

# 9

## Level 5 Individualized Support



Individualized support is needed by relatively few patients. Level 5 Individualized Support involves use of the same principles of using sound and coping techniques to manage tinnitus that are presented in Level 3 Group Education. However, at Level 5 some patients use ear-level noise/sound generators or combination instruments, and the education and support is provided in a one-on-one format with more intense and individualized assistance. Also, Level 5 counseling is less structured and allows for flexibility in what is covered during the sessions. The individual counseling should reinforce the Level 3 principles, but the clinician has latitude to modify or expand on the counseling information as needed. Level 5 intervention normally requires up to six months of repeated appointments with an audiologist and/or a mental health provider.

### Level 5 Standard Protocol for Audiologists

#### Level 5 Appointments

At each Level 5 appointment with an audiologist: (a) the functioning and proper use of ear-level instruments is verified (if applicable); and (b) one-on-one PTM counseling is conducted—focusing on updating the Sound Plan Worksheet (see Appendix N) to ensure that the patient is optimizing the use of therapeutic sound to address tinnitus-problem situations. If the clinician feels that it is necessary, the patient's progress is evaluated, and current needs are assessed using any of the questionnaires that were administered at the Level 4 evaluation, including the Tinnitus Handicap Inventory (see Appendix F),

Tinnitus and Hearing Survey (see Appendix D), Hearing Handicap Inventory (see Appendix G), and the Tinnitus Interview (see Appendix R). If the Tinnitus Interview is used, then it is best to select individual questions that are relevant to the patient's complaints rather than administering the entire interview. Audiometric testing is repeated only if the patient reports a significant auditory change.

### **Schedule of Appointments**

Following the initial Level 5 appointment, return counseling appointments normally are scheduled at 1, 2, 4, and 6 months.

### **Why Are Return Appointments Important?**

Return appointments are an essential, but often neglected, aspect of ongoing management for patients who have a severe problem with tinnitus. It is unreasonable to expect these patients to accomplish all management objectives without the guidance and support of a tinnitus specialist. Consequently, they require repeated appointments on a prescribed schedule until their problem is sufficiently resolved and/or they are capable of performing self-management effectively.

From a health education perspective, patients need to return for repeated counseling because they recall only about half of the information, and some of the health information is remembered incorrectly (Margolis, 2004; Shapiro, Boggs, Melamed, & Graham-Pole, 1992). It also has been reported that patients immediately forget as much as 80% of the information (Kessels, 2003).

Repeated appointments are required for all Level 5 patients to ensure that they are using their ear-level devices properly and that they remember the key points of counseling (J. A. Henry, Trune et al., 2007a; P. J. Jastreboff & Hazell, 2004). Return visits also are necessary to ensure that patients are (a) implementing their individualized sound plans developed at previous visits, and modifying the plans to optimize their efficacy; and (b) using the specific coping skills that are taught by the mental health provider. Compliance with a schedule of periodic appointments optimizes the potential to achieve successful results.

### **Adherence to the Appointment Schedule**

Adherence to the recommended schedule requires motivation and commitment on the part of the patient. Normally, only patients with the most problematic tinnitus are so inclined. Patients who live at a distance may not be able to return to the clinic as often as advised. These patients should at least be counseled via telephone, using the self-help workbook *How to Manage Your Tinnitus: A Step-by-Step Workbook* (J. A. Henry et al., 2010a) as a general guide to implementing self-help strategies.

### **Six-Month Appointment**

The appointment at six months is the final appointment for most patients receiving Level 5 services. If this is the final appointment, then the same procedures are conducted as for the standard protocol that is recommended for all of the Level 5 appointments (see Level 5 Appointments above). In addition, the Tinnitus Handicap Inventory (see Appendix F) and the Tinnitus and Hearing Survey (see Appendix D) should be administered and results compared to previous responses to evaluate the patient's progress through all levels of PTM. If problems were reported on the Tinnitus Interview (see Appendix R), then it would be important to repeat any pertinent questions from the interview.

### **Exceptions to the Level 5 Standard Protocol for Audiologists**

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#### **Final Appointment**

The patient's final Level 5 appointment may be earlier or later than six-months. Regardless of when the final appointment takes place, the procedures described above for the six-month appointment should be performed during the final appointment.

#### **Making the Decision to End Intervention Before or After Six Months**

The decision to end intervention should be made jointly between the clinician and patient. Ideally,

this decision would be corroborated by the patient's responses to outcome questions on the Tinnitus Handicap Inventory (THI) (see Appendix F) and Tinnitus and Hearing Survey (see Appendix D) (although such corroboration is not essential). As a reference, it has been reported that a 20-point reduction in the THI index score reflects "clinically significant improvement" (C. W. Newman & Sandridge, 2004). When intervention is complete, patients should be advised to telephone the clinician whenever questions or issues arise, and to request special appointments if needed.

### **Extending Intervention Beyond Six Months**

If the patient requires intervention beyond six months, then the progress made to this point should be reviewed with the patient along with discussion of the potential benefit of further intervention. Multiple issues can be discussed as potentially contributing to a lack of sufficient progress:

- The patient's tinnitus problem was so severe that more time and support are needed for the patient to be able to adequately self-manage reactions to tinnitus.
- Effective sound plans (using the Sound Plan Worksheet—Appendix N) have not yet been identified.
- The patient (for any reason) has not implemented the sound plan(s) from the Sound Plan Worksheet.
- A psychological component has not been properly managed through help from a mental health professional.

Every possible contributing factor should be explored, and referrals to other services may be indicated more strongly at this point. If, after thorough review with the patient, there is agreement that further intervention may be helpful, then Level 5 appointments can be extended beyond six months. It is critical for these patients to know that further services are accessible and available if needed.

### **Telephone Counseling**

Patients may not be able to attend the recommended series of return appointments because they live at a distance or for other reasons. These patients can be counseled adequately over the telephone if they have the self-help workbook (J. A. Henry et al., 2010a) to refer to during the counseling.

### **Self-Help Workbook**

At the initial Level 5 appointment, patients should be asked if they have a copy of the workbook (*How to Manage Your Tinnitus: A Step-by-Step Guide*, J. A. Henry et al., 2010a), which normally is dispensed at the beginning of Level 3 Group Education. If not, then a new copy should be provided. The workbook should be reviewed with the patient and portions of the workbook that are most applicable should be discussed. Patients should be aware that the key PTM counseling principles are described in the workbook, along with step-by-step instructions for developing plans to manage their tinnitus problem using both therapeutic sound and coping techniques. They should be encouraged to read the workbook and adhere to its recommendations.

### **PTM Level 5 Counseling**

The education provided by audiologists to patients at all levels of PTM is designed primarily to help patients develop, and experience success using, self-management strategies that address the situations when their tinnitus is most problematic (using the Sound Plan Worksheet—Appendix N). The main difference at Level 5 is the one-on-one setting that facilitates direct interaction between patient and clinician. Some patients do better by receiving ongoing individualized attention from a caring and knowledgeable clinician. Some patients also need the opportunity to resolve any questions or concerns about their tinnitus in a private setting where they can express feelings and concerns that

they might not have been comfortable discussing in a group setting.

A patient counseling guide (*Progressive Tinnitus Management: Counseling Guide*, J. A. Henry et al., 2010b) is used during the Level 5 appointments. The counseling guide is used like a flip chart, but laid flat on a table between clinician and patient. When the book is open, one side faces the clinician and the other side faces the patient. The clinician's pages contain bulleted counseling points, and the patient's pages show simplified bulleted points and illustrative graphics. The counseling guide was designed to be used primarily by audiologists. A similar guide is in development that will be intended primarily for use by mental health providers.

The Level 5 patient counseling guide includes three sections: an introductory section, follow-up section, and supplemental sound tolerance (hyperacusis) section. The first two sections correspond with the Level 3 PowerPoint presentations (*Managing Your Tinnitus: What to Do and How to Do It*) that are included on the CD in the back of this handbook. Using the counseling guide, most patients at Level 5 will start with the follow-up section (because the material covered in the introductory section was already covered during Level 3 Group Education). The introductory section normally is used only with patients who have not completed Level 3. The introductory section, however, serves as a resource for fundamental PTM counseling information that can be accessed as needed during counseling sessions.

### **Demonstrating Personal Listening Devices and Stationary Devices**

Appropriate use of augmentative sound can be very effective for helping to manage reactions to tinnitus. Unless the various personal listening devices and stationary devices are demonstrated in the clinic, however, patients may not appreciate their full value. There is no formal protocol for demonstrating these devices—they simply should be available in the clinic and demonstrated as appropriate during the Level 5 appointments.

### **Level 5 CBT**

The Level 4 Interdisciplinary Evaluation informs the intervention provided by a mental health provider at Level 5. The mental health services at Level 5 involve a review of the CBT coping techniques taught during Level 3 Group Education (and included in the self-help workbook that is provided to patients at Level 3) and an individualized examination of patients' unique achievements and challenges so far during PTM. Further integrating coping skills by attending to challenges patients face when implementing the skills allows themes to emerge. Patients learn more about setting and achieving goals with behavioral modification by tracking their progress using clearly defined measures of change. For example, if a patient is having difficulty managing stress, charting stress on a scale from 0 to 10 is an effective way to quantify the patient's response to stress and observe change as a result of modification in behavior. During Level 5, patients learn how to accept their individual strengths and weaknesses while gaining a sense of control in the event that change is realistic and obtainable.

In order to provide CBT, clinicians must be trained by another professional experienced in this modality of psychotherapy. Mental health clinicians may or may not have received this training, thus the involvement of mental health at this level will depend on the availability of CBT-trained mental health providers. A mental health provider who is experienced in providing CBT is skilled in explaining the process of CBT to patients, possesses skill in conceptualizing underlying themes that arise for individuals, and assists patients in developing their skills to problem solve. Such clinicians refer to themselves as "psychotherapists," which is a title regulated by state licensing boards based on qualifications and training. A psychotherapist has received years of training and supervision on establishing a good working relationship with patients (also known as rapport). Psychotherapists adhere to a code of ethics and guide patients through the therapeutic intervention. Psychotherapists who specifically provide CBT understand the importance of behavioral and cognitive theories

of the intervention. They assist the patients in learning ways to evaluate and change their thoughts and behaviors.

During Level 5 CBT, psychotherapists help patients understand their tinnitus as it relates to the entire mind-body system. Often, tinnitus is accompanied by symptoms of depression such as increased or decreased appetite, problems falling or staying asleep, and decreased pleasure when doing activities that once were pleasurable, among other symptoms. By simultaneously addressing a patient's reactions to tinnitus and depressive symptoms, the patient recognizes the importance of addressing both the mind's reactions to physical symptoms, and the physical symptoms that might influence emotions.

Occasionally, patients place more emphasis on the problem of tinnitus than on other more difficult emotional problems, such as unresolved trauma. Perhaps because tinnitus adds to frustration that already exists for some patients who struggle when negative emotions arise or because tinnitus is something that can be described physically, learning ways to cope with tinnitus may be how patients prefer to begin looking at the way they cope with stress, emotions, and problems in general. Nonetheless, several patients during one of our studies (see Chapter 2, Fifth Study) who began using CBT to cope with tinnitus realized that their tinnitus was just one problem among many in their lives. CBT for tinnitus for these particular patients offers an introduction to positive thoughts, behaviors, and attitudes in what might be perceived as a less formidable environment than what would be required to address the "other problems." Such patients are then primed to use these coping skills in other areas of their lives. Level 5 CBT gives patients the opportunity to start using the skills of CBT on a concrete, diagnosable, physical problem (tinnitus) from which they can apply the skills to more global emotional problems and behaviors.

#### Case Study: Sam

Sam has received ongoing Level 5 Individualized Support from an audiologist and psychologist for three months. He reports that his

combination instruments have been helpful, but lately has been finding that he has to turn up the noise generator higher and higher to completely "mask out" the tinnitus. He also reports that once he has set the noise generator to a high level, sometimes the tinnitus returns after several minutes. He also feels like he is carrying around his own portable noisy environment and believes he cannot hear as well when the noise is on.

Sam needs to be reminded that the goal of using sound is never to mask the tinnitus. The three types of sound (soothing, interesting, and background) should be reviewed. It should be clarified that the sound generator portion of the combination instrument can be used as soothing sound or background sound, neither of which requires masking. It may also be helpful to point out that the hearing aid portion of the device can make it easier for him to understand interesting sounds—like speech. It also can be explained that when hearing is the predominant need, he can turn the noise to either a very soft level or turn it off completely.

The audiologist should summarize the contents of the meeting with Sam and make it available to the psychologist providing Level 5 support to ensure that the psychologist is aware of Sam's difficulties with using sound.

### Beyond Level 5 Individualized Support

If a patient does not make satisfactory progress after about six months of Level 5 Individualized Support, then a different approach can be considered. Options for extended intervention at Level 5 include further PTM audiologic counseling (modified as necessary), further CBT counseling (including the addition of different components of CBT that may not have been covered to this point), tinnitus masking, tinnitus retraining therapy, and neuromonics tinnitus treatment. There is no definitive evidence that any one of these behavioral methods is more effective than any other.

## Cognitive-Behavioral Therapy

The objectives of CBT are to identify negative behaviors, beliefs, and reactions in patients and to assist them in substituting appropriate and positive reactions (see Chapter 7). CBT initially was used as an effective treatment for depression and anxiety. A standard CBT protocol as adapted for tinnitus involves up to ten sessions. These sessions can be conducted with individual patients or with groups of patients.

CBT normally is performed by mental health providers. It can, however, be administered by other health care providers who have received the proper training. Training to conduct CBT for tinnitus is not offered on any routine basis for non-mental health clinicians, but must be obtained from a professional who has this expertise. Books are available that describe CBT clinical procedures in detail (J. L. Henry & P. H. Wilson, 1998, 2002).

## Tinnitus Masking

The method of tinnitus masking (TM) became available as a clinical technique in the late 1970s (Vernon, 1977). It was popular through the 1980s and continues to be used (Schechter & J. A. Henry, 2002). The main objective of TM is to use broadband noise to provide a sense of relief from tension or stress caused by tinnitus. Because of the label “masking,” however, the main objective has commonly been misunderstood to be to cover up or “mask” the tinnitus (J. A. Henry, Schechter, et al., 2002). Maximizing a sense of relief is accomplished with complete masking for some people, partial masking for others, and sometimes even with no masking effect (J. A. Henry, Rheinsburg, & Zaugg, 2004).

TM patients normally are fitted with ear-level instruments (“maskers”) that present wide-band noise to the ears. Patients are instructed to adjust the noise to the level that provides the greatest sense of relief. With respect to the PTM combinations of sound (see Figure 7-1), TM is an example of *using environmental sound as soothing sound*. Patients also are advised to use various sound-producing devices to achieve relief, including CDs, tabletop fountains, sound machines, sound pillows, and so

forth. Counseling is used with TM, but the use of therapeutic sound to induce a sense of relief is the primary mode of intervention. There is no training program available for TM. Clinicians must learn TM on their own or be trained by an individual who has expertise in this method.

## Tinnitus Retraining Therapy

The method of tinnitus retraining therapy (TRT) has two basic components: educational (“directive”) counseling and “sound therapy” (J. A. Henry, Trune, et al., 2007a, 2007b; P. J. Jastreboff & Hazell, 2004). Unlike TM, the use of therapeutic sound with TRT is not meant to give a sense of relief (J. A. Henry, Schechter, et al., 2002). With TRT the patient should hear the tinnitus clearly, but with constant sound in the background. The background sound reduces the contrast between the tinnitus and the quiet environment, thus making the tinnitus less likely to attract attention (passive attention diversion). Patients are supposed to use sound in this way every day to eventually achieve habituation, that is, reduction or elimination of tinnitus reactions and perception.

Evaluation of patients for TRT results in their placement into one of five categories: 0, 1, 2, 3, and 4. Patients in all categories are counseled to “enrich their sound environment” at all times with soft, pleasant, or neutral background sound. Category 0 patients have tinnitus that is not severe enough to warrant the use of ear-level devices, thus they receive TRT counseling only. Category 1 patients are severely bothered by their tinnitus, and ear-level instruments (sound generators, combination instruments, or hearing aids) are advised for use each day for at least one year. With respect to the PTM combinations of sound (see Figure 7-1), the use of broadband noise with TRT is an example of *using environmental sound as background sound*.

Category 2 patients also have a severe tinnitus problem, but in addition they have hearing loss requiring amplification. These patients are fitted with hearing aids or combination instruments, and sound therapy is conducted as for Category 1 patients. Patients in Category 3 require primary management for hyperacusis, which involves special

desensitization procedures using sound to increase tolerance levels (J. A. Henry, Trune, et al., 2007a, 2007b). Category 4 refers to patients whose tinnitus is exacerbated by exposure to certain sounds. These latter patients require judicious use of sound to systematically reduce their reactions to sound.

The originators of this method contend that it is necessary to attend their training courses in order to properly conduct TRT. However, books are available that describe TRT clinical procedures in detail, and numerous clinicians who are trained and experienced in conducting TRT may be available to provide training and clinical supervision.

### Neuromonics Tinnitus Treatment

Neuromonics tinnitus treatment (NTT) is unique among tinnitus therapies in that providers who offer this technique work directly with a company to receive all training, materials, therapeutic devices, and support. After a provider has received training, company representatives attend the provider's first appointments with patients to ensure that all clinical procedures are conducted according to the prescribed protocol. The method cannot be implemented without the company's endorsement and support.

Intervention with NTT involves six months or more of using a proprietary, wearable listening device 2 to 3 hours per day (P. B. Davis, 2006). The device is similar to an MP3 player and plays baroque and new age music that is specially selected for having relaxation-inducing qualities. For each patient, the device is customized by the company so that the sound output is adjusted (equalized) for any hearing loss. The device is used to implement desensitization to the tinnitus in two stages as the prescribed protocol. During the first two months of treatment (stage 1) wide-band noise ("shower sound") is added to the music. The objective of stage 1 is to attain a sense of relief and control over the tinnitus—generally to reduce anxiety. Relative to the combinations of sound as described for PTM (see Figure 7–1), the use of sound during stage 1 of NTT is an example of *using a combination of music and environmental sound as soothing sound*. During the next four months (stage 2) the wide-band

noise is removed from the audio signal. Patients are instructed to gradually reduce the volume of the music. The objective of stage 2 is essentially the same as for TRT: less awareness of, and less reaction to, the tinnitus. The use of sound during stage 2 of NTT is an example of *using music as soothing sound*, transitioning to *using music as background sound* (see Figure 7–1) prior to discontinuing daily use of the device.

### Conclusion

All audiologists routinely encounter patients who complain of tinnitus. Different methods of intervention for tinnitus have been available to audiologists for years. However, relatively few audiologists have received adequate training in providing clinical services for tinnitus. Audiologists need the skills to evaluate patients and provide the needed level of care. The method of PTM is a definable program of care that is based primarily on goal-oriented counseling of various uses of sound for managing reactions to tinnitus, and the provision of specific coping skills fundamental to CBT.

Standardized clinical guidelines for managing reactions to tinnitus are unlikely to be established in the near future for audiologists. Training in tinnitus clinical services is highly variable among audiology graduate programs (J. A. Henry, Zaugg, et al., 2005a). Any training that exists reflects biases, which is understandable because research does not conclusively support any one form of management. There are four broad areas that require consensus to achieve standardization. These include: (a) defined clinical procedures; (b) research evidence to support clinical procedures; (c) audiology graduate training; and (d) patient educational programs. PTM establishes basic procedures that can be used by audiologists until more formal standardized techniques are developed and validated.

The effectiveness of intervention with PTM depends on the effectiveness of the education that is provided to patients. It is essential that evidence-based methods of patient education are utilized. Previously, we have reviewed a variety of learning theories that have particular relevance to PTM

(J. A. Henry, Zaugg, Myers, Kendall, et al., 2009). This review shows that PTM adheres to a number of principles that have been demonstrated to optimize effective patient learning of skills for self-management of health.

We recognize that counseling for facilitating health behavior change presents challenges that can result in frustration for patients and clinicians alike (Rollnick, Mason, & Butler, 1999). Behavioral changes do not come easily, especially when the target behaviors and their underlying cognitions are long-standing, sometimes even lifelong habits. However, counseling with PTM is a patient-centered method that addresses the uniqueness of each patient and his or her particular tinnitus-

problem profile. This patient-centered approach has been shown to greatly enhance individual motivation for making adaptive changes for improving health (Stewart et al., 2000). In PTM, patients participate in the process of defining the problem and identifying specific behavior changes for managing the problem. Each patient becomes an active participant in making decisions and ultimately is in charge of making lifestyle adjustments to mitigate his or her own tinnitus problem. Understanding that the patient is an expert in his or her own life circumstances, problems, resources, and abilities is the key that enables this collaborative tinnitus self-management approach to succeed.