

# Meditation Training for People with Amyotrophic Lateral Sclerosis and Their Caregivers

Francesco Pagnini, PhD,<sup>1,2</sup> Chiara Di Credico, MS,<sup>3</sup> Ramona Gatto, MS,<sup>4</sup> Viviana Fabiani, BS,<sup>3</sup> Gabriella Rossi, MS,<sup>4</sup> Christian Lunetta, MD,<sup>4</sup> Anna Marconi, MS,<sup>4</sup> Federica Fossati, MS,<sup>4</sup> Gianluca Castelnuovo, PhD, PsyD,<sup>1,5</sup> Aurora Tagliaferri, MS,<sup>1</sup> Paolo Banfi, MD,<sup>6</sup> Massimo Corbo, MD,<sup>4,7</sup> Valeria Sansone, MD,<sup>4</sup> Enrico Molinari, PhD,<sup>1,5</sup> and Gherardo Amadei, MD<sup>3</sup>

## Abstract

**Objectives:** Amyotrophic lateral sclerosis (ALS) is a progressive and fatal neurodegenerative disease that is clinically characterized by progressive weakness leading to death by respiratory insufficiency, usually within three years. Although the patient's intellect and personality usually remain unimpaired, as the disease progresses, the patient becomes immobile, develops wasting, and speech becomes impaired, often resulting in social isolation and a high degree of psychological suffering. Mindfulness meditation has proven to be effective technique for reducing distress in many chronic diseases. However, to date, no study has investigated the effect of mindfulness meditation on patients with ALS.

**Design:** A mindfulness meditation training program for ALS patients needs to consider the particularities of ALS symptoms, including the loss of muscular functions and difficulties in respiration, together with the subsequent emotional impairments. With these caveats in mind, a modified protocol, based on original mindfulness meditation interventions, has been created specifically for the ALS population.

This article describes the protocol and preliminary results.

## The Psychological Impact of Amyotrophic Lateral Sclerosis

**A**MYOTROPHIC LATERAL SCLEROSIS (ALS) is a rare, neurodegenerative disease that affects nerve cells in the brain and spinal cord. People who have been diagnosed with ALS face progressive muscular weakness and the consequent loss of strength. As the disease progresses, their speech becomes impaired, and they lose the ability to move their arms, legs, and body. Over time, the course of the disease often leads to what is known as a "locked-in" state in which only residual muscular movement is possible. So far, there is no treatment that reverses or blocks this progression.<sup>1</sup> The incidence of the disease is reported to be between 1.5–2.7/100,000 population/year, or an average 1.89/100,000/year in Europe and North America.<sup>2</sup>

The psychological and social impact of the disease is severe for both patients and caregivers. For patients, depres-

sion and anxiety as well as despair and hopelessness may arise in response to the diagnosis and during the course of the illness.<sup>3</sup> Moreover, the burden for ALS caregivers is often severe, and they too are at risk of depression and anxiety.<sup>4,5</sup> To date, however, despite the severity of the psychological impact, there is an absence of research on the efficacy of psychological interventions.<sup>6</sup>

## What Is Mindfulness Meditation?

Some of the most promising clinical treatments for improving the quality of life (QOL) for people with chronic illnesses are based on the concept of mindfulness. At present, there are two primary definitions of mindfulness.<sup>7</sup> One has been developed from Ellen Langer's experimental research on mindlessness.<sup>8</sup> Based on Langer's research, mindfulness is the process of actively making new distinctions about objects

<sup>1</sup>Department of Psychology, Catholic University of Milan, Italy.

<sup>2</sup>Niguarda Ca' Granda Hospital, Milan, Italy.

<sup>3</sup>Department of Psychology, University of Milano Bicocca, Italy.

<sup>4</sup>NeuroMuscular Omnicentre (NEMO), Fondazione Serena Onlus, Ospedale Niguarda Cà Granda, Milan, Italy.

<sup>5</sup>Istituto Auxologico Italiano Istituto di Ricovero e Cura a Carattere Scientifico (IRCCS), Psychology Research Laboratory, San Giuseppe Hospital, Verbania, Italy.

<sup>6</sup>Department of Neuromuscular Disease, Fondazione Don Gnocchi, Milan, Italy.

<sup>7</sup>Department of Neurorehabilitation Sciences, Casa Cura Policlinico, Milan, Italy.

in one's awareness. Such a process cultivates sensitivity to subtle variations in context and perspective about the observed subject rather than relying on entrenched categorizations from the past.<sup>8-11</sup> The other definition of mindfulness was developed by Jon Kabat-Zinn. Kabat-Zinn's definition is based on the use of Buddhist meditative practices in behavioral medicine. His approach defines mindfulness as remembering to pay attention in a certain way, that is, on purpose, in the present moment, and nonjudgmentally.<sup>12</sup>

More than three decades of research on mindfulness, whether as it is defined by Langer or by Kabat-Zinn, indicates that mindfulness has a variety of positive effects on health, both physical health and psychological health. Although studies<sup>13-15</sup> have reported that increased mindfulness leads to a better quality of life, both in the general population and in clinical samples, there are different ways to improve mindfulness, based on the definition used.<sup>7</sup> No matter what definition is used, however, meditation is considered the most common way. While Langer focuses on variability, novelty seeking, and relativity thinking exercises,<sup>11</sup> Kabat-Zinn has developed a specific protocol, known as Mindfulness-Based Stress Reduction, or MBSR.<sup>12</sup> For the purposes of this study, we will focus on the Kabat-Zinn MBSR approach. Other work will be required to investigate the potential of the Langer's approach in the field of ALS care.

Rooted in Theravada Buddhism, MBSR uses a combination of mindfulness meditation and behavioral exercises in weekly sessions over a period of 8 weeks. Interest in MBSR has grown over the last two decades, and its practice has been shown to significantly improve symptoms of stress and mood disturbance in individuals with a variety of diagnoses, including pain,<sup>16</sup> cancer,<sup>17</sup> depression, and anxiety,<sup>18</sup> as well as in healthcare providers.<sup>19</sup>

#### *Why mindfulness meditation for ALS people?*

When first begun, the practice of mindfulness meditation leads to an awareness of what is happening in the body. As the practice continues, it leads to a partial decoupling of actions, including physiological reactions, and mental events. As a consequence, a more serene and balanced emotional and affective state is achieved, which is a good precondition for stress resistance and resilience.<sup>20</sup> This type of meditation has proven to be a powerful instrument for the enhancement of well-being in people from both the general and clinical populations,<sup>15</sup> and there are a number of reasons to believe that its potential impact on the ALS field could be great.

First, a focus on the present moment, together with the unconditional acceptance of sensations and emotions, may allow people with ALS to better manage their feelings and reaction to their illness. This kind of unconditional acceptance enhances the importance of the present, of "what I am doing now; how I feel now," rather than obsessive attention on "what I am not doing." For people with ALS, attention on "what I am not doing" can easily become "what I cannot do anymore," and consequent negative thoughts. Second, negative beliefs sometimes lead to rumination with depressive loops. Mindfulness training allows the mind to step back and escape from these depressive loops.

Third, it has been suggested that mindfulness meditation alters the power that death holds over us. Mindful people

have a more receptive consideration of death and are less apt to become defensive during—or avoid entirely—discussions of death.<sup>21</sup> This may be particularly useful in the case of a terminal illness, especially ALS in which the final stage is often a locked-in state in which no residual movement is possible but brain activity remains constant, suggesting that the mind is working. It is possible that mindfulness meditation, which is sometimes seen as a relationship with elements that we experience, may provide a coping strategy for this condition.<sup>22</sup> Because it is difficult to understand the subjective experience of a person who cannot communicate, this hypothesis is difficult to prove. However, meditation training does increase the ability to remain physically passive (i.e., without movement) for long periods and maintain a positive experience.

Finally, the impact of ALS is not limited just to the person with the illness but, instead, encompasses both family and close friends. The psychological impact on the primary caregiver is often particularly strong.<sup>5</sup> A mindfulness intervention can improve the caregiver's acceptance and coping abilities. Furthermore, previous studies have indicated that the existential well-being of the person with ALS is highly related to the caregiver's QOL.<sup>23</sup> Therefore, an improvement of the patient's condition may reduce the burden experienced by the caregiver and, in turn, improve the well-being of the patient.

#### *Problems related to ALS and mindfulness meditation*

For people with ALS, a mindfulness meditation program presents a number of challenges. Difficulties with movement and breathing may hinder some of the MBSR exercises. Even if the process of the exercises, not on their outcome, is emphasized, the individual with ALS may feel negative emotions (e.g., sense of inadequacy, hopelessness).

Another issue concerns the intensity of the emotional reactions. Unexpressed and unexplored emotions and beliefs often arise during MBSR sessions. In people with ALS, the perception of the nearness of death, caused by the consciousness of the irreversibility of the illness, may bring to the surface great anger or sadness. These feelings, which the ALS patient may have buried in his or her metaphorical Pandora's box, may "explode" during the sessions. Mindfulness meditation may force contact with that part of the self (e.g., fears), that the ALS patient wishes to avoid, resulting in an initial increase in the level of stress.

Bringing an ALS patient's attention to the body may give rise to painful emotional reactions that may, at first, increase feelings of hopelessness and comparisons with the past when the patient's physical functions were better. Even if mindfulness training provides the instruments to cope with these issues, the issues are obstacles, particularly during the initial phases of the MBSR course. Moreover, the intensity of emotional reactions that may arise during the course suggests the need to consider these issues carefully.

#### **An Intervention Protocol**

Our intervention protocol is derived from the MBSR protocol but adapted to the clinical peculiarities and challenges of ALS. Each session lasts about 90 minutes, which is less than the length of time required for a MBSR session. The final

intensive day at the end of the MBSR protocol has been removed for both logistical and physical reasons. First, transportation of a group of ALS people may be difficult. Second, because of the nature of the disease and its psychological impact, a long, intensive lesson may be too exhausting for some ALS patients, given the intense emotions that may arise during a session.

Whereas only one mindfulness meditation trainer conducts a MBSR session, in our protocol, there are two trainers for each session. We believe that the presence of a second teacher significantly reduces the risk of professional emotional burnout. Moreover, from a purely practical point of view, two people can better manage situations in which, for clinical reasons, it may be useful to separate participants or to temporarily split the group (e.g., between caregivers and patients).

Our participants are given the opportunity to contact the trainers for any needs, questions, or practice support at any time outside the class setting. Because the emotional reactions that may arise from the course may require a mental health specialist, the protocol should be conducted within a multi-disciplinary framework that includes the presence of a psychologist.

We believe our protocol is open to all ALS patients whose diagnosis occurred no more than 18 months earlier and who have an Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFERS) score above 24.<sup>24</sup> The protocol does exclude patients with comorbidity or with a personal history of psychiatric disorders. The primary caregiver, that person who provides the most care and assistance, is invited to join the group.

The structure of a session, which includes both ALS patients and caregivers, is similar to the structure of a MBSR session, and most of the same topics are treated, but with respect to the peculiarities of the disease. In our protocol, arguments, metaphors, and sharing moments between participants are adapted to the daily reality of ALS patients and caregivers in order to allow them to feel understood and accepted in accordance with their new lifestyles. Sessions emphasize accepting (or, at least, "living with") the discomfort and physical limitations of ALS, appreciating what can still be experienced, despite the gradual deterioration of physical condition, and the impact physical limitations may have on stress, with particular attention to the expression of anger (e.g., aggressive feelings against the caregiver). While stress is the core theme of the original MBSR protocol, in the ALS protocol, acceptance of the difficulties caused by new physical limitations is emphasized. We point out the importance of a kind approach to physical limits. We are careful not to stress the rapid adaptation to life difficulties, which may occur in healthy people. We do not discuss how the practice of mindfulness may improve health. Instead, we emphasize how the practice may improve the care of self, the love for self. Finally, we never emphasize the concept of free choice.

Based on patients' physical challenges, we have changed, or replaced, six exercises derived from the original MBSR protocol:

- (1) Mindful eating: Because swallowing becomes difficult as ALS progresses, we use a lump of sugar rather than raisins for this exercise.
- (2) Breathing awareness. In the original protocol, paying attention to one's own breath plays an anchoring role in the development of a mindfulness attitude and the ability to remain focused. Since ALS progressively impairs respiratory function, paying attention to one's own respiration can be emotionally challenging and may produce resistance to the exercise or the course. Therefore, breathing awareness exercises are employed only if patients have already started to manage their anger. In the initial phases, we opt for alternative anchorages, equally simple, that will not be compromised by the development of the disease. For example, participants are asked to pay attention to the contact points of the body on surfaces. Depending on the severity of the ventilatory compromise, different breathing awareness approaches are possible, however.
- (3) Body scan: body scan was used according to the original protocol, in particular during the initial phases of the treatment.
- (4) Practice of loving kindness: This element, which aims to awaken attitudes of compassion for the self and others, is a key element of the protocol. It is present in all sessions, and practice at home is highly recommended. The practice is particularly useful in case of suffering as it has a positive impact on symptoms of depression and anxiety. Moreover, it helps both patients and caretakers to understand and accept the importance of receiving help from others.<sup>25</sup>
- (5) Hatha yoga: We have replaced Hatha yoga exercises with minimal awareness movements derived from those Feldenkrais techniques that we judge to be accessible to all people of all ages and physical conditions. With these criteria in mind, we use eye movements exercises, because these movement are among the last to be impaired by the progression of ALS.
- (6) Music meditation: Music meditation training is included in our protocol. Music is used as a stimulus of feelings that might be felt and accepted. We believe that this mindful exercise provides participants with another tool to better deal with the development of the disease, particularly in its final stages.
- (7) Visualizations and motor imagery: Unlike the original MBSR protocol, we use meditation techniques based primarily on visualization. In addition to two meditations based on visualizations proposed by Kabat-Zinn, we use the visualization of a safe place to provide participants with an effective technique of self-soothing that is not based on breathing awareness. We also introduce motor imagery tasks (i.e., tasks through which a person imagines making a movement without actually doing so).

Participants are asked to do homework on a daily basis. While some assignments are based on the original MSBR protocol, new ones have been introduced according to protocol changes (e.g., music meditation). ALS subjects with physical impairments that hinder writing tasks (e.g., keeping a diary), are helped by their caregivers.

## Conclusions

The mindfulness meditation protocol presented here is an attempt to provide a psychological intervention to improve

the QOL of ALS patients and their caregivers. Despite the clinical importance of such an intervention, there has been a lack of research on the topic.<sup>6</sup> Our program is derived from the MBSR protocol, which has been shown to be an effective means of improving psychological well-being in a great variety of chronic conditions.<sup>13</sup> No one has ever tried to adapt the MBSR program to the needs of ALS patients, and there are many issues and obstacles to such an adaptation. Despite these challenges, it is our conviction that a mindfulness meditation program may significantly improve the well-being of both ALS patients and their caregivers. We believe this protocol can increase the acceptance of self and of the illness, thus reducing distress and depressive thoughts.

Existential well-being is a key issue for general well-being,<sup>26</sup> especially in people who are dealing with a terminal disease. Mindfulness meditation provides techniques that ALS patients and caretakers can use when they need them. Most of the exercises in this protocol can be used by severely compromised patients. If learned in the early stages of the disease, we believe that the acceptance of self and the non-judgment and nontrying features transmitted by the program can have a very positive impact in the final stages of ALS. We are now conducting a randomized controlled trial to test the effectiveness of this intervention.

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#### Author Disclosure Statement

No competing financial interests exist.

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Address correspondence to:  
 Francesco Pagnini, PhD  
 Department of Psychology  
 Catholic University of Milan  
 Via Nirone 15  
 20123, Milan  
 Italy

E-mail: francesco.pagnini@unicatt.it