



TINNITUS

A U S T R A L I A

ROADMAP

Draft for Consultation

Tinnitus Australia and Soundfair – working for change

Soundfair Australia is a not-for-profit, independent organisation working to eliminate the social and emotional impacts of hearing conditions. We centre people with lived experience. We work to create change and aspire to drive innovation in services. We also promote society-wide awareness and empathy for people that live with hearing conditions.

Tinnitus Australia (TA) is an initiative of Soundfair. It is a collaboration of people working professionally, passionately, and ethically to eliminate the suffering experienced by people with tinnitus and the burden this places on their friends and families.

Launched in 2015, TA was created by a previous dedicated board member of Soundfair Australia, formerly known as Better Hearing Australia (Vic). Since then, TA has been led by a volunteer group and funded through fundraising and Soundfair reserves.

TA members contribute by:

- Participating in small project teams to progress the Roadmap
- Telling their story, since we know the power of the lived experience of tinnitus
- Supporting people with tinnitus, as we develop our support groups and helpline over time
- Raising awareness, in their local communities, professional domains and through advocacy to opinion and policy makers
- Joining our research or advisory committee

Seven years ago I went to my GP for advice and treatment for the persistent ringing and buzzing in my ears. I was stunned to learn that there was, and still is, no cure for tinnitus. The only available treatment was counselling, sound enrichment, psychological support and the use of hearing aids. I truly felt like my tinnitus condition was dismissed and treated as insignificant.

It took eight long months of desperate searching to find relief and effective outcomes for my Tinnitus trauma. I finally found that support with multi-disciplinary coping strategies and counselling through Soundfair. My counsellor helped me to understand that, while there is not a cure for tinnitus, there are many ways to manage it.

Since then, I've discovered the great work going on globally to improve the lives of people with tinnitus and the growing urgency for a cure. We get closer every day.

I welcome you to Tinnitus Australia.

I am proud to be affiliated with a unique alliance of people and associations working hard to empower tinnitus sufferers, health practitioners and researchers so that we can transform the lives of millions of people who are impacted by troubling tinnitus and return them to a place of better health and wellbeing.

I encourage you to consider our draft Roadmap. Let us know what you think and join us on the journey. Everyone deserves to experience peace and wellbeing. Help us help remedy the ringing and silence tinnitus-once and for all!

Victoria Didenko – Tinnitus Australia Advisory Committee Chair

The Tinnitus Australia Roadmap

The Tinnitus Roadmap outlines key actions to create better support, better care and better information for the many people in Australia who suffer from tinnitus. This draft version of the Roadmap is open for your input until April 2, 2021 – options for feedback are provided at the end of the document and questions for your consideration are included throughout.

Guided by the Roadmap, TA will engage with partners in the community and health sector to create a diverse and dynamic network for professionals to:

- Share information
- Develop and deliver education and training about tinnitus
- Promote high-quality research
- Develop new ways of supporting people with tinnitus
- Advocate for effective resourcing and national approach for tinnitus prevention and treatment

What is tinnitus?

Tinnitus is a hearing condition where people hear noises, hisses or hums that have no external source and is often called 'ringing in the ears'. It can be constant or occasional, loud or soft, mild or severe and can be heard in one or both ears or "in the head". People develop tinnitus because there is damage in their auditory system. It may start because of damage to the inner ear, but it is actually generated by the brain.

A damaged inner ear deprived of sound can send messages to the brain when there is not sound present in the real world. These messages are saved in the emotional centre of the brain and can lead to stress and anxiety.

Tinnitus is not a disease, but a symptom of other hearing conditions. There are many causes, but exposure to loud noise - industrial or music – is the most common one.

Tinnitus often manifests as a symptom of other underlying conditions, such as hearing loss, ear injury or circulatory system disorders and some cases the impact of tinnitus on the lives of people can be greater than the impact of the underlying condition that causes it.

For the first couple of months I was a wreck, a complete wreck.

I couldn't fathom how I was going to live this way and retain any sanity. How was I going to be a father or a husband when I can't stop crying and obsessing about this sound in my ear?

I would constantly monitor it by sticking my finger in my ear to see how loud it was...was it still there etc....I was in a constant state of high alert. I could barely hold it together at work, and often times had to excuse myself to go to the restroom and just let the fear envelop me, and just pray that this would somehow go away...

Andrew – 35-year-old tinnitus sufferer

The current situation

Tinnitus is not well understood and there is little agreement about prevalence, impact and burden of disease for tinnitus.

Estimates of prevalence vary greatly around the world, but the Australian government accepts that about one in three people in Australia have experienced tinnitus at some point in their life and about one in six struggles with constant tinnitus.ⁱ Between 70 and 85 per cent of people with hearing loss suffer from tinnitusⁱⁱ, and it is not only older people who are affected. A study by Hearing Australia (formally known as Australian Hearing), a federal government agency, showed that up to 70% of people aged 18–35 years have experienced tinnitus and 16% experience it more than once a weekⁱⁱⁱ.

The direct and indirect costs of tinnitus to Australian society are difficult to quantify. However, as an indicative figure, a study from the Netherlands estimated an annual productivity cost of €3702 per person with tinnitus and mean societal cost of illness of €6.8 billion in 2009. By way of comparison, a top-down study of low-back pain in the Netherlands reported total societal costs of €3.5 billion in 2007. The authors concluded: the economic burden of tinnitus to society is substantial and the severity of tinnitus is an important predictor of the costs that patients make to the healthcare system

Studies have established links between depression and anxiety for people with tinnitus to the extent that 45 per cent of tinnitus sufferers experience anxiety and 33 per report major depression^{iv}.

For these people, the impact of tinnitus on a person's life can be devastating, increasing risk of depression, anxiety and even suicidal ideation.

At this stage, as there is no objective test for tinnitus, many health professionals find it difficult to recognise, refer, or support people with tinnitus. An all-too-common experience is to be told 'it's just in your head, there's no treatment, you must learn how to cope.'

Currently, the market is flooded with untested, and at times even fraudulent, 'cures' and solutions. People with tinnitus are confronted by a deluge of disinformation and often don't know where to turn to for reliable, trusted support.

While the Australian government's *Roadmap to Hearing Health* recognises tinnitus as a hearing-related condition, it proposes no specific action to alleviate or address tinnitus in the community. Of the 144 recommended actions in the Roadmap, only one includes specific mention of tinnitus.

This means that one of the most prevalent health conditions in Australia has no government-sponsored research base and no public funding for support and treatment. We don't think that sounds fair.

How Tinnitus Australia will help

The primary role of TA is to provide improved responses for tinnitus sufferers and much greater recognition of the impacts of tinnitus among health professionals and policy makers. We do this by facilitating a lively and active forum for discussion and debate that progresses a shared understanding of tinnitus, and by identifying and undertaking projects that align with our three goals:

- **Inform:** To be a source of quality, evidence-based and accessible information on tinnitus for those living with it, and professionals working with it.
- **Empower:** To advocate for individuals living with tinnitus for improved healthcare services, as well as to help provide the tools needed for professionals to provide that care.
- **Transform:** To fund the research needed to transform the lives of individuals with tinnitus through improved knowledge and understanding in the area.

Over the next three years we will work to achieve these three goals in many ways. The 'Roadmap on a page' sets out a range of possible projects until 2024 and beyond and these are described in more detail under four themes below. We've included some questions around each of these themes for you to consider.

Awareness and understanding

Even though tinnitus affects most of us at some point in our lives, too few people know about tinnitus or appreciate the impact it can have. Tinnitus Australia will work hard to raise awareness and increase understanding of tinnitus in the community, among health professionals and in government. We will focus in our first year on developing partnerships with government, business and philanthropy to raise awareness and secure the funding we will need for our work.

Among other things we will:

- Engage with a high-profile Tinnitus Ambassador
- Create high quality and engaging information resources
- Support community awareness-raising events and activities
- Promote tinnitus resources to health professionals
- Advocate for recognition of tinnitus as a health priority and for inclusion in health policy

We'd love to hear what you think:

- What key messages would you like to see included in a tinnitus awareness campaign?
- Would your community or organisation benefit from a tinnitus awareness event or activity? How can we help you do this?
- How can we best connect with you to raise awareness, do mutually beneficial work, and build our tribe?
- How do we build a partnership with you to ensure that tinnitus support, advocacy and research is properly funded and resourced?

Support when it's needed most.

Tinnitus Australia will develop better ways to support people who have tinnitus. We will enable people to seek the help that they need and manage the physical and mental health impacts of their tinnitus better on a day to day to basis. We will provide a bank of independent quality information for people who have tinnitus and the professionals who work with them. We will work to combat the flood of disinformation about tinnitus. The Tinnitus Australia website will become the 'go to' place for tinnitus information and news.

We know that the tinnitus journey can be lonely and isolating, so we will develop a network of peer-to-peer support groups for people with tinnitus. Support groups assure people that they are not alone and provide a vehicle for the sharing of information and coping strategies.

Over time, we will work to develop a professionally supported tinnitus helpline and online chat function that is accessible at any time of the day, so that people can get the support they need when they need it.

We'd love to hear what you think:

- What kind of information would you like to see on www.tinnitus.org.au?
- Would you or those you work with benefit from a tinnitus support group? What would this look like for you?
- How can we help you form a local, online or workplace group? What kind of information, training and support do you need to form a support group?

Professional education and training

We will establish and run a series of webinars and workshops that explore and share different aspects of tinnitus treatment and research. We will commence this year with a short series to gauge interest and build our capability and explore different ways to engage with health professionals to provide the information they need.

Our aim is to develop a database of highly skilled and well-resourced professionals across a range of health disciplines who can provide the best possible support for people who have tinnitus. We will prioritise the development of a web-based list of trusted professionals who we know can people manage their tinnitus.

We'd love to hear what you, as a health professional, think:

- What training and information do you need to better support people with tinnitus?
- Would you attend an online webinar about tinnitus? What does a great learning experience look like for you?
- Can you contribute to a webinar series about tinnitus? How can we help you contribute?
- Are you a health professional with tinnitus expertise? How can we connect you to those who need you and promote your work?

Finding the answers

We will foster, promote and connect high-quality research and provide a lively and creative forum for sharing research ideas and outcomes. We will facilitate research partnerships within Australia and across the world, working productively with likeminded organisations, particularly in the UK and the USA. We will advocate for a viable level of funding for tinnitus research and promote tinnitus as a research priority.

We'd love to hear what you think:

- Are you engaged in research, or do you know of research, that Tinnitus Australia should be aware of?
- As a researcher, how can TA better support your work?
- Would you join a Tinnitus Research Forum or Network sponsored by Tinnitus Australia? What would this look like for you?
- Is your organisation or foundation in a position to help fund and resource high quality and impactful tinnitus research? How can we form a partnership with you to make this happen?

Tinnitus Australia Roadmap on a page

Goals/timing	Year 1	Years 2–3	Year 3 and onwards
INFORM	<ul style="list-style-type: none"> • Create an outstanding website that is a trusted source of quality, evidence-based information and resources for the public and professionals • Develop soft and hard copy information packs for the public and professionals • Establish and run a series of professional webinars and workshops exploring and sharing different aspects of tinnitus research and treatment. 	<ul style="list-style-type: none"> • Develop a Tinnitus Manifesto for Australia, using the UK model. • Deliver an annual awareness and fundraising campaign supported by our Tinnitus Ambassador • Explore the potential to market verified technological aids for people with tinnitus 	<ul style="list-style-type: none"> • Add an additional Tinnitus Ambassador(s) • Continue to deliver annual awareness and education campaigns • Partner with advocacy groups in high need groups – (e.g. Defence, Music Industry, Agriculture) to raise awareness.
EMPOWER	<ul style="list-style-type: none"> • Build the membership base (consumers, supporters and professionals) passionate about the cause, working together • Create a professional network to share resources, support good practice and establish clear referral systems • Develop a pathway for professionals to become credentialled as Tinnitus Specialists (e.g. Tinnitus Masterclass) 	<ul style="list-style-type: none"> • Grow the professional network to include credentialled Tinnitus Specialists • Develop support groups – online and in person • Explore the potential to establish a tinnitus help line to provide 1:1 phone or computer-based 24-hour support for people with tinnitus 	<ul style="list-style-type: none"> • Advocate for a nationally agreed set of practice standards for audiologists who are working with people with tinnitus. • Hold a national tinnitus conference or symposium, together with a convention for people with tinnitus
TRANSFORM	<ul style="list-style-type: none"> • Develop a research participation pathway that connects people experiencing tinnitus with current, quality research. • Establish a tinnitus research database • Develop an expert panel of researchers 	<ul style="list-style-type: none"> • Determine and publicise tinnitus research priorities • Advocate for properly funded research • Have a group of committed and regular donors to the research fund and other TA programs 	<ul style="list-style-type: none"> • Establish Australia’s first Tinnitus specific research fund. • Provide grants to individuals and organisations (eg: PhD scholarships, Professorial chair) • Build on the Tinnitus Manifesto by advocating for meaningful changes to government policy

Your feedback and next steps

The Roadmap is open for consultation until **2 April 2021**.

We want to hear your ideas about how we can take the work of Tinnitus Australia forward and create a movement for change across Australia. We welcome your thoughts on the questions for discussion included in this document, as well as any other views you might have about:

- The main goals of TA over the next three years
- Achievable, but aspirational, actions and projects we should undertake to reach these goals
- Likeminded organisations and individuals with whom we can work with to deliver our objectives.

You can provide feedback:

- via email to john@soundfair.org.au; or
- by contacting Soundfair on +613 9510 1577 to arrange a meeting with your organisation, or to discuss the roadmap in more detail; or
- by completing a short online survey by selecting this link <https://www.surveymonkey.com/r/TinnitusAustralia>

ⁱ <https://www.healthdirect.gov.au/tinnitus#>. Viewed 20/8/20

ⁱⁱ [Characterization of Tinnitus in Different Age Groups: A Retrospective Review](#), Jamil Al-Swiahb, Shi Nae Park, Noise Health. 2016 Jul-Aug; 18(83): 214–219. Viewed Oct 6, 2020

ⁱⁱⁱ Sindhusake D, Mitchell P, Newall P, Golding M, Rochtchina E, Rubin G. Prevalence and characteristics of tinnitus in older adults: The Blue Mountains Hearing Study. International Journal of Audiology. 2003;42(5):289-94. Viewed Sept 22, 2020

^{iv} Ziai K, Moshtaghi O, Mahboubi H, Djalilian HR. Tinnitus Patients Suffering from Anxiety and Depression: A Review. Int Tinnitus J. 2017; 21(1): 68-73 Viewed Oct 12, 2020