

# **MUSIC THERAPY AS AN INTEGRATED METHOD OF PSYCHO-EMOTIONAL AND COGNITIVE SUPPORT IN MULTIDISCIPLINARY ALS CARE**

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MULTIDISCIPLINARY TEAM APPROACH IS RECOMMENDED TO MANAGE THE COMPLEX, CONSTANTLY CHANGING PSYCHOLOGICAL AND PHYSICAL NEEDS OF PEOPLE WITH AMYOTROPHIC LATERAL SCLEROSIS. MUSIC THERAPY, AS AN INTEGRATED TREATMENT MODALITY, CARRIES POTENTIAL FOR SUPPORTIVE REHABILITATION OF PERSONS WITH ALS. SCIENTIFIC AND CLINICAL EVIDENCE VALIDATE INCLUSION OF A MUSIC THERAPIST INTO MULTIDISCIPLINARY ALS CARE STARTING EARLY IN THE DISEASE COURSE. Keywords: ALS, FTD, MDT, music therapy, rehabilitation, neurology

## **Non-motor symptoms in ALS**

Amyotrophic lateral sclerosis (ALS) is a group of rapidly progressive fatal neurological diseases involving the brain and spinal cord. ALS affects over 400,000 of the world's population and kills over 100,000 every year. At least 90% of ALS cases are considered sporadic, which means the disease seems to occur at random with no clearly associated risk factors and no family history of the disease [1]. Clinical presentation of ALS is phenotypically heterogeneous and depends on the type of onset: limb onset is the most common and the first symptoms include compromised gait and manual dexterity; bulbar-onset ALS patients first experience the symptoms in head and neck region such as slurred speech or difficulty swallowing; there are also rare truncal-abdominal (axial) and respiratory onsets.

Whilst in the past ALS was considered distinctly a disorder of the motor system, current evidence suggests that some cognitive (ALSci) or behavioural (ALSbi) impairment occurs in up to 50% of cases, and co-morbid dementia (ALS-FTD) occurs in approximately 14% of patients with a new diagnosis of ALS [2]. The notion that "pure" ALS and "pure" FTD may present two extremes of one disease continuum [3] is reinforced by identification of transactive response DNA-binding protein 43 (TDP-43) as a major pathological substrate underlying both diseases [4]. ALSci and ALS-FTD patients are more severely impaired in executive function, attention, language and memory than the cognitively intact ALS patients. ALS patients with frontotemporal syndrome also had shorter survival times than those without cognitive or behavioural impairment [5]. Cognitive impairment has a potential to influence the treatment and equipment needs of persons with ALS (PALS) and to impede their safety and medical decision making; emotional perception deficits may lead to impaired relationship with caregivers [6]. Lack of motivation was found to be one most prominent behavioural change in PALS, and disinhibition and impulsivity were found to be particularly stressful for caregivers of people with ALS (CALs) [7]. Emotional lability (pseudobulbar affect), a symptom frequently correlated with bulbar involvement in ALS, may also

be confusing and disruptive, especially when communicating with those who are not aware of the nature of the problem [8].

Although there is no consensus regarding the real morbidity of depression and anxiety in ALS [9], [10], it is currently believed that depression is less prevalent in PALS than estimated by caregivers and healthy people [11]. High level of anxiety is often present in PALS during the diagnostic phase and the earlier period after the diagnosis [12]. Later, weakening of the respiratory function and adherence to NIV become the leading causes of anxiety [13], [14].

### **Music therapy in multidisciplinary model of ALS care**

PALS have multiple and complex needs. In addition to many physical symptoms such as gradual loss of motor functions, spasticity, fasciculations, dyspnoea, dysphagia, dystussia, dysarthria and pain, and overall emotional load of dealing with a devastating disease, cognitive and behavioural changes experienced by PALS present additional difficulties for patients and families. The National Institute for Health and Care Excellence (UK) guideline [NG42] suggests coordinated care for people with ALS, using a clinic-based, specialist ALS *multidisciplinary team approach*. American Academy of Neurology recommends MDT model of care where patients are seen by a comprehensive team of health care professionals who each focus on specific health domains including walking, breathing, speaking, eating, activities of daily living, and psychosocial needs during one clinical visit [15]. Such team often includes a physician, physical therapist, occupational therapist, speech language pathologist, respiratory therapist, nurse coordinator, and social worker. Additional specialists, such as nutritionists, pulmonologists, gastroenterologists, assistive technology experts, psychologists, palliative care providers, chaplain or priests, may also be present [16]. Multidisciplinary ALS care has been shown to increase survival of PALS and to improve their mental QoL [17].

*Music therapy* (MT) is the clinical use of music and its elements to accomplish individualized health goals within a therapeutic relationship. Music therapists are allied health professionals who hold a degree and certification in music therapy, have theoretical and practical knowledge of music, human psychology and physiology, and work closely with a multidisciplinary team to provide individualized, evidence-based, problem-oriented treatment for every clinical situation. Growth of scientific knowledge about music perception and production and the effects of these on nonmusical brain and behavior functions in the recent decades enabled music therapists to develop effective clinical techniques to treat cognitive, sensory, and motor dysfunctions that come from human neurologic diseases and allowed for successful application of music therapy principles in neurorehabilitation [18].

Currently music therapists mostly work with PALS in the end of life, as a part of hospice care at the time when motor functions are mostly lost and natural communication is limited. There is evidence that MT may increase comfort and relaxation, as well as reduce anxiety for terminally ill [19], [20], and music listening may have a beneficial effect on heart rate, respiratory rate, and anxiety in mechanically ventilated patients [21]. Little research has been done to understand the effects of MT interventions conducted with patients at earlier stages of ALS. MT technique of music assisted relaxation was found beneficial for psychological wellbeing of PALS during NIV

use [22], as well as for increasing communication, improving quality of life and decreasing the physical symptoms of the disease for ALS patients during hospital stay [23]. No published research addressing the use of music therapy techniques for neurorehabilitation (e.g. supporting motor, cognitive, respiratory, swallowing, speech functions of PALS) has been found, even though empirical evidence and research with other clinical populations [24], [25], [26], [27], [28], [29] suggest that such interventions may be beneficial. MT has been shown effective for managing and treating behavioural and psychiatric symptoms of people with non-ALS FTD [30], [31].

In the absence of a cure, more rehabilitation options have to be considered for PALS [32], enabling them to reach their fullest potential, delaying disease progression and prolonging lifespan [16]. Professionally trained music therapists are well equipped to provide symptomatic care for people with neurodegenerative diseases [33], adapting to increasing and changing disability of each patient as the disease progresses, whilst maintaining and developing trusting therapeutic relationship established early in the disease course. These considerations provide a strong basis for inclusion of a music therapist into MDT model of ALS care.

### **Music therapy at ALS Centre Moscow**

ALS Centre Moscow is a collaboration between three Moscow hospitals providing home-based multidisciplinary care for PALS and their families since 2012. Approximately 110 ALS patients out of roughly 950 PALS residing in Moscow region are followed by the team. MT was first introduced to the patients of ALS Centre Moscow in 2013. An experimental MT protocol consisting of interchangeable blocks of exercises was developed to address the varying and constantly changing physical, social, communicative, cognitive and spiritual needs of the patients and their families. Two music therapists worked with the patients at the Centre intermittently from 2014 to 2016. In 2017, following the increased demand for service, two specialists formally trained in MT applications for neurological clinical practice were added to ALS Center Moscow MDT. These specialists are regularly referred by the medical team to patients at various stages of the disease progression and work with a wide spectrum of non-physical and physical needs.

Disbelief, grief, anger, confusion, distorted sense of self, and social disconnectedness are common consequences of ALS diagnosis. Evidence from psychosomatic and health psychology research fields demonstrates close bilateral interrelation between mind and body, with emotions affecting cardiovascular and immune system responses and physiological events impacting an individual's psychological state [34]. MT, in form of song singing, song writing, lyrics substitution, listening to and discussing music, meditating and reminiscing to music, and interactive improvisation, can decrease stress, strengthen the mind-body connection and help PALS to regain coherent self-image. Music assisted relaxation may be used to alleviate anxiety, to ease manifestations of pseudobulbar affect and to provide relief from distressing thoughts.

Overwhelming emotions and co-morbid cognitive and behavioural impairments, especially apathy, may prevent PALS from making timely, informed decisions regarding their treatment, such as use of NIV, gastrostomy or tracheostomy. Whereas PALS in Russia are generally reluctant to accept psychotherapy services, a music therapist is often able to establish a working relationship with patients and, through live music making and meaningful conversation, to increase motivation,

enhance mood, decrease apathy and create a safe emotional space – a “container” for the overwhelming feelings and reactions, thus freeing up mental energy and focus necessary for treatment planning and compliance.

Similarly, MT sessions create a psychologically safe environment for PALS and CALS to explore the changing dynamics of their relationship, and the peak experience of cooperative music making provides opportunities for positive socialization and communication. Interactive music improvisation utilizing simple instruments or adaptive music technology may become a way of nonverbal communication, self-expression and playful, though meaningful, relating to others. Other techniques, such as free associative singing [35] and musical life review [36], can facilitate deeper psychotherapeutic work with ALS patients and their families. At the end of life music can carry the five messages of relationship completion: “I forgive you”, “Forgive me”, “Thank you”, “I love you”, “Goodbye” [37].

Though further research is needed to explore the applications of music therapy for physical rehabilitation of PALS, clinical evidence suggests that structured, individualized breathing and vocal exercises have a potential to sustain bulbar and respiratory functions for PALS. Finally, active music making, such as playing simple music instruments to the beat, and moving to music can serve as a form of moderate physical exercise for PALS who are not able to engage into physical therapy program.

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Positive feedback from the patients and their families supports our tenet that introducing MT as a supportive modality of multidisciplinary ALS care has a potential to increase quality of life and wellbeing of PALS:

*“I feel lighter and happier after we do music” – Patient*

*“I can relax, I cry less and feel less nervous after a (music therapy) session” – Patient*

*“Unless I do my (music therapy) exercises, it is difficult for me to start speaking in the morning. I notice that after the exercises speech is easier for me, and my family understand me better” – Patient*

*“My swallowing improved, I can again take water with my lips and I have almost stopped gagging when I eat – something I constantly experienced in the past” – Patient*

*“Music therapy was very important for mom. She always smiled when she spoke about the sessions” – Caregiver*

## Conclusion

The emerging empirical evidence and limited research suggest that MT should be considered as a supportive treatment in ALS rehabilitation, with the potential to improve function and QoL of the patients across various presentations and stages of the disease. MT interventions tailored to individual clinical needs, preferences and capabilities of PALS can be designed to provide opportunities for psycho-emotional support and counseling, relaxation and sleep facilitation, verbal and nonverbal self-expression and communication, mood enhancement, energy boost and motivation, pain management, improving relationship dynamics, socialization, behavioural and cognitive symptoms management, and, with proper precautions, bulbar and respiratory functions support and moderate physical exercise. MT can also address caregiver's stress as one of the main factors contributing to the caregiver burden in ALS [7], as well as provide respite care and appease grieving for CALS, including children.

Music engages vast network of regions located in both hemispheres of the brain and shares processing components with other functions, such as those involved in language, movement, reasoning and experiencing emotions [38], [39], [40], [41]. Albeit currently underused, music therapy could be one of the modalities of supportive rehabilitation in ALS [23], potentially providing multiple benefits for PALS and their families. There is a pressing need for continued research and higher levels of evidence for MT applications in multidisciplinary ALS care.

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