arran (32%) and Greater Glasgow & Clyde (19%).

The vast majority (83%) of respondents were aged 55 or over, with those in the 65-74 age range accounting for 37%.

223 respondents identified as male, 227 as female and nine did not answer.

Table 1: Survey responses by NHS health board area

| NHS health board | Respondents |
|-------------------------------|--------------------|
| NHS Ayrshire and Arran | 146 |
| NHS Greater Glasgow and Clyde | 85 |
| NHS Lothian | 37 |
| NHS Grampian | 36 |
| NHS Highland | 31 |
| NHS Tayside | 27 |
| NHS Fife | 24 |
| NHS Lanarkshire | 20 |
| NHS Borders | 19 |
| NHS Forth Valley | 15 |
| NHS Orkney | 11 |
| NHS Dumfries and Galloway | 4 |
| NHS Shetland | 1 |
| NHS Western Isles | 0 |
| Uncategorised | 3 |
| Total | 459 |

Experiences of tinnitus

Tinnitus is the sensation of noise in the head or one or both ears when there is actually no external sound. Tinnitus is an individualistic experience and, in some cases, each person can ‘hear’ more than one type. Many survey respondents described having similar experiences of hissing, ringing, buzzing or whistling sensations and individuals also perceived ‘sounds’ such as clicks, trains or classical music.

Table 2: Sound of respondents’ tinnitus

| Perceived sound | Responses |
|-----------------------------|-----------|
| A hissing sound | 48% (220) |
| A ringing sound | 34% (153) |
| A buzzing sound | 24% (111) |
| A whistling sound | 21% (97) |
| A humming sound | 14% (65) |
| A roaring sound | 11% (48) |
| Other | 23% (103) |
| Total number of respondents | 454 |

The majority (52%) of 450 respondents have lived with tinnitus for 11 or more years whilst approximately one in four (26%) have experienced the condition for fewer than five years.

Table 3: Time respondents have experienced tinnitus

| Period of time | Responses |
|-----------------------------|-----------|
| 1-6 months | 2% (11) |
| 7 months – 1 year | 2% (11) |
| 13 months – 5 years | 22% (100) |
| 6 years – 10 years | 20% (90) |
| 11 years – 15 years | 14% (65) |
| Over 16 years | 38% (173) |
| Total number of respondents | 450 |

On an average day, 75% of respondents are ‘almost always’ (42%) or ‘often’ (33%) aware of their tinnitus, and more than half of respondents (53%) said the condition has a ‘very big effect’ or ‘fairly big’ effect on the quality of their life.

Respondents reported that their tinnitus affects life in various ways. More than half (55%) of 402 respondents said their tinnitus made them feel frustrated. 52% said that their concentration is affected and 49% said tinnitus affects their sleep. Almost a quarter (23%) said their tinnitus affects their mental health. Those who responded as having ‘other’ effects on life provided examples including not being able to sing, enjoy socialising, play musical instruments and suffering exhaustion.

Table 4: Aspects of life affected by tinnitus

| Aspects of life affected | Responses |
|---------------------------------|------------------|
| Makes me feel frustrated | 55% (219) |
| Affects my concentration | 52% (211) |
| Affects my sleep | 49% (195) |
| Affects my mental health | 23% (93) |
| Affects my work/education | 13% (54) |
| Affects my relationships | 12% (48) |
| Other | 19% (75) |
| Total number of respondents | 402 |

Hearing loss and stress were identified by 45% and 38% of 437 respondents as the two most common factors for triggering a perceived temporary worsening of tinnitus (sometimes referred to as 'spikes'), whilst a lack of sleep (31%) and loud noise (30%) were triggers for around three in 10. Individuals also cited various triggers including music, spicy food and alcohol.

Table 5: Triggers for respondents experiencing tinnitus spikes

| Tinnitus spike triggers | Responses |
|--------------------------------|------------------|
| Related to hearing loss | 45% (198) |
| Stress | 38% (166) |
| Lack of sleep | 31% (134) |
| Loud noise | 30% (132) |
| Medication | 7% (29) |
| Other medical condition | 5% (22) |
| Other | 35% (154) |
| Total number of respondents | 437 |

Seeking support with tinnitus

The Scottish Tinnitus Advisory Group (STAG) produced tinnitus protocols in February 2017 which set out a proposed minimum standard of practice when a patient is referred to health care professionals.

Patients should be asked to complete Hospital Anxiety and Depression Scale (HADS) and the Tinnitus Handicap Inventory (THI) questionnaires provide an opportunity for people to explain how tinnitus is affecting their lives, establish their medical history and include expectations of treatment.

The person should be referred to a senior audiologist who has a special interest in tinnitus. Potential support options include using hearing aids, sound therapy products, hearing therapy, cognitive behavioural therapy (CBT) or counselling which may help alleviate distress suffered by individuals.

The use of hearing aids for people who have hearing loss can help reduce the perception of the tinnitus sensation – possibly due to the person's brain not needing to work as hard to hear or the amplification of environmental sounds being sufficient to tune out to the tinnitus. Most cases of tinnitus are associated with a person's hearing loss.

Another option is peer-to-peer support offered by the British Tinnitus Association (BTA), Action on Hearing Loss and localised tinnitus groups. For example, in Northern Ireland, a specialist tinnitus service delivered by Action on Hearing Loss provided one-to-one support to 201 people, and 75% of attendees who responded to a survey feel that they can cope better living with the condition.

If a person with tinnitus reveals they have experienced suicidal thoughts, an urgent referral for psychological support should be made.

Our survey respondents were asked to give details of their experiences when they sought information or support to cope with their tinnitus – whether that was by contacting their General Practitioner, audiology service, Ear, Nose or Throat clinic, counsellors or NHS 24.

GP experiences

Most (64%) of 418 respondents visited their GP to seek information and support regarding their tinnitus in the first instance. Almost half (47%) of 314 respondents said their GP did not provide information about tinnitus and although more than half (56%) of 325 respondents were referred by their GP to audiology services, around one in five (21%) were not referred to any service.

Table 6: Information about tinnitus provided by GP

| | |
|-----------------------------|-----------|
| Yes | 43% (136) |
| No | 47% (149) |
| Don't know | 9% (29) |
| Total number of respondents | 314 |

Table 7: GP referrals to other services

| | |
|--------------------------------------|-----------|
| Audiology | 56% (181) |
| ENT (Ear, Nose and Throat) | 30% (99) |
| I did not get a referral | 21% (69) |
| A counsellor | 1% (3) |
| I wasn't referred to another service | 21% (69) |
| Other | 13% (41) |
| Total number of respondents | 325 |

More than one in three (37%) of 315 respondents were 'very satisfied' or 'satisfied' and around the same number (38%) were 'neither satisfied nor dissatisfied' with the information, treatments or support offered by their GP. One in four (25%) respondents, however, were 'dissatisfied' or 'very dissatisfied'.

Table 8: Satisfaction with information, treatments or support offered by GP

| | |
|------------------------------------|-----------|
| Very satisfied | 8% (24) |
| Satisfied | 29% (92) |
| Neither satisfied nor dissatisfied | 38% (121) |
| Dissatisfied | 15% (46) |
| Very dissatisfied | 10% (32) |
| Total number of respondents | 315 |

Audiology experiences

Audiologists can offer support and information on tinnitus as well as undertake hearing tests to determine if the individual has hearing loss. Audiologists may suggest hearing aids to support someone with tinnitus as well as deciding whether the patient needs follow-up appointments or referred to another health professional.

In this research project, survey respondents were asked if the audiologist requested that they complete a questionnaire about their tinnitus; whether information, treatment or support were offered and if a follow-up appointment was suggested. The respondents were also asked about their satisfaction with the audiology appointment and if they felt more empowered to cope with their tinnitus.

On arrival at audiology, only 15% of 261 respondents were given a questionnaire about their tinnitus. 63% said that they didn't get a questionnaire and 22% didn't know.

The vast majority (71%) of 364 respondents were offered hearing aids, three in 10 (30%) were told about sound therapy products and one in ten (10%) were directed to a website or local support group. Smaller proportions of respondents were told about stress management (5%) and counselling (5%) or Cognitive Behavioural Therapy (CBT) (3%).

Table 9: Information, treatments or support suggested by audiologist

| | |
|--------------------------------------|-----------|
| Hearing aids | 71% (185) |
| Sound therapy products | 30% (79) |
| Signposted to website or local group | 10% (27) |
| Counselling | 5% (12) |
| CBT | 3% (9) |
| Other | 20% (52) |
| Total number of respondents | 364 |

Fewer than one third (31%) of 263 respondents were offered a follow-up appointment by their audiologist, while the majority of respondents (63%) were not.

Table 10: Audiology follow-up appointment

| | |
|-----------------------------|-----------|
| Yes | 31% (82) |
| No | 63% (166) |
| Don't know | 6% (15) |
| Total number of respondents | 263 |

Three in five (61%) of 151 respondents were not given an explanation as to why their audiologist did not offer a follow-up appointment, whilst one in four (25%) were advised that no further appointments or referrals were necessary.

Table 11: Reasons for audiologist not offering a follow-up regarding tinnitus

| | |
|---|----------|
| I wasn't given an explanation | 61% (92) |
| I was advised no further audiology appointments or referrals were necessary | 25% (37) |
| I was referred to ENT | 13% (20) |
| I was advised to go to my GP for wax removal | 3% (5) |
| Signposted to website or local group | 1% (1) |
| Total number of respondents | 151 |

Following their visit to audiology, one in three (33%) of 257 respondents felt empowered to deal with their tinnitus, whilst almost half (47%) said they didn't feel empowered and 19% of people didn't know.

Table 12: Feelings of empowerment to manage tinnitus as a result of audiology visit

| | |
|-----------------------------|-----------|
| Yes | 33% (85) |
| No | 47% (122) |
| Don't know | 19% (50) |
| Total number of respondents | 257 |

One in three (33%) of 259 respondents were 'very satisfied' or 'satisfied' and around two in five (41%) were neither satisfied nor dissatisfied with the information, treatments or support offered by their audiologist. One in four (25%) respondents, however, were 'dissatisfied' or 'very dissatisfied'.

Table 13: Satisfaction with information, treatments or support offered by audiology

| | |
|------------------------------------|-----------|
| Very satisfied | 9% (24) |
| Satisfied | 24% (65) |
| Neither satisfied nor dissatisfied | 41% (105) |
| Dissatisfied | 13% (32) |
| Very dissatisfied | 13% (33) |
| Total number of respondents | 259 |

Ear, Nose and Throat (ENT) experiences

Patients are often referred to ENT to find out if there are any medical factors associated with their tinnitus, have their hearing assessed and receive information.

Table 14: ENT tinnitus questionnaire

| | |
|-----------------------------|----------|
| Yes | 13% (17) |
| No | 61% (81) |
| Don't know | 26% (35) |
| Total number of respondents | 133 |

Table 15: Information, treatments or support suggested by ENT to manage tinnitus

| | |
|--------------------------------------|----------|
| Hearing aids | 59% (65) |
| Other | 27% (30) |
| Sound therapy products | 17% (19) |
| Signposted to website or local group | 8% (9) |
| Stress Management | 5% (6) |
| CBT | 5% (5) |
| Total number of respondents | 111 |

Table 16: ENT follow-up appointment

| | |
|-----------------------------|----------|
| Yes | 18% (23) |
| No | 72% (92) |
| Don't know | 10% (13) |
| Total number of respondents | 128 |

Around two in five (39%) of 101 respondents were not given an explanation as to why ENT did not offer a follow-up appointment, almost one in three (32%) were referred to an audiologist and 15% were advised that no further ENT appointments or referrals were necessary.

Table 17: Reasons for ENT not offering a follow up regarding tinnitus

| | |
|--|----------|
| I wasn't given an explanation | 39% (39) |
| I was referred to audiology | 32% (32) |
| I was advised that no further ENT appointments or referrals were necessary | 15% (15) |
| I was advised to go to my GP surgery for wax removal | 2% (2) |
| Other | 18% (18) |
| Total number of respondents | 101 |

Fewer than one in four (23%) of 120 respondents felt empowered to deal with their tinnitus following their visit to ENT, whilst more than half (56%) said they didn't feel empowered and around one in five (21%) didn't know.

Table 18: Feelings of empowerment to manage tinnitus as a result of ENT visit

| | |
|-----------------------------|----------|
| Yes | 23% (28) |
| No | 56% (67) |
| Don't know | 21% (25) |
| Total number of respondents | 120 |

Just fewer than one in four (23%) of 123 respondents were 'very satisfied' or 'satisfied' and almost half (46%) were 'neither satisfied nor dissatisfied' with the information, treatments or support offered by their ENT. More than three in ten (31%) respondents, however, were 'dissatisfied' or 'very dissatisfied'.

Table 19: Satisfaction with information, treatments or support offered by ENT

| | |
|------------------------------------|----------|
| Very satisfied | 8% (10) |
| Satisfied | 15% (18) |
| Neither satisfied nor dissatisfied | 46% (57) |
| Dissatisfied | 20% (24) |
| Very dissatisfied | 11% (14) |
| Total number of respondents | 123 |

Counselling experiences

Counselling, including the sharing of coping techniques to deal with negative feelings due to tinnitus, may be offered to people if the condition is causing distress. A total of only 70 respondents shared their experiences of seeing a counsellor regarding their tinnitus. Only three (4%) respondents were given a questionnaire about their tinnitus. 58 (83%) said that they didn't get a questionnaire and nine (13%) didn't know.

Table 20: Information, treatments or support suggested by counsellor

| | |
|--------------------------------------|----------|
| Hearing aids | 69% (38) |
| Other treatment | 24% (13) |
| Sound therapy products | 15% (8) |
| Counselling | 9% (5) |
| Signposted to website or local group | 6% (3) |
| Stress management | 4% (2) |
| CBT | 2% (1) |
| Total number of respondents | 55 |

Table 21: Counsellor follow-up appointment

| | |
|-----------------------------|----------|
| Yes | 12% (5) |
| No | 73% (31) |
| Don't know | 15% (6) |
| Total number of respondents | 42 |

Around two in five (38%) of 34 respondents were not given an explanation as to why their counsellor did not offer a follow-up appointment, almost three in 10 (29%) were referred to an audiologist, 15% were referred to another service, 9% were referred to ENT, 3% signposted to a local tinnitus group and 12% were advised that no further counselling appointments or referrals were necessary.

Table 22: Reasons for counsellor not offering a follow up regarding tinnitus

| | |
|--|----------|
| I wasn't given an explanation | 38% (13) |
| I was referred to audiology | 29% (10) |
| Referred to another service | 15% (5) |
| I was advised that no other counselling appointments or referrals were necessary | 12% (4) |
| I was referred to ENT | 9% (3) |
| I was referred to a local tinnitus group | 3% (1) |
| I was advised to go to the GP for wax removal | 3% (1) |
| Total number of respondents | 34 |

Fewer than one in four (24%) of 33 respondents felt empowered to deal with their tinnitus after speaking with a counsellor, whilst almost half (44%) said they didn't feel empowered and around three in 10 (32%) didn't know.

Table 23: Feelings of empowerment to manage tinnitus as a result of counsellor visit

| | |
|-----------------------------|----------|
| Yes | 24% (8) |
| No | 44% (14) |
| Don't know | 32% (11) |
| Total number of respondents | 33 |

Just more than one in four (27%) of 37 respondents were 'very satisfied' or 'satisfied' and two in five (43%) were 'neither satisfied nor dissatisfied' with the information, treatments or support offered by their counsellor. Almost three in 10 (29%) respondents, however, were 'dissatisfied' or 'very dissatisfied'.

Table 24: Satisfaction with information, treatments or support offered by counsellor

| | |
|------------------------------------|----------|
| Very satisfied | 8% (3) |
| Satisfied | 19% (7) |
| Neither satisfied nor dissatisfied | 43% (16) |
| Dissatisfied | 24% (9) |
| Very dissatisfied | 5% (2) |
| Total number of respondents | 37 |

Other information and support

NHS 24

Table 25: NHS 24 provision of information about tinnitus

| | |
|-----------------------------|----------|
| Yes | 20% (25) |
| No | 70% (90) |
| Don't know | 10% (13) |
| Total number of respondents | 128 |

One in four (25%) of 89 respondents were 'very satisfied' or 'satisfied' and almost two in five (39%) were 'neither satisfied nor dissatisfied' with the information, treatments or support offered by NHS 24. More than one in three (36%) respondents, however, were 'dissatisfied' or 'very dissatisfied'.

Table 26: Satisfaction with information, treatments or support offered by NHS 24

| | |
|------------------------------------|----------|
| Very satisfied | 9% (8) |
| Satisfied | 16% (14) |
| Neither satisfied nor dissatisfied | 39% (35) |
| Dissatisfied | 20% (18) |
| Very dissatisfied | 16% (14) |
| Total number of respondents | 89 |

Local support groups

Only 11 (3%) of 379 respondents were aware of local tinnitus support groups.

Table 27: Awareness of tinnitus support groups in local area

| | |
|-----------------------------|-----------|
| Yes | 3% (11) |
| No | 97% (368) |
| Total number of respondents | 379 |

Improving access to information and support

Themes emerged from our research project which shows that individuals with tinnitus in Scotland have good access to some types of information and support, but not all.

Up to 37% of participants were satisfied or very satisfied with the information, treatment or support they received from their GP, audiology service, ENT clinic or counsellor. One in four participants, however, expressed dissatisfaction and approximately half did not feel empowered to manage their tinnitus after their appointments.

Only 15% and 13% of respondents said their audiologist and ENT clinic provided Hospital Anxiety and Depression Scale (HADS) or the Tinnitus Handicap Inventory (THI) questionnaire, but the most concerning finding is the lack of information about tinnitus provided by GPs and NHS 24.

Almost half of 314 respondents were not provided with information by their GP and one in ten were unsure if they received any, whilst only one in five of 128 respondents were provided with details of the condition by NHS 24.

Research participants were often told by their GP that 'nothing could be done' or simply 'there was not cure' for their tinnitus. It is important that GPs and health professionals frame conversations regarding tinnitus on what can be done rather than what cannot, otherwise there is a risk of increasing distress which in itself can exacerbate the condition.

Although using hearing aids and/or sound therapy products are not solutions for everyone who experiences tinnitus, the fact that 71% of respondents were fitted with hearing aids and 30% were provided with sound therapy equipment is a positive finding.

It is not surprising that only 11 research participants are aware of a tinnitus support group in their local area as there are only two running in the whole of Scotland – one in Edinburgh and another in Glasgow.

We recommend that:

- GPs should be provided with tinnitus awareness training to be better informed about the range of support available for people who with tinnitus. Action on Hearing Loss Northern Ireland partnered with the British Tinnitus Association (BTA) to create an e-learning module and we want to see a similar resource provided for GPs in Scotland.
- GPs should refer people with persistent tinnitus who may also be experiencing anxiety, depression or sleep disturbance to have audiology and Ear, Nose and Throat appointments within a similar timescale, in order to cut down the wait for individuals initially going to ENT before then being referred to an audiologist.
- People who are particularly distressed by their tinnitus should be fast-tracked through the audiology service process so that individuals who can benefit from using hearing aids gain quicker access.
- Every patient who has tinnitus should be asked by their GP, audiologist or ENT to complete Hospital Anxiety and Depression Scale (HADS) and the Tinnitus Handicap Inventory (THI) questionnaires, as proposed in the Scottish Tinnitus Advisory Group (STAG) protocols.
- Health professionals who engage with potentially distressed tinnitus patients should be required to complete continuing professional development counselling or psychotherapy training, and their department/service should have dedicated support from a fully qualified counsellor.
- Patients who request counselling or show signs that their mental health has been substantially affected by tinnitus – e.g. a risk of suicide or significant neurological symptoms – should be immediately referred for psychological support from a trained counsellor/mental health professional.
- More tinnitus support groups should be established in communities throughout Scotland to provide easily accessible peer-to-peer support, similar to the service run by Action on Hearing Loss in Northern Ireland.
- A finalised gold standard should be published which details the full range of information and support options available for people in Scotland who have tinnitus and how individuals can progress through pathways to access person-centred potential solutions.

Action on Hearing Loss Scotland is a charity that supports people who are Deaf or have hearing loss or tinnitus to live the life they choose. We campaign for equality, develop technology and treatments, and provide information and services to meet individual needs.

To find out more, visit www.actiononhearingloss.org.uk/Scotland

Telephone: 0141 341 5330

Textphone: 0141 341 5350

Email: campaigns.scotland@hearingloss.org.uk

Facetime or SMS message: 0738 8227 407

 **Action on Hearing Loss Scotland**

 **@hearinglossSCO**

Action on Hearing Loss Tinnitus Helpline

Telephone: 0808 808 6666

Textphone: 0808 808 9000

SMS: 0780 0000 360

Email: tinnitushelpline@hearingloss.org.uk

British Tinnitus Association (BTA) Helpline

Telephone: 0800 018 0527

SMS: 07537 416841

Email: helpline@tinnitus.org.uk

www.tinnitus.org.uk



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